Discharge Planning with Older Adults: The Influence of Social and Political Systems and Contexts

by

Evelyne Marie-Claude Louise Durocher

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Graduate Department of Rehabilitation Sciences
University of Toronto

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Abstract

Discharge planning is a complex process in which intersections of competing norms, demands and expectations often beget ethical challenges. Returning home or moving to a more supportive setting can have tremendous personal, social and financial implications for older adults and families. Institutional concerns with patient safety and expedience can overshadow healthcare professionals’ commitments to client-centred approaches. In light of many competing demands and agendas, it can be unclear what is driving discharge-planning processes and outcomes.

The research purposes were to 1) explore perspectives of older adults, family members, and healthcare professionals engaged in discharge planning from inpatient rehabilitation; 2) examine the influence of underlying beliefs, valued approaches and conventional processes on participants’ perspectives, behaviours and practices, and on discharge-planning outcomes.

Using a microethnographic case study method, observations and interview data were generated from five case studies, each consisting of an older adult, involved family members and
healthcare professionals. Taking a critical bioethics perspective and using relational autonomy theory, this research examined how social and political contexts shaped discharge-planning processes and outcomes.

Discourses of aging-as-decline, beliefs privileging healthcare professionals’ expertise and conventions guiding discharge planning marginalized older adults. The prioritization of safety and focus on discharge superseded approaches to maximize function: the stated aim of rehabilitation. A profession-centric approach and the focus on safety and discharge from the time of admission intersected to promote 24-hour care recommendations in all cases.

Taking a critical bioethics perspective informed by relational autonomy revealed that discharge planning was driven by paternalistic norms and that the ‘best interests’ of older adults were aligned with ‘protecting physical safety’ at the expense of any other considerations, thereby marginalizing older adults and impeding client-centred practice. These findings suggest that adopting a relational approach could promote practices that uphold older adults’ agency and align professional responsibilities with intended program aims.
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To my father I dedicate this thesis.

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1952 - 2012
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Chapter 1
Introduction

1 - Statement of the problem and gap in knowledge

Older adults are rapidly becoming the largest segment of the Canadian population and the heaviest users of healthcare services (Canadian Institute of Health Information (CIHI), 2011; Health Canada, 2002; Statistics Canada, 2011). Timely and appropriate discharge planning is an important component in preparing individuals to leave, or discontinue use of, healthcare services. In the case of inpatient care settings, discharge planning involves deciding where an individual will live upon discharge, identifying if care will be needed, and if it is, arranging services to ensure that individuals’ medical and personal care needs will be met. Discharge planning with older adults can be a complex process and the intersection of competing expectations and demands of individuals involved in the process often begets ethical challenges (Blumentfield, & Isaacs Lowe, 1987; Cummings & Cockerham, 1997; Durocher & Gibson, 2010; Potthoff, Kane & Franco, 1997; Swidler, Seastrum & Shelton, 2007; Wells, 1997). Many individuals, including the older adult, family members, informal caregivers, and healthcare professionals may be involved in discharge planning with older adults. Each of these individuals may be subject to, and may also hold, differing expectations and agendas, which can stem from personal experiences, contextually-specific social and political systems of thoughts and conventional practices and processes. Perspectives on how discharge planning should proceed can vary widely with respect to who should be involved in making decisions, how older adults’ autonomy should be mediated and what norms and values take precedence. Older adults’ family members may have a personal interest in their relative’s well-being and living circumstances, and they may also be called upon to provide care and support. Healthcare professionals may have a professional interest in their clients’ welfare, yet they are also accountable to their institutional employer and to society as stewards of healthcare services (Connolly et al., 2009). Decisions for situations of discharge from inpatient care to the community are also influenced by increasing demands for finite community care services in Ontario (Williams et al., 2009). In light of the competing wishes, expectations, demands and influences and the increasingly complex and limited options for care in the community, ethical conflicts can arise and it can be unclear which
interests are driving discharge planning and shaping the outcomes. Differences in perspectives and sometime contradictory agendas can result in conflict and be challenging for all involved individuals. There is little research aimed at understanding how such competing demands and expectations may set up situations of conflict (Atwal, 2002; Connolly et al., 2009; Huby, 2007). Furthermore, there is little research exploring how competing agendas may result from the contextual policies, practices, systems of thought, and how these intersect to affect perspectives and behaviours in discharge-planning decision making, which in turn shape the outcomes of the process (for exceptions see Connolly, 2009; Dill, 1995; Huby, 2007; Wells, 1997). The present study builds on previous research to explore the nature and impact of social and political influences on discharge planning with older adults. The goal is to create knowledge to inform the development of policies and practices to align professional and institutional demands with the needs of older adults and families to better meet the needs of all individuals involved in discharge planning.

For older adults who are being discharged, the decision to return home or move into a long-term care facility can have tremendous implications for their health and well-being (McCullough, Wilson, Teasdale, Kolpakchi & Skelly, 1993; Moats, 2006; Potthoff et al., 1997). One’s home environment has a significant impact in shaping the social, occupational, healthcare and personal aspects of one’s life; one’s home may hold great emotional significance and be closely related to one’s identity and sense of self (Dupuis & Thorns, 1996, 1998; McCullough et al., 1993; Wise, 2000). Where one lives both determines, and is dependent on, which individuals are part of the social environment; what support or services are available; how and by whom health care will be provided and funded; and finally what opportunities and activities are available to, or required of, the individual. The combination of all of these aspects determines what capabilities must be regained or developed for a discharge home.

In Ontario, publicly funded home and community supports are limited and it can be difficult for older adults, family members and healthcare professionals to coordinate services to meet individual needs (Williams et al., 2009). In the current age of tightening budgets and
increasing demand for healthcare services, hospital lengths of stay are getting shorter\(^1\) (Canadian Institute of health information (CIHI), 2013; Potthoff, Kane & Franco, 1997; Watts, Pierson & Gardner, 2005; Wells, 1997; Wells, LeClerc, Craig, Martin & Marshall, 2002) and individuals who are admitted for inpatient care services are being discharged with more medical and physical needs than ever before (Brown, 1995; CIHI, 2013; Clemens, 1995; Jackson, 1994; Moats, 2006; Potthoff et al., 1997). In light of increased individual and population needs and constrained publicly funded options for service and care in the community, the role of discharge planning in ensuring that individuals’ needs are being met following discharge from hospital is increasingly important (Bull & Roberts, 2001; Connolly, 2009).

As discharge planning with older adults is a complex process with many different stakeholders having varying interests, it has been the subject of much research and scholarship. The literature includes explorations of potential ethical issues faced by healthcare practitioners assisting older adults and their families in discharge planning (Dill, 1995; Durocher & Gibson, 2010; Swidler, Seastrum & Shelton, 2007) and specifically with older adults with dementia (Brindle & Holmes, 2005; Cummings & Cockerham, 1997). Other research examines discharge-planning processes with the aim of identifying factors that enable and impede discharge planning (Bobay, Jerofke, Weiss & Yakusheva, 2010; Bull & Roberts, 2001; Crennan & MacRae, 2010; Moats, 2006; Pethybridge, 2004; Potthoff et al., 1997; Wells, 1997). Some studies examine the experiences of various individuals involved in discharge planning (Clemens, 1995; Efraimsson, Sandman & Rasmussen, 2006; Huby, Steward, Tierney & Rogers, 2004; Huby, Holt Brook, Thompson & Tierney, 2007; Jette, Grover & Keck, 2003; McCullough et al., 1993; Procter, Wilcockson, Pearson & Allgar, 2001; Roberts, 2002; Rydeman & Törnvist, 2005; Watts, et al., 2005; Wells, 1997). (Please see Chapter 2 for a fuller discussion of these studies.)

While extant research provides valuable information about specific practice and policy influences on discharge planning and the behaviours of those involved in the process, there is little to no research examining the social and political structures that may be shaping and influencing discharge-planning perspectives, behaviours and practices. Such structures could

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\(^1\) According the CIHI (2013), in the 16 year period between 1996 and 2012, on average inpatient care lengths of stay decreased by 7.25% in Ontario and by 4% across Canada, thus representing changes from 6.9 to 6.5 days and 7.5 to 7.2 days respectively. On average this represents a difference of 12 hours in Ontario and 4 hours across Canada. Data specific to older adults’ lengths of stay was not available.
include values, expectations and systems of thought circulating through social and political networks that are influencing and being influenced by practices and behaviours. These could also include policies that guide practices and processes, and further shape ways of thinking and behaving, which in turn influence policies. Research examining how these structures may be setting up situations of conflict for the individuals involved in discharge planning, and what outcomes such conflicts may promote is also scarce. Furthermore, there is only one study (Pearson et al., 2004) examining specific discharge situations from the perspectives of various individuals involved in the same situation. That study focused on the outcomes following discharge however and attempted to identify factors that put individuals at risk of an unsuccessful discharge. It did not explore influences affecting the process of planning or making discharge decisions.

The present research examined social and political influences in discharge planning with older adults and the nature of normative ethical problems that can arise in light of competing perspectives in the process. This study built on previous literature and aimed to examine social and political influences and how their intersections affected and shaped perspectives and behaviours of individuals involved in discharge planning. Additionally, this study provided an examination of the different perspectives of older adults, family members and healthcare professionals involved in the same discharge situations. This approach offered a breadth of viewpoints from which to consider the different influences on discharge-planning processes, thereby enabling a broader understanding of the nature of influences, their interpretations and intersections, as well as their potential and actual impact on discharge decisions. Finally, this study examined how older adults’ agency and autonomous choices were mediated in light of social and political influences and how the differing perspectives and behaviours of involved individuals determined discharge decisions and outcomes. This study contributes new knowledge to inform changes in the formulation of policies and practices to better align with the varied and competing needs and demands of individuals in the process.

In order to examine social and political influences on discharge-planning processes with older adults, I take a critical bioethics approach informed by relational autonomy theory.
1.1 A critical bioethics approach informed by relational autonomy theory

Critical approaches to research are concerned with questions of a social and political nature to examine the hidden forces that may be created and reproduced by social and political structures, practices and processes, as well as by systems of thought underlying these (Eakin, Robertson, Poland, Coburn & Edwards, 1996; Harvey, 2013). Critical bioethical approaches seek to examine ethical issues in the provision of healthcare in relation to social and political structures, practices and processes. Such approaches are reflexive and empirical and apply an ethical framework to research in order to generate findings that are applicable to, and informed by, clinical practice (Hedgecoe, 2004; Twine, 2010). Feminist perspectives are also concerned with the intersection of social and political structures, beliefs, practices and norms (Sherwin, 1998) and as such align with critical bioethics approaches. While feminist viewpoints were traditionally focused on the oppression of women, these perspectives have expanded to include examinations of other marginalized groups. Feminist theories of relational autonomy complement critical bioethics perspectives in their framing of individuals as inextricably embedded in their contexts (Friedman, 2000; MacKenzie & Stoljar, 2000; MacKenzie, 2008; Sherwin, 1989, 1998; Sherwin & Winsby, 2010). The focus on the inextricably embedded nature of individuals in their contexts in relational autonomy theory implies that individuals’ values, capacities, perspectives and expectations are seen as having been formed by the values, systems of thoughts, norms, and opportunities embedded in their social and political contexts. The use of a critical bioethics perspective informed by relational autonomy theory focuses on revealing the hidden and potentially oppressive intersections of power within particular social and political contexts. Relational autonomy theory complements the use of a critical bioethics perspective and sharpens the focus on the implications of dynamics and outcomes of various social and political influences.

Complex discharge-planning situations can be an ethical challenge for all individuals involved. The use of a critical bioethics perspective informed by relational autonomy theory, as it is developed in Chapter 3, provided a framework for the examination of social and political influences on behaviours and perspectives in discharge planning. Consideration of how these factors intersected illuminated conflicts, practices and outcomes that contributed to ethical challenges. This approach further incited consideration of how older adults’ autonomy is
mediated in discharge planning and how older adults may be vulnerable to oppression by family members, healthcare professionals or systemic healthcare policies and practices. Undertaking this research through the lens of relational autonomy theory challenged me as a researcher to consider which underlying beliefs, explicit approaches and conventions and norms in the setting of study were reflected or resisted by my participants, and how the intersection of these factors influenced individual and collective perspectives and behaviours of those involved and the process itself.

1.2 Research Questions

Taking a critical bioethics perspective informed by relational autonomy theory to examine the intersection of social and political influences on discharge planning, my overarching research question was:

*How is the discharge-planning process with older adults, families and healthcare professionals shaped by the dominant social and political systems and contexts?*

Sub-questions to help answer the main questions included:

*How are conventional processes, valued approaches and underlying beliefs influencing older adults’, family members’ and healthcare providers’ perceptions of their roles, duties and responsibilities in the discharge-planning process?*

*How are conventional processes, valued approaches and underlying beliefs intersecting to influence how autonomy is mediated in decision making?*

*How are conventional processes, valued approaches and underlying beliefs intersecting to influence decisions and outcomes of discharge planning with older adults in inpatient rehabilitation settings?*

The research purposes are:

- To explore discharge planning from the perspectives of older adults, family members, and healthcare professionals;
- To examine social and political influences affecting discharge perspectives, behaviours and practices in discharge planning with older adults;
- To explore how discharge recommendations, decisions, processes and outcomes for/with older adults are influenced by social and political influences.
1.3 Clarification of terminology

Throughout this thesis, terms and phrases that can have different meanings are used. In order to avoid misunderstandings, I delineate here what I mean when using particular terms.

**Social and political context** – In this thesis I discuss individuals with respect to their social and political contexts. In line with Turner (1997), I consider the ‘social’ aspects of contexts to be related to individuals living among other individuals; within the context of this society, social aspects such as unspoken beliefs, values, norms and behaviours are formed. My use of ‘political’ refers to aspects of the contexts that are related to governments and societal leadership (Merriam Webster, n.d.), which in turn relate to laws and policies as well as the structure of institutions. I also consider that these two are very closely interrelated and strongly influence each other.

I consider that individuals are embedded within various micro and macro social and political contexts. These, could for example include the context of their immediate family, of their extended family, or of their community. It could also include the context of the inpatient care unit where I did my research or of an urban centre in a province in the country of Canada. A number of delineations of social and political contexts exist for each individual.

While I rarely depict specific policies or political structures in the discussion, embedded in the various contexts are laws, policies and systems of thought that guide the development of infrastructure, processes, practices and norms, as well as reinforce, shape and create new laws, policies and systems of thought. For example, as Canadian citizens residing in the province of Ontario in this urban centre, the participants live within a particular socio-political structure, where laws that govern legal and illegal behaviour have been determined at all levels of government and are applied. Policies determining the nature and quantity of health care that is allocated to each individual have been determined by the federal, provincial and district Local Health Integration Networks (LHIN). All individuals are subject to these in the determination and distribution of their healthcare. Similarly, policies governing the behaviours, capabilities and limitations of healthcare professionals are imposed by federal, provincial and professional regulatory policies.
The focus of this study was not to conduct a policy or discourse analysis. (Please see below for an explanation of the term ‘discourse’.) Rather, this work examined individual perspectives within the social and political contexts of discharge planning with older adults and explored how these influenced individual actions in discharge planning. When I mention social and political contexts I am referring to the written and unwritten, implicit and explicit, contextually-specific influences that influence, shape, and govern individual behaviour.

**Discourses**: Discourses are particular ways of thinking and behaving based on specific knowledge, practices and systems of thought that circulate within social and political contexts. Discourses can be viewed as interrelated systems of knowledge, and the practices that are associated with this knowledge (Seale 2004). Put more simply, discourses include beliefs, views or ideas that pervade throughout society, which then affect and potentially shape all actions by all individuals. Discourses are shaped, influenced and reproduced by knowledge and behaviours, which are themselves shaped by discourses.

**Client or patient** – In contemporary Canadian healthcare systems many terms are used to delineate individuals who are receiving health care. For the purposes of this thesis, based on the terminology used by my participants, I will use the terms ‘client’ and ‘patient’ interchangeably to refer to individuals receiving care.

**Healthcare system** – By ‘healthcare system’, I mean the sum of all healthcare institutions and services, which are governed by institutional, municipal, provincial and federal policies.

**Long-term care** – My use of the term ‘long-term care’ aligns with the definition provided by the Ontario Ministry of Health and Long-Term Care, which describes long-term care homes as:

[facilities] designed for people who need access to 24-hour nursing care, supervision or higher levels of personal care. These homes are also known as nursing homes, municipal homes for the aged, or charitable homes (Ontario Ministry of Health and Long-term Care, n.d. a)

Long-term care homes are considered to be individuals’ permanent residence.

**Individual** – Susan Sherwin (1989) states that:

although we may consider the individual to be a key unit of ethical analysis to the extent that we value persons as unique individuals whose lives are of concern to us, most
feminists reject the assumption of individualism underlying contractarian approaches to ethics through which individuals are encouraged to consider themselves and their interests as independent from others. Persons do not exist in abstraction (i.e., not apart from their social circumstances)... Moral analysis should examine persons and their behaviour in the context of political relations. (p.64)

In alignment with this perspective, I use the term ‘individual’ to denote unique beings and their unique sets of circumstances (including but not limited to their identities; strengths; capabilities; difficulties; social, political and physical environments; and what these may offer to, or demand of, individuals and social relationships). My use of the term ‘individual’ denotes the unique intersection of the individual in his or her circumstances, but defines the individual as embedded in, and indivisible from, the aspects that compose the circumstances.

**Community Care Access Centre (CCAC) and Local Health Integration Network (LHIN) –**

Publicly funded health care in Ontario is regulated through the direction of 14 geographically delineated Local Health Integration Networks (LHINs) (LHIN, n.d. a). Each LHIN is a not-for-profit corporation that integrates and funds health services for their geographic area including hospitals, Community Care Access Centres (CCACs), community support services, long-term care, mental health and addictions services as well as community health centres (LHIN, n.d. b). Each LHIN is also connected to one or more Community Care Access Centres (CCAC), which provides the coordination of home care and long-term care, information and referral, certain services, pieces of equipment and supplies (Williams et al., 2009).

**1.4 My positionality**

Critical approaches reject the idea that research is ‘value-free,’ but rather acknowledge that research is completed by individuals within a social process, which inherently locates the research within social and political contexts (Green & Thorogood, 2009). The use of reflexivity enables researchers to acknowledge the social and political contexts in which they and the research are located (Eakin et al., 1996). Taking a critical bioethics approach to the research therefore demands an examination of my positionality in relation to the object of study, as well as the examination of how my own position may influence my conduct, analysis and interpretations of my research.

My musings about the influence of home on one’s life, about power differentials, and about the oppression of vulnerable individuals began when I was twenty-two. Having just
finished an undergraduate degree in math and physics, I sought a contrast from my academic education and moved to a rural setting to live in a L’Arche\(^2\) community with adults with disabilities. There, I met a woman very close to my age whom I will call Krista. Krista had a rare form of muscular dystrophy. When Krista was born, she had been given up for adoption as her parents felt that it would be too difficult to care for her. When her sister was born with the same difficulty, the parents felt they could not give up two daughters, but feared that bringing up both girls would be too difficult. They kept the younger child.

In getting to know Krista, I became acutely aware of how similar we were in what we sought and hoped to get out of life. We both wanted to love, to be loved, and to see and experience as much as we could, yet the circumstances that were shaping our lives, and what opportunities were offered to each of us had been, and would continue to be, so very different. Krista had grown up in orphanages and long-term care institutions. There were few opportunities for disabled children in her rural community. Krista had been segregated in ‘special needs’ classes until she finished high school, at which point she had moved to L’Arche as a full-time core member. On my end, I had grown up in a loving home with my parents and brothers. I had had a breadth of opportunities and the support to develop the capabilities and means to complete a university degree. I had the luxury of taking a year to do as I pleased. The mere fact that I was ‘volunteering’ to help Krista and others while they had little choice in where they lived, what they did and who was helping them with intensely intimate and personal aspects of their lives and bodies provided for me a stark contrast of the differences in our lives and circumstances, and of the great opportunity and power differentials that existed between us.

This contrast illuminated a perspective that individuals’ lives are not just the product of what they do with the opportunities they are presented as I had been told in my white middle-class capitalist and socialist context, but that the specific opportunities that arose were shaped by the social and political contexts in which individuals lived. Additionally, this experience first meaningfully placed me in the position of being an outsider. Of all the places where I have been,

\(^2\) L’Arche is an international organization concerned with the inclusion of intellectually disabled individuals in community life. L’Arche provides residential and non-residential programs to offer customized opportunities to disabled and non-disabled persons to “discover, develop and share their unique – and often hidden- talents” (n.d.). In L’Arche communities, approaches are tailored to individual capabilities and needs in order to maximize individuals’ autonomy in determining the circumstances of their lives and the activities in which they partake.
the L’Arche community was the one that offered to disabled individuals the greatest level of agency, dignity, opportunity and choice, yet power differentials remained. Some individuals were core members and some were assistants. Although L’Arche promoted a view that I share - that everyone has something to learn and everyone has something to teach - core members were helped and stayed the rest of their lives. Assistants came, helped and went. Invisible barriers shaped each person’s opportunities and choices. This personal experience and the particular contrast between Krista and me illustrated for me the power differentials inherent in our social and political contexts and what impact such invisible delineations might have on individual lives.

Several years later, in my position as an occupational therapist in a complex continuing care facility, I was struck by the similarities and differences between this setting and L’Arche. Both were settings where individuals lived for a significant period of time and potentially even the rest of their lives. Both settings overtly aimed to provide care to meet the perceived needs of individuals who required assistance. In contrast to L’Arche, however, in complex continuing care individuals had little to no choice about aspects of their care or of the opportunities they had for activities. There was a marked difference in how ‘core members’ were perceived, addressed and respected in comparison to ‘patients’ in complex continuing care.

As an occupational therapist, I found myself in the role of a healthcare professional in possession of all the powers and expectations that accompany such a role. Later working in inpatient rehabilitation, I could influence the living circumstances of my older adult clients. I had the power to assess and make determinations about cognitive capabilities. I advised the doctor about whether or not individuals should have their driver’s licence revoked, thereby affecting their potential to get around. I had the power and was expected to make recommendations that influenced discharge decisions, and therefore whether individuals returned home or moved to different settings. In doing so, I was influenced by my impressions of what home was at L’Arche or in complex continuing care, and what it looked like for me in terms of my own freedom and independence as a white, able-bodied, single, educated, employed and self-supporting woman. Looking at the healthcare system, what services were offered, for whom and for how long, and seeing what differences existed for individuals having various life circumstances or attributes, I became very uncomfortable in my role of healthcare professional with all of the power I had over individuals’ lives. Who was I to make recommendations when
these decisions made so little difference to my own life once the patients had been discharged? In addition, limitations in the system restricted the options available to my clients and thereby inhibited my potential to provide care that I deemed to be of value. How was I supposed to uphold what I felt was in the patient’s best interests when my time with them was so limited by the heavy caseloads and shortened lengths of stay? How was I supposed to create a discharge situation for them that met their wishes and our collaborative understanding of their needs in light of the limited options in the healthcare systems?

Putting all of these experiences together, I remain acutely aware of the contrast in the agency experienced by Krista as a core member in the L’Arche community, by older adults as patients in complex continuing care or in rehabilitation, and by me in the various roles and positions that I hold. These experiences sensitized me to inequities and brought me to the study of their nature and influence in discharge-planning processes with older adults. As the researcher conducting this study, I bring the perspective that while chance may dictate where one is born and in what body, social and political forces mediate the opportunities that are available to each individual in his or her contexts and in relation to his or her body. I bring my experience as an insider as well as an outsider having relative degrees of power attributed to me because of my body, my abilities, my experiences, and my current roles. In the research setting, I was both an insider and an outsider in different aspects in relation to the various participants.

In relation to the older adults, I was an outsider because I was much younger, did not have mobility challenges and was not in the precarious position of not knowing where I would go. Additionally, I was not perceived as being dependent on others as the older adults reflected they were. I was also an outsider as a student, researcher and healthcare professional.

Similarly with family member participants, I was an outsider again because of a difference in age and in my position as a student, researcher and healthcare professional, but I was an insider as a person having aging family members and being concerned about balancing various needs and navigating healthcare systems.

In relation to the healthcare professionals, I was an insider because I am also a healthcare professional and I have worked in a position similar to theirs. I was perceived to understand some of the struggles they experienced in relation to role and service limitations and
expectations. I was also of a similar age and social class as many of the healthcare professional participants. I was an outsider however because I was not part of that team and was in the role of a researcher. My being an insider gave them a level of comfort and understanding and enabled them to share with me details of their experiences that they may not have shared with someone they felt would not understand. As an outsider to the team however I may be given the putatively “right” answers and descriptions that aligned with and promoted contemporary institutional and professional healthcare rhetoric. Additionally, as an outsider with respect to all perspectives, I was able to see connections and relationships that may have been difficult to depict for those embedded in them.

As a healthcare professional having practiced in a setting similar to that of the study, I brought my experiences and expectations. These inevitably shaped my observations and understanding of the research environment. I attempted to be aware of my experiences and how these may be influencing my perceptions in data generation and analysis through the practice of writing frequent memos and engaging in discussion with my supervisors.

1.5 Organization of the thesis

In Chapter 2 I review the existing literature about discharge planning with older adults. In this review, I first present descriptions of the process of discharge planning from inpatient care services. I then consider involvement in the process in terms of what is meant by ‘involvement’, who is involved, and how the context- or setting- specific influences may affect involvement or related practices. I finally explore discharge planning with the specific population of older adults and what ethical issues related to this process might arise.

In Chapter 3 I elaborate on the theoretical approaches guiding this work. I describe a critical bioethics perspective and situate this approach in terms of critical social science, bioethics and feminist perspectives. I then develop the theoretical underpinnings of relational autonomy in relation to traditional frameworks of autonomy and depict the interpretation of relational autonomy that informed the research.

The fourth chapter includes a description of my methodology, and my rationale for selecting specific approaches to data generation and analysis. In this chapter I describe the study setting, the participant sample and my recruitment, data generation and analysis procedures.
Chapter 5 describes the sources of data and presents interpretive descriptive findings. The five cases are explained through descriptions of the circumstances, of the different individuals involved, of their perspectives on their own situation with respect to the discharge-planning effort, and of the discharge process in that scenario. The process of data generation for each case study is reviewed before the presentation of the details of each case.

In Chapter 6 I share the results of the cross case data analysis. This presentation is structured into three different sections: Underlying beliefs influencing discharge planning; valued approaches in the provision of care and their effect on discharge planning; and conventional practices and processes. These are described individually and their interrelationships are briefly considered before being discussed in greater detail in Chapter 7.

Chapter 7 provides a discussion of the findings in relation to the literature, and in consideration of potential implications of the findings with respect to the aims of discharge planning and the provision of healthcare services. This chapter is separated into three sections. The first provides an examination of how the underlying beliefs, valued approaches and conventional practices identified in the analysis intersect to marginalize older adults in the discharge-planning process. The second identifies the conflict between the aim of rehabilitation to maximize function and the prioritization of safety and discharge in this setting, which inherently precludes interventions aiming to maximize function. The third section examines the trend of frequently recommending 24-hour care. In this section I argue that such a practice reduces considerations of older adults ‘best interests’ to the promotion of their safety and does not meet the needs of older adults.

Finally, in Chapter 8 I discuss some ethical considerations related to the results of the analysis. I explore the links between a relational approach and client-centred practice, and make suggestions for clinical practice informed by a relational approach that may address some of the ethical considerations. I discuss the contributions of this research to clinical practice as well as to the realm of research in the area of discharge planning and healthcare provision for older adults, and make suggestions for further research. Lastly, I consider some of the methodological, research, and clinical implications, as well as the limitations of this work.
Chapter 2

Review of the literature

2 Introduction

Discharge planning is the complex process of preparing for an individual to be released from a healthcare service (Bauer, Fitzgerald, Haesler & Manfrin, 2009). This process is determined by setting specific policies and practices related to the provision of these services, which are in turn shaped by financial limitations, values and priorities of the institution, and by government policies. Discharge planning with older adults may involve many different stakeholders including the older adult, family members, and healthcare professionals. Involved individuals may have very different backgrounds and experiences, and as such may approach the situation from distinct perspectives and with different agendas. Furthermore, there can be differing expectations about older adults’ autonomous choices in discharge planning and how these should be upheld and balanced with family wishes and professional priorities. With all of these intersecting influences, it can be unclear who or what is driving the process and being prioritized in determining outcomes.

In this chapter I review and analyze how discharge planning with older adults has been approached, investigated, discussed and critiqued in the literature. Discharge-planning processes are relevant to any level or type of healthcare service (e.g. inpatient or outpatient services). Although the focus in this research is discharge from older adult inpatient rehabilitation settings, due to the limited amount of literature focussed on discharge planning from such settings, in this review I consider literature about discharge planning with older adults from all inpatient healthcare settings. Both clinical and theoretical literature is included with the exception of literature specifically focussed on relational autonomy, which is discussed in Chapter 3.

I begin with a description of my search strategy. I then provide an examination of the discharge-planning process as it is described in the literature and include an overview of how of older adults, family members and healthcare professionals are reported to be involved. I discuss the influence of context-specific attributes shaping the process such as length of stay and funding
policies. Finally, I consider how discharge planning is unique with the older adult population and may present ethical challenges.

2.1 Search strategy

In order to obtain literature in the area of older adults and discharge planning, I searched the following 20 databases: AgeLine, ASSIA: Applied Social Sciences Index and Abstracts, Biological Sciences, BIOSIS Previews, CINAHL, Conference Papers Index, Embase (1947 – March 7, 2013), Francis, General Science Abstracts, HealthSTAR (1966 –March 7, 2013), ISI Proceedings, Medline (OVID) (1950 – March 7, 2013), Philosopher’s Index, PsycInfo (1806 – March 7, 2013), PubMed, Scopus, Social Sciences Abstracts, Social Services Abstracts (1968 – March 7, 2013), The Cochrane Library, and Web of Science. These databases were selected because the University of Toronto Libraries classifies them as including literature relevant to the fields of research informing this study: bioethics, aging, rehabilitation, occupational therapy, and medicine. The primary concepts of interest were older adulthood, discharge planning, and autonomy.

The following sets of search terms were used:

- For concepts of aging: (Older OR Senior* OR Ageing OR Aging OR Geriatric* OR Gerontolog* OR Aged OR Elder*);
- For the process of discharge planning: (“discharge plan”* OR “discharge-plan”* OR “patient discharge”);
- For autonomy: (“Relational autonomy” OR “personal autonomy” OR “functional autonomy” OR “patient autonomy”).

These search terms were initially compiled in collaboration with my research supervisors and then broadened with the advice of a University of Toronto Libraries research consultant having a specialization in healthcare research. Searches used the following combinations of terms:

- Only the phrase “relational autonomy”;
- The set of terms relating to aging AND the set of terms relating to discharge planning AND the set of terms relating to autonomy;
- The set of terms relating to discharge planning and autonomy.

The sum of these searches yielded 1121 articles, books, or book chapters. I first read the titles of each and retained all articles having titles that either a) discussed relational autonomy or autonomy, as well as decision making with older adults; or b) addressed discharge planning in the older adult population. I excluded titles that were a) focused on a different population or
issue; b) drug studies; c) specific to mental health diagnoses or psychogeriatric teams; d) evaluations of intervention outcomes. Following this initial culling, 312 works remained. Using the same exclusion criteria, I read the abstracts of these works and further reduced the included literature to 113 works. If works did not have an abstract I retrieved the full text to evaluate its applicability to this research. I read the remaining 113 works in their entirety, and also hand-searched their reference lists to identify further relevant citations. Again, I excluded works using the same criteria. The majority excluded at this point were eliminated because they were concerned with outcomes after discharge or because they were not focused on discharge planning. A total of 71 works are included in the review. These consist of four books, ten book chapters and 57 journal articles. In order to present a broad overview of discharge planning, literature was not excluded based on quality; the strengths and weaknesses of studies, however, are discussed where relevant.

The 71 pieces of literature reviewed include quantitative (n=6), qualitative (n=17), and mixed methods studies (n=8), as well as theoretical articles (n=33) and reviews (n=7). The literature includes research that was conducted mainly in developed countries including Australia, Canada, England, New Zealand, Norway, Scotland, Sweden, and the United States. The literature is diverse and includes such research foci as examinations of individual experience in discharge planning, studies aiming to identify factors that served as enablers or barriers to the process, and theoretical literature that explores ethical issues in discharge planning with older adults.

In the remainder of the chapter, I summarize the literature to first present an overview of discharge-planning processes in section 2.2.1. In section 2.2.2 I then examine how and to what extent older adults, family members and healthcare professionals are involved in discharge planning and in section 2.2.3 I consider the influence of contextual attributes on the process such as policies guiding funding and length of stay. Finally, in sections 2.3 and 2.4, I discuss how the process of planning for discharge with the older adult population presents with unique challenges and ethical issues. A more specific examination of the literature about various conceptions of autonomy and how these are discussed in the literature with respect to discharge planning is included in Chapter 3.
2.2 What is discharge planning?

2.2.1 What does the discharge-planning process entail?

Discharge planning is broadly conceptualized as an interdisciplinary process aiming to prepare for an individual’s release from a healthcare service (Atwal, 2002; Bauer et al., 2009; Brown, 1995; Cummings & Cockerham, 1997; Jackson, 1994). Based on their review of English-language literature about discharge planning with older adults published between 1995 and 2008, Bauer, Fitzgerald, Haesler and Manfrin (2009) summarize ‘successful’ discharge planning as “the development of a comprehensive and effective plan to meet the needs of the patient after discharge with a goal of maintaining or improving health outcomes” (p.2540). Various authors also suggest that in addition to the development of a plan, successful discharge planning entails patient assessment, the provision of information to patients and their involved family members or caregivers, as well as the coordination of follow-up services and evaluation of the discharge plan (Bauer et al., 2009; Huby et al., 2004; Jankowski, Seastrum, Swidler & Shelton, 2009). To summarize, there is a broad consensus that the central aim of discharge planning is to prepare for their discharge individuals who are being released from hospital and their families, and to ensure their care needs will be met where they go.

A multidisciplinary approach to discharge planning is commonly reported in the literature. An element in this process is a multidisciplinary discharge-planning family conference (also called a ‘family conference’ in this text), which is attended by older adults, family members and healthcare professionals (Efraimsson et al., 2006; Griffith, Brosnan, Lacey, Keeling & Wilkinson, 2004). The family conference is intended to be a collaborative information-sharing forum where everyone is working towards the same goals in creating a plan for discharge and where patients and family members can participate in decision making (Efraimsson et al., 2006; Griffith et al., 2004). Efraimsson and her colleagues (2006) state that this meeting is intended to uphold ‘autonomy and integrity’ as it is a means to include patients and families in the discharge-planning process. They state that the aims of the family conference are: “to make a patient’s relocation from hospital as easy as possible, to secure quality of care in home care settings, and to reduce readmissions” (Efraimsson et al., 2006, p.647). The discharge-planning family conference is therefore used to further promote these aims in some settings.
One of the aims of discharge planning identified in the literature is to maximize the efficiency of healthcare services by both reducing lengths of stay as well as decreasing the number of readmissions following discharge (Bobay, Jerofke, Weiss, & Yakušheva, 2010; Crennan & MacRae, 2010; Cummings & Cockerham, 1997; Moats, 2006; Pethybridge, 2004). Some researchers suggest that economic efficiency is the primary goal of the discharge-planning process, intended to meet the cost-reduction needs of the healthcare system rather than of the individuals involved (Moats & Doble, 2006; Pethybridge, 2004).

In summary, discharge planning is conceptualized ideally in the literature as a process of shared planning and decision making by patients, families and healthcare professionals in preparation for the termination of one type of healthcare services. Planning includes deciding how and where an individual’s needs will be met, and putting in place resources to meet anticipated needs. Additionally, expected discharge-planning outcomes include maintaining and improving health, maximizing cost efficiency by reducing lengths of stay and decreasing readmissions. Questions are raised in the literature regarding whether or not collaboration is achieved in planning for discharge, and whether or not the aims of discharge planning are impeded by local practices or processes (Dill, 1995; Huby et al., 2004; Leclerc, Wells, Craig & Wilson, 2002; Moats, 2006; Pethybridge, 2004; Potthoff, et al., 1997; Rydeman & Törnkvist, 2006; Watts et al., 2005; Wells, 1997). Having explored broad descriptions of discharge planning and its intended purposes, I now move to review research exploring the different roles and levels of participation of various individuals involved in discharge planning.

2.2.2 Who is involved in discharge planning and what setting-specific factors may influence participation in the process?

Research suggests that good collaboration between patients, families and interdisciplinary healthcare teams facilitates discharge-planning processes (Bull & Roberts, 2001; Cummings & Cockerham, 1997; Dill, 1995; Rydeman & Törnkvist, 2006). Reports about patient and family member involvement however are varied and are contradictory over time and place. Some early quantitative research indicates that older adult patients and their families are included in discharge-planning decision making, while other qualitative, mixed methods and quantitative studies suggested older adults and family members have limited involvement. These differences may be largely attributed to how family involvement is defined and assessed across the studies.
Older adult and family involvement

What is meant by older adult and family ‘involvement’ or ‘participation’ in discharge planning and how this was measured varies widely in the literature. These terms tended to be used interchangeably. In some qualitative studies exploring different roles in discharge planning (Atwal, 2002; Huby et al., 2004; Pethybridge, 2004), no descriptions were included to accompany observations about levels of involvement or participation. In two studies involvement was not defined and was measured using descriptive phrases such as ‘very involved’ or ‘not involved’ on a rating scale completed by older adult patients (Brown, 1995) or by healthcare professionals or family caregivers (Clemens, 1995). In another study, Abramson (1988) determined involvement using the number of hours healthcare professional participants reported they spent collaborating with different individuals (older adults or family members) in discharge planning in conjunction with nine questions measuring their perceptions of older adult and family participation. These nine items measured awareness of medical issues, functional limitations and discharge options as well as what was briefly described as ‘evidence of discussion, planning activity and decision making’. A second more recent study (Foss & Hofoss, 2011) also used a nine-question measurement tool; however, the questions in this second study differed from Abramson’s (1988). Six of the questions were related to how much information participants had received and how much of a contribution they had been enabled to make, and three questions were related to how important various aspects of the discharge plan were to them. The difference in questions may in part be related to the difference in participant perspectives in the study; Foss and Hofoss (2011) explored older adult participants’ perspectives of their own participation in discharge planning while Abramson (1988) explored social workers’ perceptions of older adult and family participation.

In addition to variations in definitions and methods of measuring participation, reports of older adult and family member participation in discharge planning also varied in the literature (despite older adult and family member participation being included as an important attribute in

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3 Abramson (1988) validated her use of the sum of the scores on the nine questions as a measurement tool by comparing the sum to a subjective percentage of participation attributed to individuals by the healthcare professionals. Based on internal consistency between the sum of the nine questions and the subjectively attributed percentages of .94 using the Alpha reliability coefficient, the researcher determined the sum of the nine questions to be a valid measure of older adult and family member participation.
discharge planning definitions described above.) Two quantitative studies reported high older adult involvement in discharge-planning processes. In the study by Abramson mentioned above, the author surveyed 57 social workers on the participation of older adults and their family members in the discharge of 148 older adults from five different acute care hospitals in the United States. Using a five-point scale, the participating social workers rated 71 percent of the older adults and 90 percent of families as having a high level of participation in discharge planning. These social workers reported spending 3.9 hours with patients planning for discharge, and 5.7 hours with patients’ families, suggesting that overall, although older adults were involved in discharge planning, their families were more involved. Further analysis by the author showed that lower older adult participation was linked with lower physical or mental well-being and higher family involvement (Abramson, 1988). Brown’s (1995) telephone survey examining the perspectives of 140 older adult patients’ following their discharge-planning process corroborated Abramson’s (1988) finding of high patient involvement in discharge. Also in the United States, Brown found that 76 percent of patients reported that they were either very involved or somewhat involved in the discharge-planning process (1995). Brown’s results, however, contrasted with Abramson’s in that Brown found that 86 percent of the older adult participants felt their family members were not involved in discharge planning whereas Abramson found that social workers reported high involvement of family members (1988). Considering the results of these two studies together, both older adults and social workers reported that older adults were involved in discharge planning, but reports about family involvement differed. Differences in the findings about family involvement may have been due to the seven year gap between the two studies, but may also have resulted from the difference in the perspective of participants (e.g. older adults or social workers).

In comparison to these two American studies reporting high older adult and family involvement (Abramson, 1988; Brown, 1995), eight studies using various methodologies reported little to no older adult and family member involvement in discharge planning. Such results were recently reported by Norwegian researchers Foss and Hofoss (2011) who used quantitative survey methods similar to Brown (1995) to examine older adults’ perspectives on their participation in their discharge-planning process. In contrast to Brown’s results almost twenty years earlier in the United States, Foss and Hofoss (2011) found that of the 254 older adults surveyed, 58 percent responded that they participated in decisions for discharge to a
‘minor degree’ or ‘not at all’. Unsurprisingly, fewer than half of these same older adults felt that they had been given sufficient information about their discharge options (Foss & Hofoss, 2011). In this same study, more than 60 percent of older adults reported that it was important to them to a moderate or high degree to be involved in decisions about medical treatment, the time of discharge, and how to solve practical issues related to discharge. These numbers rose to around 80 percent if responses of ‘important to a minor degree or more’ were also included (Foss & Hofoss, 2011). These results suggest that, at least in Scandinavia, the outcomes of discharge planning are important to older adults and that they desire both more information and a greater role in the process.

In addition to Foss and Hofoss’s (2011) quantitative study, authors using mixed methods and qualitative work also reported findings of older adults and family members having little involvement in discharge planning. Clemens (1995), for example, conducted a mixed-methods study examining perceptions of 37 healthcare professionals and 37 family member caregivers in which she also found that older adults were generally seen as ‘minimally involved’ in their discharge plans, if at all. Similarly to Brown (1995), Clemens’ study was also in 1995 and set in the United States; differences in findings could potentially be attributed to the difference in participant perspectives as Clemens had interviewed healthcare professionals and family caregivers, while Brown had surveyed older adults.

More recent qualitative work using observations and interviews with older adults and healthcare professionals, supported findings of low older adult participation. Three British studies and one Canadian study all reported low older adult involvement. In England, Pethybridge (2004) used qualitative methods including twelve weeks of ward observations, focus groups and interviews with members of six inpatient healthcare teams to investigate the factors that promoted or inhibited discharge-planning processes for older adults returning home from hospital. In this work, Pethybridge expressed surprise that patients were not considered in decision-making processes despite the decisions being made about them. Atwal’s (2002) qualitative study presents another example of low older adult involvement in Britain. This author examines the perspectives of 19 nurses working in an acute physical care unit about the process of discharge planning. The findings did not report patient or family involvement in any of the discussions for discharge (Atwal, 2002). Still in England, in their qualitative research
using conversational interviews to examine the perspectives of 23 older adults who experienced delays in their discharge, Swinkels and Mitchell (2008) found that older adults tended to be ‘uninvolved’ in their discharge-planning process. These participants reported that they felt powerless to affect the discharge-planning process and relinquished involvement to others they perceived as having more expertise and knowledge, or who were in better health (e.g. their children) (Swinkels & Mitchell, 2008). In a Canadian study using photovoice and in-depth interviews examining 14 older women’s perceptions of their discharge-planning process, LeClerc, Wells, Craig and Wilson (2002) found that few of the participating women could articulate the discharge-planning process or what had been put in place in preparation for their return home. These authors interpreted this finding to mean that the women had had little involvement in their discharge-planning process.

Thus, the participation of older adult and family members in discharge planning varied with different participant perspectives, research settings and countries, as well as over time. Professionals tend to rate older adult and family participation as higher than clients do. More recent studies generally suggest that older adults’ participation rates are low. My research built on the findings of these studies by examining older adults’, families’, and healthcare professionals’ perspectives on the contributions of each in the discharge-planning process in a Canadian context.

**Setting-specific practices influence older adult and family involvement**

Setting-specific influences on older adult and family involvement may not be easily captured using quantitative methods or were not investigated in the studies described above. Two ethnographic studies investigated the influence of setting-specific practices on older adult involvement in discharge planning.

In a Canadian urban centre, Wells (1997) conducted an ethnography examining the discharge-planning process in a large acute care facility where she found that patients and families felt that they were not sufficiently involved in discharge-planning decision making. Wells found that older adults felt they were “being asked to act on decisions made by professionals without being given adequate information” (1997, p. 693). Wells linked older adult participants’ perceptions of a lack of information and insufficient involvement in discharge planning to the healthcare professionals’ practice of making discharge decisions during formal
inter-professional rounds and informal professional communications, both being situations from which older adults and family members were excluded. She concluded that the setting-specific systemic organization of discharge planning and the related practices precluded the involvement of patients and their families in the discharge decision-making process.

Wells’ (1997) findings were supported by a more recent ethnographic study by Huby and her colleagues that included observations of interactions and meetings involving healthcare professionals and patients, as well as semi-structured interviews with 22 older adult patients and 11 key informant healthcare professionals (Huby et al., 2004, 2007). These authors found that in the institutional culture in which they conducted their study, discharge-planning processes focussed heavily on institutional risk management (Huby et al., 2004). This risk-focussed approach relied greatly on formal assessment of patients’ cognitive and physical abilities, which prevented the natural exchange of views and “excluded both patients and staff from active decision making, something, which, in turn, removed all parties’ control of the situation and produced new risks” (p.115). In a later paper, Huby and her colleagues (2007) identified that care processes in the inpatient care units “structured interactions and prevented engagement and negotiations between staff and patients about discharge” (p.65). These authors further observed that assessment practices and the structure of formal meetings precluded open communication between patients and healthcare professionals.

Not only did they find that specific practices impeded communication, Huby and her colleagues (2004) also found that patients were reluctant to be involved in discharge decisions. Patients expressed that they had declining physical and cognitive capacities, and as such, they deferred discharge decisions to younger members of their family or to the healthcare professionals whom they perceived to have more knowledge (Huby et al., 2004). Older adult patients also feared that their participation in decisions might be interpreted as criticism of the care they were receiving or of the decisions being made on their behalf and they did not wish to be seen as complaining (Huby et al., 2004). A similar reluctance was expressed by patients in the previously-mentioned study by LeClerc and her colleagues (2002), in which the older women participants did not wish to be perceived as complaining about their care for fear that their care would be affected; as a result they did not participate in decision making. These four studies (Huby et al., 2004; Huby et al., 2007; Leclerc et al., 2002; Wells, 1997), set in Scotland and
Canada, indicate that for both personal reasons as well as in response to setting-specific practices, patients and family members are not as involved as they could be or as they might desire to be in discharge-planning processes. The present study explores the question of what is impeding involvement and how participation can be enabled.

While the literature suggests that discharge planning is intended to be a collaborative process between older adults, family members and healthcare professionals, there are differing accounts about how much older adults and their families are indeed involved. Some of the variation may be due to the different perspectives examined in the studies (e.g. older adults, family members or healthcare professionals), or may also be due to the different times and locations in which the studies were conducted, which may reflect different contextual foci to care. Nonetheless, there were differing levels of participation in different settings. This implies that setting-specific factors enable or impede older adult and family involvement in discharge planning. The identification of such influences will serve to inform the development of policies and practices to better enable older adult and family involvement in discharge planning.

2.2.3 Setting-specific fiscal policies and their influences on the process

While institution or setting-specific practices influence older adult and family member involvement in discharge planning, on a broader scale and at various levels, policies that determine what services are offered, for whom they are funded, and for how long. These policies in consequence shape practices and processes that affect, as previously mentioned, older adult and family member involvement as well as discharge-planning outcomes. (Note that, in Canada, policies shaping healthcare can be federal or provincial as well as institution-specific; in Ontario, policies can also differ based on district specific Local Health Integration Networks.) In the literature, various institutional and regional policies and practices are reported to affect discharge-planning outcomes in many countries in the developed world (Dill, 1995; Huby et al., 2004; Moats, 2006; Pethybridge, 2004; Potthoff et al., 1997; Rydeman & Törnvist, 2006; Watts et al., 2005; Wells, 1997). Common threads across these studies are twofold: the pressure of shorter lengths of stay, and the impact of funding structures on options for care. These two threads will be discussed separately.
**Length of stay**

Policies and payment systems influence the amount of time that is afforded for care, and consequently for discharge planning. Policies limiting lengths of stay can pressure healthcare professionals involved in discharge planning to make discharge decisions quickly, which can in turn affect the decision-making practices as well as the involvement of various individuals in making decisions (Moats, 2006). Moats (2006) conducted a unique qualitative study in which she examined contextual influences by comparing discharge-planning processes in three different settings in Winnipeg, Manitoba. The author examined the perspective of 10 occupational therapists involved in discharge planning with older adults; these included four therapists in a community acute care hospital, four therapists in geriatric rehabilitation in a tertiary care hospital, and two therapists in a specialized rehabilitation program in a geriatric facility. Although she had a small sample in each setting, Moats found considerable variation in discharge-planning processes. Specifically, in older adult rehabilitation settings, more time was afforded for the inpatient stay and for planning for discharge, which resulted in more time for assessment and involvement of older adults in the discharge-planning process. In acute care on the other hand, Moats described that a lack of time for discharge planning resulted in pressures to make decisions quickly, which resulted in less time to gather information and therefore, in more professionally-dominated decisions.

Institutional policies aimed at cost reduction may moreover promote practices for discharge-planning decision making to begin early in patient stays, as early as the point of admission to drive prompt discharges (Atwal, 2002; Wells, 1997). Shortened lengths of stay were found to result in less time for patients to recover from the acute illness that prompted the admission, less time for healthcare providers to assess patients’ previous levels of function and current prognoses, less time for consultation between healthcare professionals in their assessments, as well as less time to put services in place for discharge. All of these issues contribute to making it more difficult to predict older adults’ care needs and potential level of functioning for their return home, which impeded discharge-planning decision making (Bull & Roberts, 2001; Cummings & Cockerham, 1997; Potthoff, et al., 1997).

Shortened lengths of stay additionally result in patients and family members having little advanced notice to prepare for discharge. In a review article examining delayed discharges in
the United Kingdom, Glasby, Littlechild and Pryce (2004) identified that individuals did not have adequate notice of when they were going to be discharged, and sometimes were not told until the actual day of discharge. These authors found that rushed discharges resulted in insufficient information being transferred and a lack of attention being paid not only to the needs and abilities of older adults, but also to that of their caregivers. These consequences resulted in difficult transitions for clients and families. In a separate paper, Glasby (2004) furthermore suggested that a lack of proper notice to prepare for discharge could be contributing to the high number of readmissions of older adults in the three months following their discharge. A lack of notice for discharge could impede the potential to put required services and supports in place, thus resulting in needs not being met and readmission to hospital.

Research from the United States, Sweden, Scotland, Canada, England and Australia suggests policies are increasingly stipulating shorter lengths of stay (Abramson, 1988; 1990; Bull & Roberts, 2001; Connolly et al., 2009; Efraimsson et al., 2006; Huby et al., 2004; Kane, 2011; Moats, 2006; Mor & Besdine, 2011; Pethybridge, 2004; Potthoff et al., 1997; Watts et al., 2005; Wells et al., 2002), thereby limiting the time available for careful discharge planning to meet patient needs. Lastly, researchers note that shorter lengths of stay are resulting in individuals going home with higher medical and rehabilitation needs than in the past. Higher medical needs may require further care following discharge, which thus increases the need for discharge healthcare planning (LeClerc et al., 2002; Wells, 1997). Length of stay policies and the subsequent amount of time afforded for discharge planning can be specific to one healthcare setting or healthcare region, and are determined largely by funding. Funding policies govern not only the length of stay, but also which care options are funded, to what extent, and most importantly, who is eligible to receive these services. Furthermore, the content and amount of care offered in the institution can greatly affect what the options are for care upon discharge.

**Funding determines options for discharge**

While funding policies may determine individuals’ lengths of stay, they also determine what options for care are available to individuals upon discharge. Funding policies delineate what type of care is available, how long this care will be available, at what cost to the patient or healthcare system, and criteria of eligibility. In the United States, Dill (1995) found that context-specific pressures for efficiency and shortened lengths of stay limited communication, which, in
conjunction with limited options for care upon discharge, sped up applications to long-term care before assessments were completed and discharge decisions were made. The intersection of these pressures, limitations, and practices influenced discharge-planning outcomes. Kane (2011) found in his review of the United States discharge-planning literature published between 1990 and 2010 that an individual’s insurance plan and healthcare history dictated the type and duration of care that insurance would cover, and that financial implications often played a large role in patient or family care choices. In their theoretical article examining ethical, legal, clinical, and practice issues in discharge planning also in the United States, Swidler, Seastrum and Shelton (2007) identified similar funding implications. When long-term care is partially or fully covered by insurance and home care is paid out of the patient’s pocket, patients and families may choose long-term care despite this being a higher level of care than required (Kane, 2011). In other instances in the United States, long-term care may not be covered and thus may be prohibitively expensive for the patient and family (Swidler et al., 2007). Although these authors discuss examples limited to the United States, similar situations arise with respect to home care in Canada. Publicly funded home-care services are increasingly limited, and individuals who cannot afford private care and do not have private insurance coverage may have limited options (Aronson & Neysmith, 2001). Funding policies for care outside of the hospital may therefore have a direct impact on the outcomes of discharge planning from inpatient care services.

In their literature review and analysis of discharge-planning processes in the United States, Potthoff and her colleagues found that “discharge planning is a challenging task under the best of circumstances and changes in the healthcare environment have made it almost impossible to do such planning well” (p. 47). Healthcare policies and practices affect collaboration between patients, family members and healthcare providers; dictate eligibility criteria for care, as well as funding for services and length of stay, which then shape the processes and outcomes of discharge planning. Discharge planning in Canada and throughout the developed world is becoming ever more necessary to support the higher care needs of individuals who are being discharged “quicker and sicker” (Clemens, 1995, p.254; Jackson, 1994, p.492; Potthoff et al., 1997, p.48) as a result of decreased lengths of stay (Brown, 1995; CIHI, 2013; Moats, 2006). Policies guiding funding shape what healthcare services are funded, for how long, and for what types of individuals. This can have a direct impact on what options are available for care, as well as on the length of stay.
The amount of time that older adults, their families and healthcare professionals have for discharge planning is dependent on length of stay, which is determined through institutional and healthcare system policies and practices. As discussed above, having less time can limit the opportunity for consultation and assessment. It can also limit the time afforded for communication with individuals who may need to be involved in discharge planning. The analysis by Potthoff and her colleagues suggests that discharge-planning outcomes are determined by the complex intersection of systemic healthcare policies and practices. This is supported by the studies of Dill (1995), Huby and her colleagues, (2004), Moats (2006), Pethybridge (2004) and Wells (1997). Healthcare providers work within the boundaries of their roles. In addition, the policies and practices dictated by the institutions and healthcare systems in which they work also place limitations and pressures on healthcare providers. The intersection of systemic policies and practices suggests that given the financial, length of stay, role expectation and service constraints inherent in the systems, it is increasingly difficult to uphold patient preferences in discharge planning.

2.3 Discharge planning with the unique population of older adults

Literature from as early as 1983 through to 2012 (M. Abramson, 1983; J. Abramson, 1990; Bobay et al., 2010; Bauer et al., 2009; Dill 1995; Foss & Askautrud, 2010; Huby et al., 2007; Holm & Mu, 2012; Moats, 2006; Swinkels & Mitchell, 2008) suggests that discharge planning with older adults presents unique challenges in comparison to other populations. There may be many family members involved, entailing intricate family dynamics. Older adults also may have multiple and complex care needs. Furthermore, older adults’ caregivers may themselves be older individuals and have their own care needs and limitations. Discharge-planning decisions thus can have a significant impact on the lives of older adults and their family members.

Discharge with older adults may entail the involvement of multiple family members and thereby multiple potential decision makers. A mixed-methods study in the United Kingdom investigated difficulties resulting from family members taking on stewardship roles for older parents (Procter et al., 2001; Pearson, Procter, Wilcockson & Allgar, 2004). The three-phase study examined unsuccessful discharges (defined as readmission within six weeks of discharge or extended delay prior to discharge). In the first phase, quantitative data for 1500 discharged older adults were analyzed to determine variables that may be linked to unsuccessful discharges.
Based on these findings, the investigators selected 30 older adult patients at greater risk of readmission and interviewed them with their caregivers. They also interviewed 121 healthcare professionals involved in the care of the 30 older adult participants. The authors reported family member caregivers faced competing demands related to their own families in addition to caring for an older parent (Pearson et al., 2004). They argued that it is important for healthcare providers to understand the complex relationships between older adults and their family caregivers, as well as to consider the needs and limitations of family member caregivers in considering the amount of care they can provide in various discharge options (Pearson et al., 2004; Procter et al., 2001).

In addition to having complex family and caregiver dynamics, older adults approaching discharge may face additional risks secondary to frailty and complex care needs, resulting from medical, cognitive, functional or social conditions (Bauer et al., 2009). Older adults and their family members may have difficulty anticipating the obstacles they will face when the older adult is discharged home and may overestimate her or his capacity to cope (Jackson, 1994; Bobay et al., 2010). The literature suggests that new and increased medical needs for which older adults and their families may not be prepared renders discharge planning all the more important to help ensure that patients’ needs will be met and that they can continue recovering post-discharge (Bull & Roberts, 2001; Huby et al., 2004; Wells et al., 2002). Moreover, discharge planning with this population often requires healthcare professionals to include the needs of the patient’s family as caregivers in planning for discharge (Bauer et al., 2009).

Numerous authors have suggested that discharge planning is of particular importance for older adults because decisions made in this process can greatly affect their lives (Kane, 2011; Moats, 2006; Mor & Besdine, 2011; Potthoff et al., 1993; Rydeman & Törnkvist, 2006). As Moats (2006) suggests, “the homes of older people take on an enlarged significance, full of social rituals and symbolism, providing a sense of personal identity and continuity” (p.306). Furthermore, because of possible changes due to aging, older adults may be perceived as vulnerable and may be viewed as incapable of making decisions, whether this is the case or not (Bobay et al., 2010; Huby et al., 2004; Wells, 1997). Such changes may affect older adults’ confidence and, as noted above, they may not have the self-assurance to voice their desires for fear that this be viewed as complaining, should their wishes differ from the recommendations of healthcare professionals (Huby et al., 2004). There are thus multiple challenges to assisting
older adults in the discharge-planning process that are not generally as salient with different populations.

In their commentary about reducing re-hospitalisation after discharge, Mor and Besdine (2011) outline many of the factors that complicate the unique situations faced by older adults:

*Frail older patients and their families are generally unprepared for the flurry of activity that occurs during a hospitalization and for how quickly they must decide where to go at discharge. The biggest challenge patients and families face as they decide their discharge destination is to establish realistic goals of care in the absence of coherent information about their prognosis and options. This decision is particularly important because of the weighty implications of their choices. (p.302)*

As discussed, many researchers concur that discharge decision making with older adults is often a complex process (Crennan & MacRae, 2010; Huby et al., 2004; Mason, Auerbach & Heft Laporte, 2009; Watts et al., 2005; Wells, 1997). The importance of the decisions made and the complexity of the process suggests that a methodical approach that considers all reasonably achievable options and the advantages and disadvantages of each is required; healthcare institutions however are more likely to push for the most expedient solution (Kane, 2011), which may not always serve older adults’ and families’ needs, and may not be the most financially sound solution in the longer term. In light of the complexity of situations, the limitations imposed on the process, and the competing demands of the various individuals and perspectives involved in discharge planning with older adults, ethical and moral challenges arise that can further complicate the process and influence outcomes.

### 2.4 Ethical issues in discharge planning

The weight of the decisions made in discharge planning, the responsibilities, permissions and limitations afforded by the roles of involved individuals, and the policies and practices influencing the process can lead to ethical challenges for everyone involved. A prevailing ethical issue discussed in the literature involves competing interests and differing opinions about what to prioritize in discharge planning. Conflicting priorities are described particularly in relation to situations where patients were making choices deemed to be unsafe by healthcare professionals and family members (Denson, Winefield & Beilby, 2013; Durocher & Gibson, 2010; Kane, 2011; Moats & Doble, 2006).
Two studies specifically examined variations in values in relation to three different perspectives of individuals involved in discharge (older adults, family members or friends, and healthcare professionals). McCullough and his colleagues (1993) conducted a mixed methods study that included interviews examining the values prioritized by 23 older adults, as well as by 23 younger family members and by relevant healthcare professionals. All interviews were conducted retrospectively after discharge. The sample included individuals who had returned home with no additional care, had returned home with increased levels of care, or had moved to a more supportive setting. The authors found variation in priorities: older adults identified ‘environment, self-identity and relationships’ as the most important values; family members identified ‘care, security and psychological well-being’; and healthcare professionals identified ‘care, physical health and a tie for relationships and psychological well-being’. Interestingly, the values identified by older adults did not focus on their care needs or their physical well-being, while those identified by family members and healthcare professionals did. A more recent related mixed-methods study examining values from the same three perspectives was conducted by Denson, Winefield and Beilby (2013). These authors used a vignette to examine differences in perspectives prospectively, interviewing 10 older adults and eight family members prior to a hospital admission, as well as 18 healthcare professionals. These authors found that older adults recommended safe and restrictive options and recommended someone assist the older adult in the vignette to make decisions. Asked about their own theoretical discharge, however, older adults stated they would want to make the decisions themselves. Older adults prioritized personal care and mental capacity in decision making. Family member participants expressed the struggle to balance the autonomy of their older relative while also feeling a need to protect them. They prioritized safety, finances and the value of living at home. Healthcare professionals prioritized safety, autonomy and personal care. The results of these two studies help illuminate the range of values and potential differences between the three stakeholder perspectives.

In light of the differing values prioritized by the stakeholder groups, the question of how to honour and to respect the multiple competing priorities is ethically challenging. In his review of the literature, Kane (2011) asks “is the primary goal to preserve the patient’s autonomy and quality of life, or is safety the larger concern?” (p.287). Potthoff and her colleagues (1997) suggest that the selection of a discharge option “involves trading off factors that patients, their families, and healthcare workers may value differently” (p.48) and Procter, Wilcockson, Pearson
and Allgar (2001) point out that it is important not to assume that the needs of patients and carers and their understanding of the situation are the same. Competing priorities can thus result in ethical challenges and make it difficult to come to an agreement about a discharge plan.

Healthcare professionals may also be faced with ethical challenges when the patients’ and family’s interests or wishes conflict with the institutional policies such as targeted length of stay, as discussed above. It has been noted that discharge planners are disadvantaged by the shortened hospital stays on several counts: they do not have enough time for assessment to gather information on which to base discharge recommendations; they have insufficient time to explore all possible discharge options; and, they are rushed to make decisions (Jette et al., 2003; Potthoff et al., 1997). Time constraints often lead to premature discharge recommendations that may be inappropriate and that may create distress for the patients and families, as well as the healthcare professionals (Wells, 1997).

The pressure to discharge patients quickly can potentially lead to many outcomes including patients being discharged before they are medically ready (Wells, 1997) or precipitous decisions being made without giving individuals enough time to progress in their recovery to predict longer term levels of function (Moats & Doble, 2006). It is reported that the push for expedient discharge often takes precedence over more client-centred decision making, thus reducing the time for adequate discharge planning (Kane 2011; Moats & Doble, 2006; Pethybridge, 2004; Rydeman & Törnkvist, 2006; Wells, 1997). In such instances, healthcare professionals reported feeling that discharge-planning processes and procedures were in place for the good of the healthcare institution and not the good of the patient (Moats & Doble, 2006; Pethybridge, 2004). Collectively, these findings suggest that despite the importance of what is at stake (Kane, 2011), discharge planners may be rushed to make decisions without sufficient information to outline all reasonable options and to fully inform decision making. The intersection of competing demands and agendas creates situations of moral distress (Durocher & Gibson, 2010; Moats & Doble, 2006) and presents ethical challenges in defining a trajectory of care.

2.5 Summary and gaps in the literature

Discharge planning is the process by which plans are made to meet the anticipated health and personal care needs of individuals upon discharge from healthcare settings, and it includes the salient decision about where the individual will live. Discharge-planning decisions
determine the physical and social environment of the older adult’s home, as well as the type and amount of care they will receive and who will provide that care, all of which can have a significant impact on their health and well-being. The discharge-planning process is described in the literature as ideally involving the collaboration of many individuals including older adults, family members and an interdisciplinary healthcare team. Research shows however that the quality and quantity of involvement of older adults and their family members varies. Conventions guiding communication practices can serve to enable or to impede older adult and family members from being provided with information and from contributing to discharge planning. Additionally, the literature suggests that institutional policies and practices shape discharge decision-making processes by determining the length of stay and subsequently the time allocated to discharge planning, as well as the cost, nature and quantity of options for care upon discharge. All of these factors intersect to influence discharge-planning outcomes, and serve to shape, sustain and reinforce the roles, expectations, and practices inherent in the process. Additionally, discharge situations can be further complicated with the population of older adults as a result of changes in older adults’ and potentially their family caregivers’ cognitive and physical health, as well as by complex family relationships. The intersection of the context-specific policies and practices in conjunction with the different wishes and perspectives and potential complications related to family dynamics and changing capabilities can lead to ethical issues for all individuals involved in the process.

To date, there is little research inclusively examining perspectives of older adults, family members and healthcare professionals in discharge planning in order to provide a more comprehensive understanding of the various influences on the process and its outcomes. The majority of the literature is focussed on the perspective of one of the stakeholder groups: older adults, family members or healthcare professionals. Three of the reviewed studies examine a combination of two perspectives, and four include the perspectives of all three. Of the studies examining more than one perspective, the focus was on the outcomes of discharge (Pearson et al., 2004), the components of a proper discharge (Bull and Roberts, 2001), the discharge-planning family conference (Griffith et al., 2004), comparisons of discharge-planning involvement (Clemens 1995) and comparisons of values important in discharge recommendations (Denson et al., 2013; McCullough et al., 1993). Although these studies explore more than one perspective in discharge planning, none of these studies link individual
perspectives together. By this I mean that older adult perspectives are grouped together, and healthcare professional perspectives are grouped together, and so on. This does not permit researchers to compare and contrast different perspectives in the same set of circumstances and show how they intersect and influence each other. Such an examination enables a broader understanding of the influence of social and political forces on individual perspectives and behaviours, which in turn influence discharge-planning processes and outcomes, the utilization of healthcare services, and more specifically, the lives and well-being of older adults and their families. Moreover only three of the studies reviewed used a critical approach to examine social and political influences that may be shaping perspectives, expectations, and behaviours in discharge planning.

Three ethnographic studies reviewed above focus on the influence of setting-specific systemic practices, expectations and limitations that affected the process of discharge, as well as options for care upon discharge. Dill (1995) in United States, Wells (1997) in Canada and more recently Huby and her colleagues (2004; 2007) in Scotland found that the intersection of context-specific policies, pressures for efficiency and the resulting practices limited communication, impeded older adult participation in discharge planning and led to decisions being made prematurely, thus influencing discharge-planning options. All of these studies were conducted in large acute care hospitals and none were in rehabilitation settings. None examined multiple perspectives within the context of the same study.

My research built on findings from the reviewed studies in providing an examination of the influence of context-specific policies, practices and discourses on the process of discharge planning with older adults. Similar to some of the previous studies (Dill, 1995; Huby et al., 2004, 2007; and Wells, 1997), I took an ethnographic approach, however, unlike previous studies, I took a microethnographic case study approach (Willis, 2007). This methodology means that I examined the process of discharge planning through case studies, each of which includes an exploration of the perspectives of the three involved stakeholders: the older adults, involved family members, and healthcare professionals. This approach enabled a focussed examination of the process and of the different forces influencing individual perspectives, behaviours, and outcomes, through an in-depth exploration of the different cases and synthesis of the data in the analysis. Additionally, previous studies have been focussed on discharge planning
from acute care, while my work examined discharge planning from inpatient rehabilitation, which may engender different types of pressures than those encountered in acute care (Moats, 2006).

Finally, none of the works reviewed focuses on discharge planning by using a theoretical framework informed by concepts of autonomy. While some of the reviewed studies consider aspects of behaviours in discharge planning that could be linked to conceptualizations of autonomy (such as involvement, as well as factors affecting involvement in decision making and discharge planning), very few of the researchers directly discuss autonomy or how conceptualizations or expectations of autonomy may also be influencing discharge planning. When autonomy was mentioned, it was associated with a right to make one’s own decisions about one’s own healthcare; respect for autonomy was often perceived as being in opposition to concerns about individual safety (Abramson, 1983; Brindle & Holmes, 2005; Clemens, 1995; Moats, 2006; Stewart, Bartlett & Harwood, 2005). How individual autonomy was conceptualized was not a point of elaboration, nor were considerations of how autonomy was being upheld or undermined by underlying beliefs or explicit practices. Specific consideration of concepts of autonomy in relation to discharge-planning perspectives and behaviours could greatly inform research about discharge-planning processes and outcomes.

Relational autonomy theory portrays individuals as indelibly shaped and influenced by their various contexts and is therefore an ideal framework to guide my examination of contextual influences on discharge-planning processes with older adults. An in-depth description of the conceptualization of relational autonomy theory that informs the present research is elaborated in the next chapter along with a discussion of traditional conceptions of autonomy and applications of these in healthcare and discharge planning with older adults.
Chapter 3
Theoretical perspective and concepts

3 Introduction

In this chapter I discuss the theoretical underpinnings of the approach taken in the study: a critical bioethics perspective informed by relational autonomy theory. Critical bioethics perspectives are grounded in philosophical bioethics and align with critical social science and feminist traditions in their critical examination of how social structures and potentially hidden forces may set up situations of marginalization, exclusion or oppression and compromised autonomy. Older adults and patients in the healthcare system are two groups that have historically been vulnerable to oppression (Butler, 1989, 2009). Older adults and patients may have, or may be perceived to have, limited capacities in comparison to younger family members or to healthcare professionals. As such, even when capable, older adults and patients are thus vulnerable to being excluded or marginalized in decision making. As older adults and patients, older adult patients are in double jeopardy of having their autonomy compromised (Butler, 1989). The process of discharge planning is a critical juncture in which opportunities for disregard for older adult patients’ autonomy may arise. A critical bioethics perspective was used to frame the current research examining social and political influences and how these intersected in discharge planning to result in situations where older adults were marginalized and their autonomy was compromised.

In this chapter I first describe a critical bioethics perspective in relation to critical social science, traditional bioethics and feminist perspectives. I then take a feminist viewpoint to examine and critique traditional conceptions of autonomy. In response to these critiques, I build the conceptualization of relational autonomy that guides and informs the research. Finally, I discuss interpretations of autonomy in health care, with older adults, and in healthcare research with older adults.

3.1 Critical bioethics perspective

Critical social science perspectives are based on the idea that knowledge is located in, and structured by, existing social relations (Harvey, 2012, 2013; Kincheloe & McLaren, 2005).
Harvey (2013) states that the aim of research using a critical social perspective is to “provide knowledge that engages the prevailing social structures.” Inherently, critical approaches examine questions of equity, social justice and furthermore, societal change (Guba & Lincoln, 2005). These approaches challenge one to look deeper than the surface to examine systems of thought that are implicit in existing social and political conditions in order to explore questions of power and relationships between theory and practice (Eakin, Robertson, Poland, Coburn, & Edwards, 1996; Harvey, 2013).

Bioethics is the branch of philosophy that emerged toward the end of the 1960s to guide medical practice in light of technical medical and biological advances and the moral questions these developments raised (Fox, 1999; Jonsen, 1998). More broadly, the field of bioethics aims to address ethical questions in the provision of healthcare services, which include questions of medical ethics, research ethics, clinical ethics and biomedical ethics (Hedgecoe, 2004). The dominant discourse in contemporary bioethics is that of ‘principlism’, which directs consideration of the principles of autonomy, beneficence, non-maleficence and justice in relation to the case at hand (Beauchamp & Chidress, 2009). The field of bioethics has been criticized as providing overly rational and formal methods of analysis, and as being highly focussed on an individualistic perspective of autonomy, which abstracts bioethical reasoning from the social and political contexts in which the moral quandaries it aims to inform arise (Fox, 1999; Hedgecoe, 2004; Sherwin, 1989; Twine, 2010). Such distance from actual contexts and circumstances has resulted in a form of reasoning that is not only difficult to apply in practice, but that is also largely uninformed by social sciences (Fox, 1999; Hedgecoe, 2004).

In response to these critiques the field of critical bioethics emerged in the early twenty-first century. The phrase ‘critical bioethics’ was coined by Lisa Parker in the late 20th century (Parker, 1995) and now describes social science research that is grounded in philosophical bioethics (Hedgecoe, 2004). Put another way, critical bioethics encompasses research that is empirically rooted but that is reflexive and that challenges existing bioethical theories to lend credence to their ideas or to suggest avenues for further development (Hedgecoe, 2004; Twine, 2010). In line with critical approaches, the adoption of a critical bioethics perspective incites a focus on reflexivity, which includes self-awareness of one’s personal context and experiences, but also an acknowledgement of the effect these may have on one’s individual perspective and
subsequently on the research, without conceding that this may threaten the legitimacy of the conclusions one is able to draw (Hedgecoe, 2004). Different perspectives are included under the term ‘critical bioethics’; Twine (2010) defines critical bioethics research as requiring three attributes: 1) that it be interdisciplinary and incorporate contributions of disciplines other than bioethics; 2) that there be a focus on reflexivity, therefore drawing attention to the social qualities of bioethical issues within, and subject to influences of, a broader context; and finally, 3) that the research take a different perspective than that of medicine, thus minimizing the risk that the research be blind to some issues or assumptions inherent in the subject matter it is examining.

Although they were historically focused on the oppression of women, feminist perspectives are consistent with critical bioethics in their concern with the oppression of individuals as a result of political, legal and social structures and take a responsibility for action to change the circumstances leading to oppression (Sherwin, 1998). Feminist perspectives take a “question-posing, consciousness-raising, action-oriented methodology” (Tong, 1997, p.75). Feminist ethics provides a reflexive framework for empirically examining practices and norms (Twine, 2010) and raises the questions “Whose interests are served?” and “Whose interests are harmed?” (Baylis, Downie & Sherwin, 1998). Taking such a perspective incites the researcher to examine existing social structures and systems of thought, and to explore the potentially unintended practices and outcomes these may promote.

The use of a feminist perspective aligns with a critical bioethics perspective as they both are concerned with social and political structures, beliefs, practices and norms, and how these intersect to create situations of enablement or oppression. In this research I take a critical bioethics approach informed by feminist perspectives to examine social and political influences on the mediation of older adult and family autonomy in discharge-planning decision-making processes.

3.2 Traditional conceptualizations of autonomy and the feminist critique

Traditional conceptions of the principle of respect for autonomy are pervasive in bioethics literature and have generally promoted views of individuals as independent rational beings having the capacity, freedom, right and authority to individually make choices and decisions to determine their fate and to shape their identity (Beauchamp & Childress, 2009; Mackenzie,
Such conceptions have been highly prioritized in the provision of healthcare services (Beauchamp & Childress, 2009; Dodds, 2000; Ho, 2008b; McLeod & Sherwin, 2000; Sherwin, 1998; Sherwin & Winsby, 2010). Traditional interpretations of autonomy however have been strongly criticized as being overly narrow in not considering individuals as interdependent and influenced by the broader social and political contexts in which they live (Mackenzie, 2008; McLeod & Sherwin, 2000; Sherwin & Winsby, 2010). While a feminist perspective does not reject the concept of autonomy, in light of these critiques, feminist theorists have presented a relational conceptualization of autonomy that considers individuals as inextricably embedded in, as well as shaped by, the social and political contexts in which they live (Mackenzie & Stoljar, 2000; Sherwin, 1998). As they propose it, relational autonomy shapes an approach to healthcare that, by considering the social location of individuals, is more attentive to the various needs of diverse individuals (Sherwin, 1998).

In the remainder of this chapter I first review traditional conceptions of autonomy. I briefly introduce four feminist critiques of such conceptions and, using the framework of the four critiques, I develop a feminist relational perspective. I then describe the conception of relational autonomy that informed this study. Finally, I consider interpretations of autonomy in health care and traditional and relational conceptions of autonomy in healthcare research and practice with older adults.

**Traditional conceptions of autonomy**

The development of traditional conceptions of autonomy has been greatly influenced by the work of two philosophers: Immanuel Kant and John Stuart Mill. Kant (1785) argued that the ideal of an autonomous being is a rational individual who acts in manners governed solely by his or her own individual reason. When considered in relation to other individuals, the humanity formulation of Kant’s famous categorical imperative dictates that individuals should always treat others as ends and never merely as means to an end (Johnson, 2012) as this would violate their capacity for free rational action and their potential to determine their destiny. Similarly, Mill (1909) argued that individuals should be free to develop according to their own persuasions as long as this does not harm others or interfere with the same freedom being afforded to them. Both of these philosophers described individuals as self-governing beings free to act within the limitations of not interfering with the same freedom of others.
More recently, in their generative text, *Principles of Biomedical Ethics* (2009), Beauchamp and Childress state that personal autonomy “encompasses, at minimum, self-rule that is free from both controlling interference by others and from certain limitations such as inadequate understanding that prevents meaningful choice” (p. 99). In line with Kant and Mill, these and other contemporary authors aver that respect for autonomy or self-determination promotes individual control over the circumstances of one’s life (Beauchamp & Childress, 2009; Mackenzie, 2008; Purtilo, 1999; Sherwin & Winsby, 2010). In bioethics, respect for autonomy mandates respect for individuals to have control over their own healthcare decisions (Dodds, 2000; McLeod & Sherwin 2000; Sherwin, 1998; Sherwin & Winsby, 2010). Conceding that conceptions of autonomy are varied (Beauchamp & Childress, 2009; Mackenzie, 2008; Sherwin, 1998; Sherwin & Winsby, 2010), Beauchamp & Childress (2009) assert that theories of autonomy most often include the two essential conditions of “liberty (independence from controlling influences) and agency (capacity for intentional action)” (p. 100) conditions that reflect the influence of Kant and Mill.

Although Beauchamp and Childress assert that respect for autonomy should not hold primacy over other bioethical principles such as justice, beneficence or non-maleficence (2009), autonomy is widely valued and has come to be central in social and political discourses; in moral, political and legal philosophy; in clinical bioethics; as well as in the provision of healthcare not only by healthcare professionals, but also by patients and caregivers (Beauchamp & Childress, 2009; Entwistle, Carter, Cribb & McCaffery, 2010; Ho, 2008b; Mackenzie, 2008; Mackenzie & Stoljar, 2000; Sherwin, 1998; Sherwin & Winsby, 2010). In healthcare settings the principle of respect of autonomy is aimed at protecting patients’ ability to decide what health services they receive. Respect for autonomy is codified in laws and policies requiring informed consent in health care. Healthcare professionals endeavour to uphold this principle through the provision of relevant information to patients and by ensuring individuals have the capacity to make decisions (Dodds, 2000; Sherwin, 1998; Sherwin & Winsby, 2010). An advantage of the prioritization of respect for autonomy in health care is that it should work to resolve issues in

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4 This aligns with the ideas of Kant and Mill, however, the relationship between one’s actions and that of others has been reversed. In the more contemporary conception, autonomy dictates one’s actions should be “free… from interference by others” whereas in Kant and Mill’s work, individuals should limit their actions such that they do not interfere with others’ freedom.
favour of patient preferences when there are conflicts between the different experiences, values and the resulting perspectives of healthcare professionals in relation to those of their patients (Dodds, 2000; Sherwin, 1998; Sherwin & Winsby, 2010).

Interpretations of autonomy however are not always straightforward in their application to actual circumstances and can be problematic in healthcare settings. Illness for example can impede patients’ capacity to exercise autonomy in the traditional sense (Sherwin, 1998). Systemic views of the primacy of medical knowledge and potential social class (not to mention financial and cultural) differences between healthcare professionals and their patients can make it intimidating for patients to ask questions, thereby limiting the information they have to make the ideally informed decisions, thus hindering autonomous decision making (Dodds, 2000; Sherwin, 1998). These and other similar barriers can result in a greater attribution of decisional responsibility to healthcare professionals; yet, it can be hard for healthcare providers to anticipate the wishes of patients, or to evaluate their interests, because as healthcare professionals, they may have differing points of reference (and may also have the added pressure of acting as gatekeepers of healthcare services and the responsibility to keep costs low) (Mackenzie, 2008; Sherwin, 1998). As we can see, applications of traditional conceptions of autonomy in healthcare settings may be more complex than an initial glance would suggest and may not be facilitating the provision of care to meet individuals’ needs. Feminist theorists have critiqued traditional conceptions of autonomy that help address the difficulties illustrated above.

**Feminist critiques of traditional conceptions of autonomy**

Feminist critiques of traditional conceptions of autonomy centre largely on the lack of consideration for the socially and politically embedded nature of individuals living in multifaceted and many-layered contexts (Barclay, 2000; Donchin, 2000; Mackenzie & Stoljar, 2000; Sherwin, 1998). One prominent critique of traditional perspectives of autonomy is of their portrayal of individuals as atomistic, rational beings who, unencumbered by social and political contexts, are capable of distancing themselves from their circumstances and the situation at hand in order to make an informed and reasoned decision (Mackenzie & Stoljar, 2000). A second

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5 Dodds (2000) paints a picture of a medical doctor who finds himself in the position of being a patient and has his autonomy threatened by societal values of medical hierarchies and particular approaches to knowledge and decision-making.
feminist critique focuses on the unrealistically high expectations of the circumstances and capacities required for autonomous decision making in traditional accounts while negating contextual influences that may hinder the actualization of these expectations (Sherwin, 1998). A third critique stems from the underlying assumption in traditional interpretations of autonomy that individuals’ decisions are based on rationally formulated values and priorities with no regard for contextual influences on the development of such values and priorities (Mackenzie & Stoljar, 2000). A related and final critique is that traditional conceptions of autonomy negate contextual influences in shaping not only one’s views, which then influence choices, but also in determining the options from which one can make a choice (Sherwin, 1998). I will now elaborate on these critiques and develop the contrasting feminist relational perspective that informs the present study.

Traditional accounts take an atomistic view of individuals.

A prominent feminist critique of traditional conceptions of autonomy is of the portrayal of individuals as atomistic and able to remove themselves from their social contexts in order to rationally consider their options at any given moment (Barclay, 2000; Friedman, 2000; Sherwin & Winsby, 2010). Counter to an atomistic view, feminist theorists consider that an integral part of an individuals’ identities includes the social relationships they may hold (Barclay, 2000; Held, 1990; Mackenzie, 2008), and that it would not be possible for individuals to temporarily excise themselves from their social context in order to deliberate about their options as if they were independent atoms in a vacuum (Friedman, 2000; Ho, 2008a, 2008b). While traditional atomistic conceptions of autonomy may view reliance or even dependence on others as barriers or threats to the realization of autonomy (Dodds, 2000; Sherwin, 1998; Sherwin & Winsby, 2010), feminist views hold that individuals are interdependent and as such rely on each other to meet various needs (Mackenzie & Stoljar, 2000; Sherwin, 1998, 2008; Sherwin & Winsby, 2010). A similar earlier view is to be found in Annette Baier (1985), who characterized individuals as interdependent beings, portraying all persons as second persons, created and raised by one other person at minimum. The interdependence of individuals is also exemplified in Virginia Held’s (1987) thought experiment exploring how society might function if instead of having a contractual arrangement, relationships were modelled after the ‘mother and child’ paradigm. These perspectives highlight that each of us would not have survived were it not for other people. We have thus been conditioned to depend on others as well as to collaborate and to
consider their needs when making our decisions. Additionally, negative views of dependence or interdependence associated with traditional views of autonomy devalue individuals who have obvious material dependencies, such as many disabled individuals, and devalue the work of individuals who provide care or assistance to others (Mackenzie & Stoljar, 2000; Sherwin, 1998; Sherwin & Winsby, 2010). Rather than conceiving of individuals as atomistic and independent, relational autonomy theorists view persons as social beings possessing distinct identities that originated in, and that continue to develop within, a network of social relationships, which individuals take into consideration when making decisions. A relational view portrays individuals as inextricably socially embedded (Mackenzie & Stoljar, 2000; Sherwin, 1998; Sherwin & Winsby, 2010), which means that social influences will always factor into their autonomous decisions.

**Traditional accounts have unrealistically high expectations of capacities and circumstances required for autonomous decision making**

A second and related feminist critique of traditional accounts focuses on the *requirements* for making rational and informed decisions that are free from external influence (Sherwin, 1998). I begin with a focus on ‘making an informed decision that is free from external influence’. This necessitates that individuals have the relevant and necessary information in order to evaluate and rationally make the decision. This requirement aligns with what is called the ‘reasonable person’ standard, which requires that the information shared be relevant and sufficient such that a theoretical ‘reasonable person’ would be able to make an informed decision (Beauchamp & Childress, 2009). Feminists critique traditional conceptions of autonomy as being generic and not considering that individuals may have varying needs (Sherwin, 1998). Individuals are not just faceless ‘reasonable persons’ as the standard dictates. A ‘subjective standard’ to the disclosure of information provides a more individual approach. This standard suggests that the information required to enable an informed decision should be tailored to the individual’s situation and needs (Beauchamp & Childress, 2009). In current financially driven and efficiency-focused healthcare climates, the endeavour of understanding the patients’ values, needs and perspectives in order to provide all the necessary information is often viewed as overly time consuming for healthcare professionals carrying heavy caseloads (Dodds, 2000; Sherwin, 1998). Additionally, healthcare professionals at times make the assumption that their medical knowledge and experience place them in a better position than the patient to decide what is in the
patient’s best interests (Dodds, 2000; Sherwin, 1998). The result of these pressures and assumptions can be that information is presented by healthcare professionals in a manner that prioritizes specific options or even omits others, thus expediting a decision that is favoured by the healthcare professionals while maintaining the illusion of an autonomous choice. (This and similar practices are discussed in more depth in section 3.4 of this Chapter.) The requirement that individuals make ‘informed decisions that are free of external influence’ is compromised by such practices (Dodds, 2000; Ho, 2008b; McLeod & Sherwin 2000; Sherwin, 1998).

Focussing now on the aspect of making *rational* informed decisions, traditional accounts require individuals to be capable of evaluating potentially large amounts of complex medical information in order to make informed decisions about their own healthcare (Sherwin, 1998). This requires one to have the time and the capacity to understand the information. In light of fiscal pressures and a drive to maximize the number of individuals served, time is often in short supply in clinical healthcare settings. As well, understanding all of the relevant information might be above the capacity of individuals who are not trained in medical care, and more so, be above the capacity of individuals who are in particularly vulnerable states as a result of illness (McLeod & Sherwin, 2000; Sherwin, 1998), or as a result of concern or feelings of responsibility for their ill family-member or friend. The expectation for individuals to have all of the information as well as the capacity to understand all of the information to make an informed decision that is not influenced by the opinion of others (namely healthcare professionals or family) may be difficult to achieve. A feminist relational approach to promoting understanding and to enabling autonomous decision making about healthcare services considers information sharing not as didactic but instead as multi-directional. While taking a relational approach to information sharing might be time consuming, such an approach might better enable patients to participate in autonomous decision making than would a traditional approach. In this approach, healthcare professionals learn about the patient’s needs, values, preferences and contextual life circumstances as the patient learns about the various options (Sherwin, 1998). In so doing, all parties learn more about the situation in order to come to a decision that might be closer to a shared understanding of the patient’s best interests.

In traditional conceptions of autonomy and decision making, an additional, less visible, requirement of autonomy is of the inherent individual capabilities required to act autonomously.
How individuals develop the capacity and comfort in their authority to make informed decisions and to take action based on these is not discussed in traditional conceptions (Mackenzie & Stoljar, 2000). Feminist theorists make no such sidestep but directly state that autonomous action requires trust in specific capacities that may or may not have been developed to the extent they are required for autonomous decision making (McLeod & Sherwin, 2000; Meyers, 1987).

More specifically, feminist theorists emphasize that in making an autonomous decision, an individual is required to have the capacity to reflect on her own values, wishes and beliefs; to understand the information at hand; to make a decision in consideration of all of these; and finally to act on the decision (McLeod & Sherwin, 2000; Meyers, 1987). Feminist theorists argue that these capabilities develop over time, or are impeded from developing, through various opportunities or a lack thereof in individuals’ relationships within their social and political contexts. Autonomous action requires the self-trust that one is skilled in each of these capacities and has the authority to speak for him or herself.

Feminist theorists make the argument that these skills are not inherently present in individuals, but rather that they need to be developed and that the development of each of these skills depends on opportunities to learn, develop, practice and reaffirm (McLeod & Sherwin, 2000). A feminist perspective considers that the social and political context in which one has grown and lived over time has enabled or impeded opportunities for the development of all of these skills and continues to afford or deny opportunities for autonomous action through the various interactions that individuals experience (Friedman, 2000; Mackenzie, 2008; McLeod & Sherwin, 2000; Meyers, 1987; Sherwin, 1998). Social and political contexts can intersect such that individuals are afforded opportunities for the development of these capacities, or in a manner that oppresses individuals and prevents this development. This is discussed by McLeod and Sherwin (2000) who state:

*Oppression tends to deprive a person of the opportunity to develop some of the skills that are necessary to exercise autonomy by restricting her opportunity to make meaningful choices and to have the experience of having her choices respected... If an agent is never exposed to an environment that fosters the development of those skills, she will lack the ability to exercise autonomy. Moreover she will have been deprived of the opportunities to develop the level of self-trust that is necessary for her to gain and use these skills effectively. She may then not be in a position to exercise autonomy even when invited to do so. Hence it is not sufficient simply to*
Broader social and political contexts can lead to oppression or situations of privilege and can implicitly or explicitly dictate what opportunities are available to individuals and in turn to what extent capacities required for autonomous action might be developed or impaired (McLeod & Sherwin, 2000). This can be illustrated through an example of an older woman who lived in a societal context where women were oppressed and not valued enough to be educated, but instead were expected to have children, to work in the home, to behave according to prescribed manners, and to participate in activities that served her husband and her children’s needs. In the familial context, as a child, this woman was dependent on her parents for all her care and upbringing. As an adult, she was dependent on her husband financially as well as for the social status of being a ‘proper’ married woman and mother. If this woman lived her entire married life in such contexts, she may never have been afforded opportunities to examine her own values and wishes or to voice these, and much less to analyze information in light of her priorities in order to make a decision and act on it. Furthermore, she may never have received affirmation confirming her development of these skills from individuals in the environment or from the outcomes of her choices. If this woman were to be widowed and for some reason required healthcare services, she might not have the self-trust in the capacities or even the capacities required for autonomous decision making in the traditional sense. Taking a relational approach with this woman could facilitate information sharing in a manner that would support her decision making and enable her to develop the skills for decision making. Without opportunities to develop the skills required to exercise autonomy being provided in one’s social and political contexts, individuals will thus be unable to act autonomously without support, even if the opportunity were presented.

Traditional accounts assume individuals’ values, morals and desires are rationally formulated

Not only does one’s social and political context shape one’s self-trust and capacity to act autonomously, but feminist theorists hold that “the social location of a given individual is influential in establishing his/her priorities, concerns, values and beliefs about himself/herself” (Sherwin & Winsby, 2010, p.184). One’s current context, as well as one’s contexts growing up, shape what one values and how one views oneself in relation to others (Friedman, 2003; McLeod
In traditional atomistic accounts of autonomy it is assumed that individual decisions are based on the agent’s morals, values and desires. In such perspectives, values, desires and morals are uninfluenced by social and political contexts but rather are rationally and intentionally formed by agents (Mackenzie, 2008). Therefore, in situations where the autonomous actions of individuals are examined, a more traditional approach to autonomy would centre mainly - as has been discussed above - on the provision of the necessary information and on a patient’s capacity to make an informed decision. The focus would be on an individual level, either on the individual making decisions (with a focus on her capacity), or on the individual(s) who provided information. While it may be acknowledged that individuals make decisions based on rational prioritization of particular values, no critical reflection would examine how individuals come to hold such values. Feminist theorists take issue with this, arguing that there is no way to ensure that one’s identity is itself not affected or shaped by oppressive forces (Mackenzie, 2008; McLeod & Sherwin, 2000; Sherwin, 1992, 1998). A feminist relational perspective argues that values and morals are shaped by social location and may in and of themselves reflect and reproduce oppressive values (Sherwin, 1998).

The practice of oestrogen replacement therapy in developed countries provides an example. In contemporary developed countries, health is highly valued (Daniels, 2008; Lock, 1998a). In these contexts as well, while medical knowledge is greatly valued in order to restore health, maintaining good health is contestably promoted as a personal responsibility (Buyx, 2008; Lock, 1998a; Steinbrook, 2006; Weyden, 2007). Aging is associated with declining health and is largely devalued and feared (Estes, Biggs, & Phillipson, 2008; Lock, 1998b). Medical practices of oestrogen replacement therapy for women arose at the intersection of dominant societal perspectives on the primacy of medical knowledge, and personal responsibility for maintaining good health. The aim of this treatment is to limit or to slow the effects of aging on the female body. In making ‘the choice’ to undergo hormone replacement therapy, women reinforce the value of health and youth, further reproducing the inherent devaluing, fear, and medicalization of aging and upholding the primacy of medical treatment. Are these the values of the woman who is choosing hormone replacement therapy? Arguably they are, as this is the

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6 Lock (1998b) elaborates on many reasons why there is a particular focus on the aging process of the female body, but these are not relevant to the discussion at hand and will not be discussed here.
choice she is making, but the question is whether these values are rationally and intentionally prioritized in her value system in spite of (or in light of) the influence of values and beliefs in her context, or if they are formed by an oppressive environment that upholds these beliefs and that she may not be rationally taking into account, even if such dominant social values have not been internalized to mediate individual choices.

Mackenzie (2008) contends that individual identity may be shaped by beliefs, norms and societal values that may inherently oppress individuals, and which would therefore contradict a presumption of autonomy. She states that “just because an agent acts in accordance with her settled character or reflectively endorses the value commitments that define her practical identity, this is no guarantee that she does so autonomously” (Mackenzie, 2008, p. 513). Taking a relational view would demand that the social, political and economic circumstances and their potential effect in shaping an agent’s values, and thus their probable influence on the individual’s autonomy, be examined and taken into consideration (Sherwin & Winsby, 2010).

**Traditional accounts are blind to systemic influences on options and choices**

Related to the previous points, a final feminist critique of traditional accounts of autonomy relates to the secondary implications of taking an individualistic view of autonomous decision making. In focussing solely on the individual and on the specific decision at hand, traditional conceptions of autonomy attribute all of the responsibility for the outcome of the decision to the individual. Not only is there no consideration for the influence of the social and political contexts in shaping individual capacities and values that inform decisions, as discussed above, there is also no consideration of their influence on shaping conventions, practices and policies that determine the options available or the reasonableness of any specific choice (McLeod & Sherwin, 2000; Sherwin, 1998; Sherwin & Winsby, 2010). Traditional approaches fail to acknowledge that systemic policies and practices shape what opportunities and potential outcomes are available as a result of a decision (Sherwin, 2008).

To explain this more clearly, I will use the example of an older gentleman facing discharge from hospital. The provincial context is Ontario, where there is a publicly funded healthcare system, but where homecare services and funding for mobility equipment are increasingly limited by specific criteria dictating eligibility. The man lives alone in his two-storey house. He now has difficulty going up and down the stairs, which he would be required to do daily. With
his limited income and the limitations on funding for mobility devices, he is not able to afford a stair lift. According to home care eligibility criteria, he would not receive assistance upon his return home as he is not considered to be at high enough risk\textsuperscript{7}. His preference is to return home without assistance. This is not considered a reasonable choice by the healthcare team and the assistance they recommend is prohibitively expensive. Other options include moving to a senior’s home, which has a significant financial cost or moving to long-term care, both of which also involve a significant personal cost in the loss of his home. A traditional autonomy perspective would focus on this gentleman’s choice. Does he value personal safety? Does he value his home? What is his rationale in making the decision to go to long-term care? A relational approach might consider how contextual constraints provide very few viable options that are consistent with his values. The lack of public funding for personal care and assistance in the home, in conjunction with the professional prioritization of safety and the provision of care over other values such as psychological security, shape his putatively ‘autonomous’ choice.

In summary, feminist critiques of traditional conceptions of autonomy centre on the latter’s portrayal of individuals as atomistic and capable of removing themselves from the context in order to make rational, informed decisions, free from social and political influence. Feminist theorists on the other hand hold that individuals are inextricably linked to their contexts. Values and capacities are shaped and develop within social and political contexts and the opportunities and interactions they afford or deny. Additionally, feminist theorists assert that context shapes not only the values and capacities that govern behaviour, but also predetermine the circumstances within which behaviour occurs – specifically, that the opportunities and choices individuals have at their disposal are a product of social and political contexts. In light of these critiques, feminist theorists propose an alternative conception of autonomy: relational autonomy.

\textsuperscript{7} In Ontario, what home care is publicly funded and for individuals meeting what criteria is directed by the Local Health Integration Networks (LHINs). Under the direction of the LHINs, home care is provided by the Community Care Access Centers (CCACs) (Williams et al., 2009), however, what care is offered for which criteria may vary in different CCAC catchment areas. According to the Ontario Health Coalition (2011), the results of the combination of decreasing allocations of funds to home care and increasing need by the growing population of older adults are long wait lists for home care services. In some CCACs, individuals who are considered to be at ‘moderate risk’ are not deemed eligible for service, while in other CCACs, individuals meeting the same criteria were put on wait lists.
3.3 Relational autonomy

The phrase ‘relational autonomy’ is an overarching term that includes many different perspectives. As with traditional conceptions of autonomy, relational perspectives may vary, yet they all share at least two interrelated beliefs. These are: individuals live within political and social contexts and are thus socially and politically embedded; and the contexts in which individuals live and have lived shape their individual identities and capacities to enact autonomy (Mackenzie, 2008; Mackenzie & Stoljar, 2000; Sherwin, 1998, 2008; Sherwin & Winsby, 2010). Susan Sherwin (1998), a leader in the development of conceptions of relational autonomy, explains her choice of the phrase:

*I propose an alternative conception of autonomy that I label “relational” though the terms socially situated or contextualized would describe it equally well... I explicitly distinguish my use of the term relational from that of some other feminist authors... who reserve it to refer only to the narrower set of interpersonal relations. I apply the term to the full range of influential human relations, personal and public. Oppression permeates both personal and public relationships; hence, I prefer to politicize the understanding of the term relational as a way of emphasizing the political dimensions of the multiple relationships that structure an individual’s selfhood, rather than to reserve the term to protect a sphere of purely private relationships that may appear to be free of political influence. (p. 19)*

Implicit in Sherwin’s conception of relational autonomy is the idea that individuals are socially situated and that their context is multi-layered, encompassing all types of human and structural interactions that individuals experience throughout their lives. Sherwin specifies that all relationships are subject to political values and forces as all relationships occur within the broader political context. Social and political values and forces ultimately result from, and are continuously created by, past and present complex human interrelations. These forces shape and sustain social norms and values on all levels of social interactions. Furthermore, these forces shape the policies and practices that determine what opportunities are available to individuals in their contexts (Sherwin, 2008). The diversity of contextual forces that influence individual choices can be appreciated through the example of the older gentleman admitted to acute care described above. The historical, social, political and material mediators of his values and choices include the experiences that have influenced and shaped his values, preferences and capabilities; his wife and their home; their children who live in the same city; as well as his room and the healthcare professionals in the inpatient care setting. These are embedded in the wider
institutional, social, and political values and forces that produced and are reflected in the functioning of the healthcare system and the hospital. Moreover they include the political, economic and structural conditions that provided opportunities for him to work, raise a family, and participate in social life. Taking a relational perspective, individuals are considered in relation to and as a part of the social, political and institutional contexts in which they exist; behaviour is not merely the choice of the individual but is the choice of the individual within a particular context that influences, mediates and constructs those choices.

### 3.4 Interpretations of autonomy in health care

Looking at applications of various conceptualizations of respect for autonomy in health care, there is widespread agreement in the clinical and theoretical literature that individuals should be enabled to make decisions about their own health care. As was mentioned above, the principle of respect for autonomy in health care is often applied through the practice of obtaining informed consent from individuals for the care they receive (or decline) (Beauchamp & Childress, 2009; Ho, 2008b; Mackenzie & Stoljar, 2000; McLeod & Sherwin, 2000; Sherwin & Winsby, 2010). Various arguments have been presented for the patient to exercise autonomy in medical decision making.

One line of reasoning has argued that individuals are the experts, are more invested than others in their own life, and are therefore best placed to evaluate what is in their best interests. In her theoretical paper examining the family’s role in medical decision making, Ho (2008a) argues that patients have “the epistemic privilege to know what is in their overall interests” (p.134). Sherwin (1998) makes a similar argument stating that “it is difficult for anyone other than the patient to make choices that will be compatible with that patient’s personal value system” (p. 21). Sherwin (1998) further argues that the individual undergoing the medical treatment in question is most vulnerable and that medical decisions can entail decisions of a very intimate nature (reproduction, self-image, death and lifestyle to name a few). Ho (2008a) echoes this argument in stating that the patient has the most at stake; the object of question is the care of the patient’s body, and thus in question is that individual’s health and potentially even their survival or death. Thus, both Ho and Sherwin suggest that a patient’s autonomy should be respected on the basis that the patient has the most to lose and is in the best position to make judgements on the potential consequences of healthcare choices.
In alignment with traditional conceptions of autonomy, it is broadly accepted in healthcare settings that in order to exercise autonomy, individuals must be capable of making informed decisions. In Ontario, Canada, under the Health Care Consent Act (1996), a person is capable to make a healthcare decision if “the person is able to understand the information that is relevant to making a decision... and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision” (1996, S.O. 1996, c. 2, Sch. A, s. 4(1)). As a result of this legislation, assessing the capacity of an individual to make decisions is recommended if there is reason to suspect an individual may not have the capacity to make an informed decision (Weisstub, 1990). Such laws and recommendations aim to protect individuals from making decisions that may have harmful consequences that the individual making the decision may not understand. In their commentary about the assessment of capacity in discharge situations with older adults, Stewart and his colleagues (2005) suggest that capacity is particularly questioned in discharge situations in which individuals make choices that are viewed as unsafe by healthcare professionals (such as a choice to return home instead of moving to long-term care). In their article examining conceptions of relational autonomy in situations of long-term care with older adults, Sherwin and Winsby (2010) argue that a focus on individuals’ capacity can be detrimental to discharge planning as it can deter the focus and take time and attention away from a deeper exploration of a wider range of choices available to patients (Sherwin & Winsby, 2010). Furthermore, they argue that it may not always be recognized that illness can temporarily or permanently threaten an individual’s capacity to make decisions. It may be assumed that individuals might have had impaired capacity to make decisions prior to the illness, or may now have permanent impairment to make decisions, and as such are not capable of making decisions related to their care (Sherwin & Winsby, 2010). Thus considerations of capacity can be helpful or be a hindrance to both respect for autonomy as well as discharge-planning processes. As has been discussed, in relational autonomy perspectives, consideration is given not only to individual capabilities in the specific skills required for decision making but also to individual strengths, needs, values, and circumstances. Asking whether capacity is required for the exercise of autonomy may be limiting the focus to the issue of individual capacity and neglecting broader considerations. Asking instead how an approach can be tailored to enable individuals to exercise autonomy even though some capacities may be compromised may offer greater potential for an approach that meets individual need and maximizes autonomy in decision making.
As was mentioned above, in law and traditional bioethical theory, respect for autonomy is discussed as requiring individuals make decisions that are free of potentially coercive influences (Beauchamp & Childress, 2009; Ho, 2008a, 2008b; McLeod & Sherwin, 2000). In situations of healthcare and decision making, potentially coercive influences could include family or friends, healthcare professionals, financial implications, or even the ignorance of certain options. With respect to family influence, Ho (2008a) expressed that families may have differing values and agendas to those of the patient and as such may influence the patient to make decisions that favour family members’ interests rather than the patient’s. Similarly, healthcare professionals may have a stake in patients making one decision over another and may intentionally or unintentionally influence decisions through the way they present options for the patient to choose (Beauchamp & Childress 2009). Ho (2008b) argued that little attention is paid to the potentially coercive manner in which the individual’s choices may be framed and presented, and that such presentations can directly and indirectly influence patients’ decisions by portraying some choices as more favourable than others. The prioritization of certain options when framed for presentation to older adult patients and their families may be inadvertently or deliberately influenced by team, institutional or societal norms, agendas and values, a practice that constitutes a weak form of paternalism. Examples of such paternalism include the intentional simplification or explanation of options in order to present the ones preferred by healthcare professionals in a more favourable light, or if options that the healthcare professionals do not feel are the best choice are intentionally omitted (McLeod & Sherwin, 2000). This approach is sometimes taken by healthcare professionals with individuals whose capacity is questioned in an effort to enable their ‘autonomous informed consent’, without explicitly acknowledging the shaping of options by healthcare professionals. By focussing on individual decisions and the influence of individuals in decision making, discussions of patient autonomy neglect the influence of the social structures in which one is receiving care and in which one is making decisions (Ho, 2008b).

**Traditional and relational autonomy with older adults: applications in the literature**

As was discussed in Chapter 2, much of the literature about discharge planning with older adults touches on aspects of discharge situations, practices, and processes that could impede autonomous decision making as formulated in the traditional sense. Sherwin and Winsby (2010) highlight that older adults in clinical settings may be at particular risk of having their autonomy
limited by an increased reliance on others and heightened vulnerability that may result either temporarily or permanently as a result of their illness. Additional risks to older adults’ autonomy include cultural prejudices devaluing older adults and assumptions linking aging and declining cognitive abilities in contemporary society. Sherwin and Winsby (2010) further argue that “there is often a significant gap between the ideal of independent, competent, fully informed, voluntary decision making and the actual conditions in which patients must choose, even when patients are living independently” (p. 184). Older adults who are admitted to inpatient care services may not fit the ideal of the autonomous individual. Such situations however should not imply the necessity to ignore or overlook respect for autonomy, or to lend disproportionate primacy to beneficence or paternalism in one’s approach. Despite widespread agreement that individuals ought to be enabled to make autonomous healthcare decisions, there is little guidance on how care should be decided in situations where individuals are not able to make autonomous decisions with the capacities that traditional conceptions would require (McLeod & Sherwin, 2000). Conceptions of relational autonomy could potentially provide guidance on how to proceed with decision making in relation to the provision of healthcare with older adults. While the development of theory and applications of relational autonomy with diverse situations and populations is growing, currently, there are limited sources of guidance for applying a relational approach to working with the population of older adults.

Applied theoretical work includes Perkins, Ball, Whittington and Hollingsworth’s (2012) model of relational theory for use in assisted living for older adults in the United States. The model’s development was based on three studies conducted between 1996 and 2002 about older adults and assisted living in Georgia. In their model, Perkins and her colleagues placed the ‘maintenance of the self’ in the centre, at the intersection of psychological, human, social and material capital, all of which were affected by the multiple contexts in which individuals live (Perkins et al., 2012). Their representation is intended to promote a relational approach in assisted living situations. Similarly, Sherwin and Winsby (2010) examine traditional and relational conceptions of autonomy and explore how a relational approach could be applied to provide a supportive approach to older adults and their experiences in nursing homes in the Canadian context. Another example of theoretical work examining relational approaches is provided by Ho (2008a) who used a conceptualization of ‘relational identity’ to examine the family’s role in decision making with older adults. A more immediate application of a relational
approach is provided by Hunt and Ells (2011) in their article examining relational approaches to autonomy in rehabilitation settings. Hunt and Ells (2011) use a fictional case study of an older man facing discharge from inpatient rehabilitation to exemplify how a relational approach can support the autonomy of the older adult while also supporting his needs and those of his family members. An example of empirical research is Moser, Houtepen, Spreeuwenberg and Widdershoven’s (2010) exploratory qualitative study examining the autonomy of 15 older adults with type 2 diabetes to demonstrate that caregiving guided by a relational approach fostered the participants’ autonomy (Moser et al., 2010). In all of these works, authors showed how using a relational approach could better support and enable older adults’ autonomy in situations of discharge or assisted living. Aside from these notable exceptions, little has been done empirically using concepts of relational autonomy to inform approaches with older adults and no work has been done using relational autonomy to frame research about discharge planning with older adults.

Discharge planning is a multi-faceted process involving many individuals with complex interrelationships and varying needs, wishes and interests as well as role expectations and limitations. Older adults facing discharge may be in particularly vulnerable situations that may be enhanced by taking a relational approach to respecting their autonomy.

3.5 Conclusion

In this research I took a critical bioethics perspective and utilize relational autonomy theory to examine the influence of material, social and political contexts on discharge-planning processes and experiences. Taking a critical bioethics perspective enabled me to examine implicit systemic values and systems of thought, along with the inherent practices that these promote. Using feminist relational autonomy theory to inform my analysis enabled me to consider social and political influences on the lives and behaviours of my participants and to examine discharge planning in the context of oppression and social justice concerns.
Chapter 4
Methods

4 Introduction

In this chapter I begin by describing the methodology of microethnographic case studies (Willis, 2007) and why it is conducive to addressing the study research question. I then describe the setting for the research as well the recruitment process and participants. I outline my data generation and analysis processes and describe methods I took to maximize rigour. Finally I discuss some ethical considerations in relation to the study.

4.1 Methodology – Microethnographic case study

I used a case study methodology (Willis, 2007) to address the research questions. Case studies are heuristic, naturalistic and particularistic in enabling a focus on a particular object of study, and in examining real people and situations within authentic and defined environments and contexts (Willis, 2007; Yin, 2003). One of any number of phenomena could constitute an object of study, including but not limited to an event, a process, an individual or social group, a program, or an institution (Merriam, 1998). Additionally, case study methods allow for the collection of rich descriptive data from different sources in the setting where the process of study is taking place (Willis, 2007). The use of case studies enabled me to examine the discrete perspectives and experiences of individuals involved in each of the discharge-planning processes in five different cases within the context of one older adult inpatient rehabilitation setting in a large urban setting in Canada.

In keeping with a critical bioethics perspective and relational autonomy theory, the case study methodology allowed an examination of how aspects of the social and political contexts may affect individual perspectives and actions in discharge planning. To this end, I employed a type of methodology called the microethnographic case study (Willis, 2007, p. 242), which is a type of ethnographic case study (Merriam, 1998; Willis, 2007, p. 242). Ethnographic case study methodology emphasizes the context in which the phenomenon of study takes place (Merriam, 1998; Willis, 2007). While ethnographic case studies examine broader social groups and communities, microethnographic case studies focus on smaller units of study such as a few individuals within an institutional context for example (Willis, 2007). Microethnographic case
studies enabled me to focus on the process of discharge planning by examining the perspectives and experiences of individuals within the social and political context of each case. Moreover this approach enabled me to observe individual behaviours in the process of discharge and to generate data to examine how context specific practices, valued approaches, and prevailing discourses about healthcare and aging shaped the processes and outcomes of discharge planning.

The data set comprised five microethnographic case studies. Each explored discharge decision making from three stakeholder perspectives: the older adult in inpatient rehabilitation preparing for discharge, one or more involved family members or caregivers, and one or more healthcare practitioners involved in the individual’s discharge-planning process. The methods for data generation included observations and one-on-one interviews, both of which are described in detail below (in section 4.4 Data Generation).

I obtained approval for this study from the Research Ethics Boards of the University of Toronto and the partner institution where the research was conducted.

**4.2 Setting – Partnering institution**

I partnered with one of the largest facilities in Canada geared towards the provision of healthcare services for older adults that also included inpatient rehabilitation – the setting for the study. This healthcare centre was an urban teaching hospital affiliated with a University in Southern Ontario. The facility had just over 60 inpatient rehabilitation beds: about half were allocated for older adults in rehabilitation with an average length of stay of four weeks (sometimes extending to six to eight weeks), and the remainder were assigned to a less intensive rehabilitation program with an average length of stay of 60 days. Considering the different expected lengths of stay, this facility discharged an average of 40 older adults per month, thus providing sufficient numbers of potential participants for the study. The partnering institution was associated with but not exclusive to a particular cultural group which may have affected the backgrounds of the individuals who sought care from this facility, but the size of the organization outweighed the potential limitations related to homogeneity for the purposes of this study. The

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8 Please note that for the purpose of maintaining confidentiality, the name of the institution has been withheld.
implications of potential limitations related to the population are discussed in Chapter 8 and may inform future research.

The inpatient rehabilitation unit in this setting offered an interdisciplinary approach in which professionals from several disciplines worked together to provide care. Upon admission, patients were assigned to professionals from the fields of medicine, nursing, occupational therapy, physiotherapy and social work; professionals from therapeutic recreation and nutrition were referred as required. Admission to this setting was limited to individuals 55 years of age or older. Individuals were admitted from acute care in instances where either the illness or injury that had prompted the admission to acute care, or the acute care stay itself, had resulted in a loss of capabilities that were expected to be regained in order to enable the individual to return to their previous living circumstances with little change in required care or services. In essence, returning to the individual’s previous living circumstances had to be an option for admission to this inpatient rehabilitation unit.

Options for discharge included (but were not limited to) moving to long-term care (nursing home), a retirement home (seniors’ home) or a family members’ home; or returning home with privately and/or publicly funded home care, or with no care. In rare instances individuals could go to a longer stay higher care inpatient facility such as complex continuing care, should they require more care than the previous options mentioned could offer or they could also be transferred back to acute care should they become more ill. Whether individuals were eligible to receive publicly-funded home care (in their own home or in that of a family member), or to move to publicly-funded long-term care or complex continuing care was dependent on an assessment by the CCAC used to determine care requirements and funding eligibility (Williams et al., 2009). In all cases, privately funded care could be added to publicly funded options.

4.3 Participants and recruitment

Participants were recruited for the study with the aim of creating case studies, which would each include participants from three stakeholder groups: 1) the older adult preparing for discharge from inpatient rehabilitation; 2) one or more involved family members or unpaid caregivers; and 3) one or more healthcare professionals involved in the care and discharge-planning process with that older adult. It was my aim to include an even distribution of men and women in the sample in order to provide a broader overview of this process and not limit the data
to experiences that may be gender specific. While it is acknowledged that gender roles may affect power relations, due to my small sample size, I was not seeking to analyze significant differences across genders, but this could be an area for further study. I also attempted to have diversity in the sample in terms of socioeconomic status, religious affiliation and ethnic origin, but again this was not the focus of this study. In terms of involved family members, I aimed to include both adult children as well as spouses.

**Recruitment and inclusion criteria**

Participants for each of the case studies were recruited strategically in order to build the case studies. This meant that for each case study, an older adult participant for whom the discharge location was not readily apparent or was contested was recruited first (as described below). Once the older adult had consented to participate, he or she would provide permission to approach his or her family members and healthcare professionals. The older adult would also provide the contact information for his or her family members. Potential older adult participants were identified in collaboration with the healthcare professionals on the unit. As a researcher, I attended weekly team rounds during which the care of all of the current inpatients who were approaching a discharge-planning family conference was discussed. Based on the healthcare team’s discussion, I identified individuals whose discharge location seemed to be undetermined at that time. Following this meeting, I approached one of the healthcare professionals who was assigned to the individual’s care and inquired about eligibility in terms of the other inclusion criteria. These other criteria stipulated that potential older adult participants:

- were aged 65 and older. (This is a criterion for admission to older adult inpatient rehabilitation units.)
- had been living independently prior to the hospital admission. Returning home was a possible option for the older adult based on his or her abilities, needs and resources; however, it was not clear that this was going to be the discharge location and thus discharge decisions remained to be made.
- had been in inpatient care for a total of three weeks or more by the time of the discharge-planning conference (this may include various levels of inpatient care). This was to identify individuals who might have been experiencing more functional change (temporary or permanent) following their admission (which I assumed might be reflected by a longer admission) and who would thus require more assistance in order to cope in their previous living circumstances.
- had one or more family members or caregivers involved in their care (e.g. visiting the older adult during their stay, communicating with the team, and who would be involved
in the older adult’s care upon discharge). This was in order to identify cases that had more individuals involved in the decision making process.

Further inclusion criteria for all participants included the ability to understand and to communicate in English, and the capacity to consent to participate in the study. Capacity to consent was first screened by the healthcare professionals assisting in recruitment. I further determined capacity to consent to the study at my initial meeting with all participants. Additional inclusion criteria for family member and healthcare professional participants were that they had to be involved in the discharge-planning process with the older adult.

Once an older adult had been identified as a potential participant, one of the healthcare professionals involved in his/her care approached the individual and discussed the study using a recruitment script (see Appendix 4). This script gave a very brief overview of the study and requested the older adult’s permission for me to come speak to them about the study. If permission was given, I met with the older adult to explain the purpose of the study and their potential involvement. If they gave consent to participate, I requested permission to contact their involved family members and healthcare professionals to seek their participation in the study. Following the initial consent of the older adult, I required the consent of a minimum of one involved family member or informal caregiver as well as a minimum of one healthcare professional to move forward with the data generation for this case study. Once the minimum group of individuals had consented, I then obtained consent from the remaining family members, informal caregivers and healthcare professionals to observe the family discharge-planning conference. A separate consent was obtained for each individual interview.

Sample

I conducted five case studies. Each case included between three and five participants. This yielded five different discharge-planning scenarios and the perspectives of a total of 20 different participants across the cases. This number was large enough to give a “conceptually dense theoretical account” (Green and Thorogood, 2011. p.119) in varied representations of the discharge planning process, but also small enough to be manageable within the scope of this project. Additionally, completing five case studies enabled me to interview each of the members of the interdisciplinary healthcare team involved in discharge planning (and two were interviewed more than once for different cases). Please see Table 5.1 for a detailed description of participants.
4.4 Data generation

For each case, I first observed the family conference, and then conducted face-to-face semi-structured interviews with the older adult, involved family members/informal caregivers, and healthcare practitioners.

Phase 1: Observations of discharge-planning conferences

Observations of the discharge-planning conferences enabled me to gain an understanding of the discharge-planning process. This also allowed me to observe how institutional processes and conventions, discharge-planning and communication practices, as well as assumptions and values, shaped the participants’ behaviours and interactions (Bodgewick, 1999).

I attended the family conference for each case study as a non-participating observer. At this meeting, the older adult, family members and caregivers as well as healthcare professionals discussed the older adult’s needs upon discharge and potential discharge options. Healthcare professionals who conventionally attended the meeting included the head nurse, social worker, occupational therapist and physical therapist. Other healthcare professionals were included if they were involved in the care of the older adult and had recommendations for his or her discharge plan. As a non-participating observer, I did not partake in the discussion but merely observed the interactions between the different individuals. In an effort not to affect the process of the meeting or make anyone self-conscious about their actions being observed or documented, which might thereby influence their behaviour, I did not take notes during the meeting. Rather, immediately following the meeting, I wrote a field note. In an effort to be thorough in my field notes, I used the following framework, which I have adapted from Bodgewick (1999):

Who is present? What formal role(s) are they playing both in relation to the older adult and in the meeting? How do these roles relate to other individuals who are present? What actions is each individual performing? Do the roles and actions differ when individuals are relating to different individuals? What roles might each individual play upon discharge? How do the roles individuals anticipate upon discharge affect their actions and interactions at the discharge-planning conference?

9 Please see Emerson, Fretz and Shaw (1995) Chapter 2 for a discussion about the consideration of taking field notes and the potential impact this may have on the behaviours and self-awareness of participants in relation to data generation.
What is happening? What are individuals doing and saying? How do people appear to be behaving? What things appear to be routine? What assumptions are spoken and unspoken? What assumptions or discourses are being reproduced through the interactions? What is the tone of communication? What body language is being used? To what extent are various participants involved? To what extent are their views communicated and reflected in the discussion? How do power relations manifest in the interactions?

When do various activities/interactions occur in the discharge-planning conference? How do various activities in the process relate? How long do different elements of the discharge-planning conference last?

Where is the discharge-planning conference happening? What part do the physical surroundings contribute to what is happening? How does it affect individual roles and interactions?

How is the discharge-planning conference organized? How is the process unfolding? What rules and norms are evident?

Using the above framework to structure my observations, I wrote my field notes, which then informed the semi-structured interviews for this and subsequent cases.

**Phase 2: Semi-structured interviews**

Following my observations of the family conference, I conducted individual semi-structured interviews with the older adults, as well as with involved family members and healthcare professionals. Semi-structured interviews gave me the opportunity to investigate specific topics while allowing the flexibility to probe or explore further both what the participants said and what I observed during the care conference, as well as the specific circumstances of their case, which could not be known ahead of time (Kvale & Brinkman, 2009). Interview guides were developed following Green and Thorogood (2009) and Kvale & Brinkman (2009), and consisted of questions exploring the perspectives and experiences of these different stakeholders on their discharge decision making. The guides were designed to avoid leading questions or the suggestion of judgement, to use open questions, and to ask about participant experiences (Green & Thorogood, 2009). They included questions of various types: introductory, follow-up, probing, direct, indirect, and interpreting (Kvale & Brinkman, 2009). The guides provided a means of exploring participants’ perspectives about decision-making processes; individual priorities, wishes and beliefs; assumptions about various roles; and, ethical challenges experienced by various individuals. (Please see Appendices 6-8 for interview guides
for each of the three stakeholder groups.) Additionally, as with the observations of the family conference, following each interview I wrote descriptive and reflective field notes (Bodgewick, 1999; Emerson, Fretz & Shaw, 1995). In these I attempted to write as many details as I could in order to help me fill out and recollect further details as I listened to the interview recordings or read the transcripts. As a guide for my field notes, I used a modification of a segment of the field note guide that I used for the observations of the family conference described above.

*What is happening? What is the individual doing and saying? How does the individual appear to be behaving? What assumptions are spoken and unspoken? What assumptions or discourses are being reproduced through the interactions? What is the tone of communication? What body language is being used? To what extent are various individuals involved in this person’s discharge? To what extent are this person’s views communicated and reflected in the discussion in relation to the family conference?* (Adapted from Bodgewick (1999))

In his discussion of field notes, Bodgewick (1999) also recognizes their value in contributing to taking a reflexive approach and being aware of how researchers co-create the research findings. About this Bodgewick says:

*The experiences we have in the field are not merely observed and recorded, they are also felt. Reflecting on the feelings is essential. Only through such reflection can the researcher determine how he or she is influencing the field experience.* (1999, p.61)

Thus, following Bodgwick’s suggestions of different types of field notes, I also included reflections about my own feelings, thoughts and frame of mind during the interview and at that point in the research. I considered how these may be affecting my perspective as a researcher.

Interviews were conducted following the observation of the discharge-planning family conference in an effort to minimize the influence of the research on the meeting or the decision-making processes and interactions of the participants. Interviews were conducted at a time and location of the participant’s choosing. In most cases, this was in the older adult’s hospital room or a quiet area in the facility. At her request, one interview with a family member participant was completed in her home. Interviews were audio-recorded and transcribed verbatim by me or by a professional transcriptionist. In the latter case, I reviewed all the transcripts for accuracy.

The final data set included descriptive and reflective field notes of my observation of discharge-planning conferences, interview transcripts, and interview field notes.
4.5 Analysis

Data collection and analysis occurred simultaneously to allow for unforeseen topics identified as relevant in the earlier case studies to be explored in subsequent case studies. The data from field notes were analyzed inductively and deductively following the process suggested by Dierckx de Casterle, Gastmans, Bryon, and Denier (2012), with slight modifications. I began as these authors suggest with a thorough reading and re-reading of the field notes and interview transcripts line by line. These were read in different orders, at times grouped by case and at other times by ‘perspective’ (all of the older adults, all of the family members and all of the healthcare professionals); they were also read again individually later on in the process when I was reviewing data about a particular concept. All transcripts and field notes were also read by my supervisors and initial impressions and lines of inquiry were discussed concurrently with data collection. Using a set of questions (included in Appendix 9) based on my research questions and my theoretical framework, as well as on Bodgewick’s (1999) framework for writing field notes, I created a narrative interview report for each case study as suggested by Dierckx de Casterle and her colleagues (2012). Each report contained descriptions and interpretations of various aspects of each case study including the circumstances of the case; the individuals involved and their perceived roles, individual wishes or recommendations; and the different relationships between individuals in the case. Additionally, at this stage I used a role-ordered data analysis matrix following the methods of Miles, Huberman and Saldaña (2013) to help me display the data (included in Appendix 10). Role-ordered matrices are structured by the different perspectives of individuals in a situation and enable the systematic display of information about specific ideas across roles. The use of this matrix enabled me to examine the different perspectives in the data within and across individuals in the case studies. Each of the reports and the role-ordered matrices were discussed and refined with my supervisors.

Based on the findings of my initial case reports and of the matrices, I revised, in collaboration with my supervisors, the initial set of questions to add targeted analysis questions exploring concepts or relationships that had been salient in some case studies (included in Appendix 9). I then revised and augmented the initial reports to more comprehensively answer the initial questions and to explore the additional concepts and relationships that arose across the case analyses. Applying a critical lens, I drew up a second set of questions (included in
Appendix 9) more explicitly focussed on how autonomy was discussed and enacted within the accounts. This second set of questions interrogated various decision-making mediators and values such as the importance of the discharge destination to the participants, their perceptions of their own roles as well as of the roles of others in the decision-making process, and values and preferences guiding their decision making. Additionally, at this stage I explored the process of discharge planning and various influences on the perspectives and behaviours of individuals involved, such as underlying beliefs and assumptions. I applied this second set of questions to the data and again reviewed all transcripts and field notes line by line. The list of questions was somewhat flexible in that based on further analysis, new questions were created to encompass the emerging ideas pertinent to the research aims. A cross case analytical summary was prepared and shared with my supervisors. In collaboration with them, I drew up a final set of questions (included in Appendix 9), more specifically focussed on relational autonomy. I repeated the above procedures using this third series of questions. Out of this analysis I “extracted the essential structure” (Dierckx de Casterle et al., 2012) to pull out underlying beliefs, explicit approaches, and institutional conventions that shaped individual perspectives and behaviours in discharge planning.

4.6 Rigour

I employed the following methods to ensure procedural and analytical rigour of the study:

*Transparency and clear exposition of methods, data collection and analysis* – I clearly documented all steps taken in recruitment, participant selection and data generation through the maintenance of a digital log, thus creating a transparent audit trail (Tracy, 2010; Creswell and Miller, 2000). I also kept careful documentation of my analysis as it evolved, providing clarity about “the process by which the raw data [were] transformed and organized into the research report” (Tracy, 2010, p. 841). I did this by creating summaries and detailed reports on a monthly basis during the analysis, which were then discussed in monthly meetings with my supervisors. Additionally, I kept detailed minutes of these discussions.

*Data Matrix* – As an additional tool for my analysis, I employed a role-ordered data matrix to display my findings in the context of each case study while examining patterns across cases (Miles et al., 2013; Patton, 2002). This matrix provided a distinct method of examining the data, which complemented my use of thick description and written analysis.
**Thick description of data** – Geertz (1973) called “thick description” the process of including as much detail as possible in order to create a texture in the description to help make sense of what is going on. According to Geertz, “the aim is to draw large conclusions from small, but very densely textured facts; to support broad assertions about the role of culture in the construction of collective life by engaging them exactly with complex specifics” (1973, p. 28). The process of creating thick descriptions about the object of study enables deeper understandings of the meaning of actions for the actors, and the social contexts in which it occurs (Geertz, 1973). In my data collection and analysis I created detailed descriptions of events and details in my field notes and analysis work. I described the events that I was observing and the concepts that I was using in consideration of their contexts, in order to show the details and the reasoning behind my understanding and related analysis findings (Geertz, 1973; Tracy, 2010). Thick description is also provided in this dissertation in the detailed descriptions of each of the five case studies in Chapter 5. This helps to inform the cross-case analysis findings and discussion provided in Chapters 6 and 7.

**Reflexivity and statement of positionality** – In taking a critical approach to this qualitative work, I acknowledge that my own experiences and perspectives affected the data generation and analysis in this research. Prior to beginning the research (and included in Chapter 1), I documented the knowledge and experience I bring to the table as the primary investigator and as an instrument of qualitative inquiry in the study (Patton, 2002). Throughout the research, through the practice of writing reflexive memos (Bodgewick, 1999) I considered how these played a role in the process of the research (Tracy, 2010).

**Crystallization** – Crystallization in qualitative research incites researchers to seek out multiple methods and perspectives throughout the various steps of the research process to enhance depth of understanding (Ellingson, 2009; Tracy, 2010). Ellingson (2009) states that crystallization requires the generation of multiple types of data using varied methods and the collaboration of several researchers in the process of analysis to provide multiple perspectives and the use of multiple genres of writing in order to make sense of the data. In line with ethnographic methods (Willis, 2007), I used two different types of data collection: observations and interviews, where the interviews were a mechanism to explore interpretations of the phenomena obtained through observations (Patton, 2002). I gathered data from multiple stakeholders to provide a rich, contextualized picture of “what’s going on” in the process of
discharge planning from different perspectives. I also involved the members of my committee in the analysis. In addition to my own review of the data, my two primary supervisors read all transcripts and reports to increase the consistency of analysis and interpretations (Patton, 2002).

In beginning this research, I carefully selected my supervisors and committee members in light of their complementary backgrounds and experiences. My committee members had expertise taking critical social science approaches and using qualitative research methods in the areas of healthcare policy and practice, occupational therapy, bioethics, interdisciplinary care, rehabilitation, community care, critical disability studies, and feminist ethics. The sum of varied areas of expertise provided a breadth of perspectives to support, challenge and deepen the analysis. Throughout the research I held regular meetings with one or both of my supervisors as well as with my whole committee to discuss my findings and ongoing analysis. My findings were reviewed in collaboration with my committee and examined for logical consistency.

Finally, I employed various genres of writing including observational field notes and reflective field notes as well as narrative and analytic reports, through the development of my data generation and analysis. All of these tools strengthened the crystallization of my research and analysis.

Use of an explicit conceptual framework - A conceptual framework identifies the key constructs and presumed relationships that are to be examined in the research (Miles et al., 2013). The use of a conceptual framework informs the research design by influencing the formulation of research purposes and questions, guiding the choice of methods, and identifying “potential validity threats to conclusions” (Maxwell, 1996, p.25). In my research I took a critical bioethics approach and used feminist relational autonomy theory to guide my inquiry and analysis. These perspectives enabled me to focus on the particular systemic structures, beliefs, practices and processes that were influencing the phenomenon of study: discharge planning.

Peer scrutiny of the research project – Throughout the research, I presented my work at various stages at different interdisciplinary, bioethics and occupational therapy, international, national and provincial conferences (including the International Conference on Clinical Ethics and Consultation; Canadian Association of Occupational Therapy; Canadian Association of Gerontology; Canadian Bioethics Society; and the Ontario Long-term Care Association). In doing so, I subjected my developing research to ongoing scrutiny by colleagues, peers and experts in the field from various academic and clinical fields. As is suggested by Shenton
(2004), doing so provided the opportunity for fresh perspectives to challenge my questions, assumptions and methods, thus strengthening the validity of the nature and methods of my research.

4.7 Ethical considerations

Informed consent - I obtained informed consent from all individuals prior to including them as participants. Consent was obtained after reviewing and discussing an information letter and consent form (see Appendices 1-3). In all but three cases, consent was obtained in writing. Three participants did not wish to sign the consent form, in which case verbal consent was obtained at the beginning of the recorded interview.

Confidentiality - I have protected the confidentiality of participants and protected their information from “unauthorized access, use, disclosure, modification, loss or theft” according to the tenets of the Tri Council Policy Statement 2 Chapter 5 (2010). All identifiable information was modified to protect participant confidentiality.

Potential benefits and harms - There were no anticipated harms from participating in this study and no adverse effects were observed or reported at any time. There were no direct benefits to individuals participating in the study other than knowing that they may be contributing to easing the process and improving the outcomes of discharge planning for individuals in the future.
Chapter 5
Interpretive descriptions of the data

5 Five case studies

This chapter is the first of two describing my findings. In this chapter, I briefly describe the sources of data and the setting before presenting interpretive descriptions of the five case studies. In Chapter 6, I look across the cases to offer an analysis of the influences of underlying beliefs, explicit approaches and context-specific conventions on discharge-planning perspectives, practices, and experiences in this setting.

5.1 Description of the data

The data for my five case studies consist of field notes taken after the observation of each of the five discharge-planning family conferences (also called family conferences in the text) and transcripts from twenty-two interviews. Each of the five family conferences lasted approximately 30 minutes. The five field notes from the observation of the family conferences were each three to five single-spaced typed pages in length. The interviews were conducted within the ten days following each of the family conferences (with the exception of one participant interview in Case Five, with whom the interview occurred seven weeks following the family conference). The interviews ranged from 10 to 60 minutes, with an average length of 32 minutes. All but two interviews were conducted with only the participant and me in a quiet location in the healthcare facility. Examples of such locations included the dining hall on the unit between meals, the atrium in the facility (which in the mornings was scarcely used), healthcare professionals’ offices, or small therapy or meeting rooms in the occupational therapy department. The two interviews that had more than one individual were cases where the participants’ spouses were present during the interview; these are identified in the respective case descriptions below. In all but one of the case studies, only one interview was conducted with each participant for that case. Because of a change in the tentative discharge plans following the interviews in Case One, second interviews were conducted with the older adult and healthcare professional participants. The older adult’s family member did not respond to telephone
messages requesting a second interview and therefore no second interview was conducted with the family member.

I interviewed five older adults, seven family members and eight healthcare professionals. (Please see Table 5.1 below for details.) The five older adults included three women and two men between the ages of 80 to 100 years. Only one was born in Canada. The others originated from Hungary, India, Ireland and Poland but each had been living in Canada more than 30 years. Three of the older adult women and one man lived alone prior to admission (two in houses and two in condominiums), and one man lived with his wife in a condominium. All lived in the city. The family members of these older adults consisted of five adult children (two daughters and three sons), a son-in-law (who was interviewed in conjunction with his wife, the older adult’s daughter), and a wife (who lived with her husband, the older adult participant). Most of the family members were born in the same country as their parents. Those born outside of Canada had moved to Canada as children. The 11 interviews with healthcare professionals involved eight different individuals, some of whom were interviewed more than once in relation to different case studies. The eight healthcare professionals included one manager, one head nurse, three occupational therapists, one physiotherapist and two social workers. All of the healthcare professionals were women and were registered with the professional colleges in their respective disciplines.

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<th>Case study</th>
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<th>2</th>
<th>3</th>
<th>4</th>
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</tr>
<tr>
<td>Family member participants</td>
<td>Tom, son</td>
<td>Rita, wife</td>
<td>David, son</td>
<td>Nancy, daughter Roy, son-in-law Peter, son</td>
<td>Teja, daughter</td>
</tr>
<tr>
<td>Healthcare professional participants</td>
<td>Monica, occupational therapist</td>
<td>Rebecca, social worker; Julie, occupational therapist</td>
<td>Erica, occupational therapist</td>
<td>Diane, social worker</td>
<td>Monica, occupational therapist; Diane, social worker; Alison, physical therapist</td>
</tr>
<tr>
<td>Healthcare professional key informants not linked to a specific case study</td>
<td>Carole, manager, physiotherapy background</td>
<td></td>
<td>Rose, Head nurse</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5.1 – Descriptions of participants

In reporting the data, all names have been changed and other identifying information has been modified or withheld. Family members of the older adults are identified as sons, daughters
or spouses, so as to clarify different types of roles or relationships. At times, in order to clarify the discussion, family members are specifically linked to the older adult in their case study. To maintain the anonymity of participants, whenever they are discussed or quoted, they are identified by their pseudonym and their study role (i.e. older adult, type of family member or healthcare professional). In quoted text, an ellipsis signifies that text has been edited out for clarity.

5.2 Description of the setting

The setting for the study was a high intensity inpatient rehabilitation unit in a sizeable, older adult healthcare facility located in a large urban centre in Ontario, Canada. The unit was one of several inpatient and outpatient rehabilitation and long-term stay units in this facility. The unit on which the study was conducted had over 30 beds and an anticipated length of stay of four weeks. Admitted individuals were over the age of 55, had experienced functional decline as a result of illness or injury necessitating an acute care admission, and at the time of discharge from acute care were not able to meet their personal and medical care needs in their pre-admission home circumstances. The aim of the unit was to “help patients attain maximum physical, communicative and cognitive functioning, while addressing emotional, social and spiritual needs to help them return to living in the community as independently as possible” (Institution name blinded, 2013). In order to achieve this goal, the unit offered multiple healthcare services including occupational therapy, physical therapy, speech language pathology and recreation, in addition to social work, dietician, nursing and physician services. Upon admission, each individual was assigned an occupational therapist and physical therapist as well as a social worker, doctor and nurse. Other professionals were referred as needed. All of the participants in this study were admitted to the unit from various acute care hospitals in the same city.

5.3 – Descriptions of the five cases

Case 1 – Maeve

The interview participants for Case 1 included the older adult Maeve, her son Tom and a healthcare professional involved in the case, Monica. The first interviews with each of the participants were conducted within the four days following the family conference. As was mentioned above, however, a change in the anticipated discharge plan occurred after the initial
three interviews. In consequence, I requested second interviews with all case participants. I was able to have a second interview with Maeve and Monica, but Tom did not return my calls requesting a second interview. The subsequent interviews with Maeve and Monica occurred seven and eight weeks following Maeve’s admission.

Maeve was a quiet and strong-willed eighty-eight year old woman. Prior to her admission to acute care, Maeve had been living on her own in the two-storey home where she had resided for over forty years. She had been widowed more than thirty years. Her three children, Kimberly, Rhonda and Tom, were grown and had families of their own. Their homes were five to fifteen minutes away from Maeve’s home. Maeve’s children and grandchildren visited several times a week, bringing her groceries and helping around the house. Other than this assistance, Maeve managed all her activities of daily living on her own.

Maeve was admitted to acute care where she was treated for pneumonia over a period of approximately five weeks, during which time her strength and endurance decreased substantially. Following this admission, she was transferred to the older adult inpatient rehabilitation unit. The discharge-planning family conference was scheduled for two weeks into her rehabilitation stay, which was approximately two and a half weeks prior to her anticipated discharge date. At the time of the conference, Maeve was having difficulty going up and down stairs, even with maximum assistance from one therapist. She also required someone to be with her when she walked with her two-wheeled walker.

The first time that I met Maeve was two weeks into her inpatient rehabilitation admission and one week prior to the family conference. Based on my observations of Maeve at that time, her interactions at the family conference and her answers and mannerisms in our first interview, I suspect that Maeve was experiencing some depression, which could have affected her participation in the discharge-planning process as well as her participation and performance in therapy interventions.

In both of her interviews as well as in the discharge-planning family conference, Maeve firmly averred that she wanted to return home. She also clearly stated that did not wish to have any more assistance than she had had prior to her admission.

*Maeve: I’d just like to go home that’s all, and be in my own place. (silence, 10 seconds)*

...
ED: When we were in the hallway, I think, before the meeting, your daughter Kimberly, she said that she and your sister come and that the two of them help out sometimes with-

Maeve: Oh well they do yes... they come and bring food so I don’t have that to worry about.

ED: And do you think there might be anyone else helping you?

Maeve: No

ED: So you wouldn’t want somebody coming in, - [Maeve: No (overlap)] - in the morning to help you a bit and-

Maeve: No. (Maeve, older adult)

During the discharge-planning conference, Maeve’s children and the healthcare team shared concerns about Maeve’s ability to care for herself and to get around her home, but Maeve did not join in this discussion. She did not put forth arguments against these concerns, nor did she suggest solutions to address them. When asked direct questions about how she would perform certain tasks in her home, Maeve simply indicated that she would manage. Based on my observations of the family conference and my interactions during the interviews with Maeve, voicing her wish to return home was the full extent of Maeve’s contributions to discharge planning. This was congruent with what her son and healthcare providers reported.

The healthcare providers recommended that Maeve live in an accessible environment with 24-hour assistance. Their rationale was two-fold: they were concerned that Maeve’s decreased strength and mobility were such that she would require assistance for all of her activities (including self-care); and, that any cognitive impairment she might have (or develop) would put her safety at risk should she return home to live alone. Their concern for Maeve’s safety was evident in Monica’s interview when she discussed her recommendations for Maeve’s discharge:

I think if they can’t provide 24-7 care, then I think long-term care is ideal, because of her cognition. I think it’d be extremely dangerous for her to be anywhere else or, like, be alone really ever. (Monica, healthcare professional)

Maeve’s children were conflicted regarding what was best for their mother. On the one hand, they wanted to support Maeve’s desire to return home; they wished to see their mother in the house where she had lived for so long. On the other hand, they were concerned about how she would manage to care for herself alone in the house. This conflict was apparent in Tom’s interview immediately following the family conference. At the beginning he stated that he wished for his mother to remain at home but that he and his sisters wanted her to have help.
My ultimate goal is to keep her at home as long as possible... I’d prefer her to die there rather than in an institution... Kimberly and I, and my other sister Rhonda, are trying to convey to her that ‘if you want to stay home, you need, you need help’. (Tom, Maeve’s son)

Later on in his interview, when asked how he would feel about his mother going to long-term care, he asserted that he and his two sisters would feel “great”.

I’d feel great about it [his mother going to long-term care]. We’d love to, all three of us would feel great about it, uh outside of my mom, my mom just doesn’t [feel great about it]. (Tom, Maeve’s son)

Tom was aware that his mother did not want to go to long-term care; he and his sisters were conflicted about what to do.

Prior to the family conference, Maeve’s discharge date had been set by the team for two and a half weeks after the family conference. This date was approximately one week longer than the average length of stay, but was selected in consideration of the upcoming holidays the following week. The holidays meant that processes would be slowed both in terms of the frequency of Maeve’s therapy in rehabilitation as well as with respect to putting services in place for her discharge. At the meeting no decision was made about a discharge plan, but, based on the discussion at the table, it seemed Maeve would return home with assistance. The amount of assistance and how it would be provided remained to be determined by Maeve’s family.

Monica, the healthcare professional participant, shared with me that she thought there was discord between Maeve’s children about Maeve’s discharge where one daughter, Kimberly, was reluctant to have Maeve return home while Maeve’s son was pushing for it. Monica speculated that Kimberly may have changed the plan for Maeve to go home after participating in a therapy session with her mother. In this session, Kimberly witnessed how fatigued her mother became with minimal walking, as well as how much assistance Maeve needed to get up from sitting, to sit down, and to use the toilet. As a result of this, Monica thought Kimberly pushed her brother to accept Maeve’s going to long-term care.

She was the one that saw her mom do the transfer. She was the one watching her walk and saw how tired she got... I think maybe she was thinking “I don’t know if this is gonna work”. On the morning of the anticipated discharge, Maeve’s son Tom called to say they would not take her home, but rather they would be pursuing for her to go to long-term care instead. (Monica, healthcare professional)
Following the change in plan, I met with Maeve and one of her healthcare providers for a second interview with each. (Her son did not return my calls requesting a second interview.) In Maeve’s second interview, despite the decision having already been made that Maeve would go to long-term care, she shared much more in terms of her plans to return home. She acknowledged she had difficulty getting around, but felt that if she could have reorganized her home to stay on one floor she could have managed and would not have required external assistance.

*I want to get around on my own, I just can’t. (emphasis in her words)...In my own eyes, I could stay upstairs all the time. (Maeve, older adult)*

I cannot be certain that she did not share this plan with her children or healthcare providers; however, based on my initial interview with her son and both interviews with the healthcare provider, I am relatively confident she did not.

Maeve’s accounts suggested that despite having strong wishes to return home, she was letting her children make plans for her. Maeve’s children however presented as reluctant to take decision-making responsibilities from their mother. They wanted Maeve to make decisions on her own, but they also hoped that she would choose to accept care. With Maeve not making the decision to accept care, her children stepped in. In doing so, Maeve’s children worked to balance competing considerations: they wished to respect their mother’s desire to return home to live without external help, which conflicted with both their own concerns about her being able to cope on her own, and the healthcare professionals’ recommendation that she be provided with a significant amount of care.

In the end, Maeve did not return home or go to long-term care. She was readmitted to acute care for a medical complication. I do not have information regarding her discharge location following her second acute care admission, but she did not return to the inpatient rehabilitation unit.

**Case 2 - Frederik**

The interview participants for Case 2 included Frederik, who was admitted on the rehabilitation unit, his wife Rita, and two healthcare professionals Julie and Rebecca. Frederik had been admitted to acute care following a mild stroke. At the time of the family conference and interview, Frederik was experiencing mild to moderate aphasia. He was able to make
himself understood, but at times it took him longer to find words and construct sentences to express what he wished to say. While it appeared to me that he was able to communicate well enough for us to have an interview alone, he stated that he had difficulty speaking since his stroke and that it would be better if his wife were present. The three of us thus met for the interview. The interview with Frederik and Rita was conducted two weeks following the family conference on the day before Frederik’s discharge. The interview with Rebecca was conducted immediately following the family conference and the interview with Julie was conducted one week following the family conference.

Frederik was an eighty year old gentleman who lived with his wife Rita, who seemed to be of a similar age. Prior to his admission, the couple lived in a two-bedroom condominium in the city. Frederik and Rita described living active social lives. They belonged to various bridge clubs. Frederik met regularly with his friends at his house or at theirs and he would go on a daily walk. They also spoke of taking public transportation to go out in the evenings and reported visiting often with their children and grandchildren. When asked what she would like in a home, Rita said she would love a pool so that she could swim. Frederik and Rita described being very busy.

Frederik was in his home visiting with two friends when he had a mild stroke. After five days in acute care, he was transferred to inpatient rehabilitation. Early in his rehabilitation stay, the healthcare team recommended Frederik hire a full-time caregiver to offer 24-hour supervision and assistance with his personal care, as they were concerned about his decreased balance and did not provide 24-hour supervision in the unit. Frederik and his family hired Terry to provide assistance with Frederik’s personal care and to supervise him while he walked around the unit or hospital with his new walker. At the beginning Terry was there 24-hours a day, but at the time of the interview, Frederik managed his own care during the night and so Terry’s assistance had decreased to daytime hours only.

Frederik and Rita emigrated from different countries in Eastern Europe in the seventies. Shortly thereafter, they met and married in Canada. Rita’s daughters from her previous marriage also lived in Canada whereas Frederik’s children remained in Europe. Both Rita and Frederik had grandchildren and great grandchildren, but they saw much more of Rita’s family than Frederik’s due to geographical proximity. Given their interactions, it seemed that Frederik and
Rita had a very close and loving relationship. They were closely attuned to each other’s actions and often completed each other’s sentences. Rita was spending several hours each day on the unit with Frederik and was very involved in his care. She attended most of his therapy sessions. She had asked the healthcare professionals many questions about his progress and the care that he would require when he returned home. In the discharge-planning family conference, when asked if he had any questions, Frederik said that Rita had raised all of his questions and more. Frederik and Rita wished to return to their condominium to resume their lives.

Healthcare professionals and Rita herself reported that Rita’s daughters were involved in Frederik and Rita’s care during the inpatient admission. Yvonne, Rita’s daughter, was present at the family conference. I was unable to interview Yvonne; however, during the family conference she indicated that she was amenable to Rita and Frederik returning home as long as Terry, the attendant, moved in with them.

For discharge, the healthcare professionals recommended that Frederik have 24-hour assistance and supervision by someone in addition to Rita.

*I think that with 24- with a caregiver, with a 24 hour caregiver, with a live-in caregiver, I think that it’s a good plan. I think that if they didn’t have the finances to do that, then it would be too much stress on his wife for him to come home. (Julie, healthcare professional)*

They felt that Frederik required assistance with his personal care as well as with all of his activities of daily living and that his wife was not able to provide this assistance due to her own frailty.

Upon discharge, Frederik returned to the condominium to live with his wife. Terry was moving in with them for an indeterminate period of time. When describing this Rita said they hoped this would be a short-term arrangement.

*She’s [Terry] moving in with us for some time now. I don’t know for how long, hopefully not long at all. (Rita, Frederik’s wife)*

This plan seemed to meet everyone’s preferences for discharge. Rita and Frederik were very involved in their discharge plan. Although Rita had reported that her daughter was quite involved in discharge planning and that they did not know ‘what they would do without her’, it is not clear to me what role she played. Rita herself was in contact with home care services and with the day program Frederik was going to be attending. She had been moving Frederik’s
belongings from rehabilitation back home and had arranged for a car to drive them home. She seemed to be taking care of all the logistical arrangements, but it was unclear who was responsible for hiring Terry. It is possible that Rita’s daughter assisted with this task.

**Case 3 - Marion**

In Case 3, the interview participants included Marion the older adult, her son David, as well as Erica, a healthcare professional. The interviews were conducted individually with each participant. The interview with David was conducted on the same day as the family conference and the interviews with Marion and Erica occurred six days later.

Marion was a hundred-year-old woman who had worked hard all her life, raising her children, running her shop and helping her husband (now deceased) with his business. In my interactions with her I observed that she was not afraid to speak up and voice what she thought and wanted. Prior to her hospital admission, Marion lived alone in a condominium. Marion’s son David lived in the same city as Marion, and her daughter Darlene lived approximately one hour away. Both children were in their sixties and also lived alone. David and Darlene were both heavily involved in decisions about Marion’s care, but being geographically closer, David was most involved and was usually the one to resolve situations as they arose.

Approximately eight weeks prior to my meeting her, Marion was admitted to acute care with pneumonia. Following a five-week stay in acute care, she was transferred to inpatient rehabilitation. Upon admission to inpatient rehabilitation, the healthcare team suggested to Marion and her family that Marion hire a full-time caregiver to provide more assistance than the healthcare team could provide. The team reported that Marion had residual weakness and decreased balance and they worried that she would be impulsive in her self-care as well as in getting around the unit and the facility. They were concerned that without full-time supervision and assistance on the unit she was at risk of falling. Marion and her family thus hired Jean. At the beginning, Jean was staying with Marion 24 hours a day, but by the time of the family conference, Marion did not require assistance overnight and so Jean was only staying with Marion in the daytime to provide minimal assistance with personal care.

The healthcare team recommended that Marion have 24-hour personal support and supervision upon discharge. Their rationale was that they assessed that Marion required
assistance with all of her care and that she had cognitive impairment. They were concerned that her safety would be at risk should she live alone and be required to perform all of her personal care and activities of daily living alone. While the team did not specifically recommend a discharge location to Marion and her children, the healthcare professional I interviewed, Erica, shared with me that she felt that Marion would benefit from moving to a long-term care facility. In her opinion, Marion did not require a significant amount of assistance, but she could benefit from cueing, supervision and the minimal assistance that could be easily provided in long-term care. Additionally, Erica felt Marion enjoyed the social atmosphere of the rehabilitation unit, which she stated was similar to a long-term care setting. Erica had not expressed this to Marion or to her family. She expressed that it was her place to recommend the amount of care she felt Marion required but that it was “inappropriate” to discuss where the care would be provided.

Marion’s wish was to return home:

*I will not leave my home. My home is my castle. I have a one-bedroom, two bathrooms, a kitchen; the washer-dryer is off the kitchen I have no stairs to walk. I’m very comfortable.* (Marion, older adult)

David, Marion’s son, preferred that Marion go to long-term care. David expressed that his mother had a ‘difficult’ personality and that it could be challenging for people (he and his sister included) to get along with her. He worried that if she returned home with assistance, he would find himself in the position of constantly having to hire new caregivers; he feared that they would quit because of his mother’s behaviour, or that she would fire them.

*David: I’d like to see her in a nursing home at this point

*ED: and why is that?*

*David: Because she’s so angry and hostile, um, I think it’s gonna be a turnstile effect with caregivers. And it’s just going to put more pressure on me because my sister lives out of town.* (David, Marion’s son)

David felt that Marion moving to long-term care would be easier for him as he would know that she had all the assistance she required, and that he would not have to be responsible for continually ensuring that she had caregivers.

According to David, his sister Darlene also wished for their mother to go to long-term care. Prior to this most recent hospitalization, they had tried having Marion live with Darlene for five weeks, but this was ultimately unsuccessful. Marion did not want to live there; she wanted to
return to her apartment. David indicated that Marion had daily “meltdowns,” making life very difficult for Darlene as well as for David who received daily upsetting phone calls from his mother.

Marion’s children wanted Marion to go to long-term care but Marion’s wish to return home strongly influenced the decision. The compromise was that if she went home, David wanted Marion to have a live-in caregiver. He felt she was not safe living alone based on her recent history of falls and hospital admissions. David was therefore trying to convince Marion to turn her den into a bedroom into which Jean could move. Marion was willing to accept assistance, but she preferred someone to come only in the daytime; she cherished her time alone and her apartment as it was. When discussing having personal assistance in her home, Marion said

> Alright I’ll go along with that, but now he wants to disrupt my second room, which is a den. Bring in a bed, so she [caregiver] can sleep. Now I have a chesterfield and if you take the cushions away, it’s almost like a single bed, so what’s wrong with it. I don’t know how long she’ll be with me. I don’t know how long I’m gonna have help. If I’m capable of doing things myself I’ll do it. (Marion, older adult)

Whilst Marion had accepted the idea of having Jean as a temporary live-in caregiver, she resisted the notion of changing the furniture in her apartment to accommodate a second bedroom for what she deemed would be a temporary arrangement.

Marion asserted that she had no choice in the decisions her son made for her:

> I don’t want a live-in, but I have no choice. (Marion, older adult)

Although she felt uninvolved in the process, Marion influenced the decision in ways she may not have recognized as long-term care was not the final outcome despite it being her children’s preference. Upon discharge, Marion returned home with Jean as a live-in caregiver. I do not know whether the den was turned into a bedroom.

**Case 4 – Sophia**

The interviews in Case 4 included one-on-one interviews with Sophia the older adult, her son Peter and one of the involved healthcare professionals Diane, as well as a joint interview with Sophia’s daughter Nancy and her son-in-law Roy. The interviews with Sophia’s children were conducted a few hours after the family conference on the same day, while the interviews
with the healthcare professional and Sophia herself were conducted five and seven days later respectively.

Sophia was an 84-year-old woman. She had moved from Poland to Toronto with her husband and children close to fifty years before I met her. Her children, Nancy and Peter, had since grown and married, each living approximately one hour away in different towns. Sophia’s husband had passed away fifteen years before and Sophia had continued to live alone in their two-storey home. Sophia enjoyed homemaking tasks and was very proud of her clean home and her garden. She reported housekeeping, gardening and yard work as her primary activities. She also enjoyed watching her favourite television show, but reported that since her admission and now that her discharge was approaching, she was too anxious to be interested in much of anything.

Sophia: *Now not interesting to me. [Her favourite television show]*

ED: *Now it's not interesting anymore? How come you think?*

Sophia: *Because I worry and then I think I have to go another two days, where I go, how going to be there, you know. That's in my mind.* (Sophia, older adult)

Sophia expressed being worried about where she would go when she was discharged and this was impeding her from enjoying activities that she had previously enjoyed.

Sophia’s children reported that prior to her hospitalization, Sophia had had a couple of falls and had been hospitalized once. They said that Sophia did not tell them about the falls, rather they found out from her neighbours. Approximately one year prior, Nancy and Peter had had a community occupational therapist do a home-safety assessment to make recommendations for modifications to reduce Sophia’s risk of falling in her home. Some of the recommendations had been followed, but others had not yet been implemented.

A few months after the occupational therapist’s visit, Nancy was visiting Sophia and witnessed her mother going up and down the steps on all fours in order to access the bathroom on the second floor. Nancy had been unaware that her mother had that much difficulty managing the stairs.

Nancy: *this one day I saw her going up the stairs, and she went with her arms and her feet, all fours, and I thought: “What's the matter, your legs hurtin' you or?” She says “Ah, yeah, my legs.” And coming back down she was the--*

Roy: *She would go on her seat.*
Nancy: --the same way.

Roy: You know, down [on her] bum.

Nancy: So I said to him and my brother said just to... I said “I think Ma's... we should look into something, cause she can't... she can't be there walking like that.” I said. Just to go to the bathroom. (Nancy, Sophia’s daughter)

This new knowledge prompted Nancy and Peter to initiate the process of finding a more accessible home for Sophia. The first step was to visit a Polish retirement home in the area. Sophia was apprehensive but had agreed to the visit. She had a friend who lived in the facility. On the day that they were to visit the home, Nancy and her husband Roy came to pick up Sophia. Sophia waved to them from the front of the house and went around to the side door to go out. After several minutes Sophia had not yet come out and when Nancy went to help, she found Sophia had fallen to the bottom of the stairs in the basement. She was alert, but had hit and cut her head. As a result of her injuries, Sophia was admitted to acute care for two weeks before being transferred to inpatient rehabilitation.

At the time of the family conference, Sophia had been in rehabilitation for three weeks. She wished to return home, but asserted she could not because of the stairs. When asked where she would like to go, she said

*Home.... I miss my house... only too bad it's two floors. (Sophia, older adult)*

Later in the interview she said,

*I’m scared of steps. (Sophia, older adult)*

Sophia required assistance to go up and down steps and averred that she was afraid of them. She did not know where she wished to go upon discharge. She reported that her son had told her that it would be too much work to make the home accessible for her and thus she had given up on the idea of returning home. She expressed that she could not know what she wanted as she had never been to any of the places that were being suggested (a Polish long-term care home and a Polish retirement home). She was anxious about where she would go both because she could not picture it and because of the potential costs associated with living in any assisted living facility.

The healthcare team recommended that upon discharge, Sophia go to an environment that was accessible for her and that did not require her to go up and down steps. They also felt that because she was so social on the unit, it would be good for Sophia to be in an environment where
she could be socially engaged. The healthcare professional participant specifically commented about cultural and social considerations in discharge options.

*I really believed that if we could get her in a place that was physically accessible and that had people who speak Polish - and it’s [the recommended seniors’ residence] a Polish community. That in and of itself in my mind was super important for her overall well being.* (Diane, healthcare professional)

The team recommended that Sophia move to the Polish retirement home, but they also indicated that Sophia moving to one of her children’s accessible homes with home care assistance would be fine if she could attend a day program. The social worker involved in the case could not find Polish day programs or community centres in the towns where Sophia’s children lived, however, and so the team felt this was not as good of an option, as Sophia would have been isolated while her children were at work.

Sophia’s children were very involved in her care. Although they lived an hour away, before her hospitalization, they each came to visit once or twice per week. Peter was going through a divorce and lived alone. Because of his work and his marital issues, he preferred that Sophia not move in with him at that time. He remained, however, very involved in her care and he maintained Sophia’s house while she was in hospital. Nancy lived with her husband Roy and his mother. Peter and the social worker reported that Nancy could often be of great assistance to her mother, but that her own mental health issues meant that it was hard at times for Nancy to be consistent in the level of care that she could offer her mother. From my discussions with Nancy and Roy it was apparent she was very involved in her mother’s care. Roy stated that he was uninvolved and that he was “only the son-in-law.” During the interview with Nancy and Roy, however, he was very vocal and expressed strong opinions about family members and about governments having a duty to care for older adults. Peter and Nancy seemed somewhat confused about the differences between long-term care and retirement homes. Peter deemed that his mother required sufficient assistance that she should be placed in long-term care. Nancy alternated between the two options. In the end it was decided that Sophia would go to the Polish retirement home for a one-month trial. Following this, they would make a decision about whether she would stay there or whether they would try to get a spot in long-term care.
Sophia’s children were very involved in both making decisions as well as in arranging for Sophia’s discharge and for the care of her home. Sophia voiced her opinion, but she felt that she was not in a position to participate in decision making.

*I got no choice to say no because they know better than me now. I can't do nothing without children now.* (Sophia, older adult)

In addition to feeling afraid to return to her two-storey home in its current state, Sophia felt that she was not in a position to make decisions in comparison to her children. Sophia felt that she was now dependent on her children and allowed them to make all the decisions and arrangements for her care.

**Case 5 - Magan**

The participants in Case 5 included Magan the older adult, his daughter Teja as well as three healthcare professionals, Monica, Diane and Alison. All three healthcare professionals were included because although Monica and Diane were most involved, Alison was also involved in discharge planning on the unit and had not been interviewed for any of the other cases. All of the interviews were one–to–one, and the interviews with Magan and the healthcare professionals were all conducted on the unit within nine days of the family conference. Teja expressed an eagerness to meet with me, but owing to her schedule, she was not able to do so until seven weeks after Magan’s discharge from rehabilitation. Because of this, in my interview with her, I was able to obtain more information than in the other cases about how Magan managed following his discharge.

Magan was an eighty-one year-old retired businessman. Magan had come to Canada with his wife and children more than 40 years before I met him. Since the death of his wife more than five years before, Magan had been living alone in his condo in an urban area. He was legally blind and an insulin-dependent diabetic. Magan also had to attend dialysis for renal failure three times per week. Although he was retired, Magan maintained many business contacts and did consulting work. Prior to his admission, he was receiving home care assistance twice per day to help with his personal care and with the management of his insulin. Magan had difficulty with his mobility and used a cane. He had had a couple of ‘falls’ during which he slowly collapsed to the floor. He had a ‘Lifeline’ service, but he did not use it. Instead, he would remain where he had fallen until his secretary, his daughter, or someone from home care found him.
Prior to his admission, Magan had a secretary who came to his home several hours daily to help him with his affairs, both personal and professional. Although he lived alone, with the home care visits and his secretary, Magan had a regular routine of different individuals coming in and out of his home. He reported that he enjoyed reading, learning, and keeping up to date with what was going on in the world. He maintained subscriptions to various newspapers and journals, which his secretary read to him. Magan stated that it was important to him that he be able to welcome individuals in his home at any time of the day. Magan sought to glean as much learning as he could from each opportunity and relationship.

Magan’s daughter, Teja, lived with her own family approximately 25 minutes away from Magan’s condo. While Teja was very involved in her father’s care, she was also very busy with her own life. She was dedicated to her job and worked long hours. Magan also had a son, Ravi, who lived in a city about 4 hours drive away. Although Ravi and Teja had joint powers of attorney, Ravi did not seem very involved in his father’s care. No one described any involvement on his part and he did not speak when he was on a conference call during the discharge-planning family conference.

Approximately eight weeks before I first met Magan, Teja went to visit him at home and found him slumped over the toilet. Magan was ill with chest and abdominal pains. He was admitted to hospital, but was released the next day. Within 24 hours, his condition had worsened and he was rushed back to hospital. He was again admitted, this time diagnosed with several medical complications that had not been observed the day before. Five weeks later, when some of his medical issues had resolved, Magan was transferred to the inpatient rehabilitation unit.

The healthcare professionals interviewed suggested that Magan move to a place where he could receive assistance, however, their specific recommendations on this point varied. Two healthcare professionals felt that he could go home: one asserted that he should have “a lot of services”, and the other suggested that he should have a live-in caregiver. The third healthcare professional felt that he should go to a seniors’ residence where services would be easily accessed.

Magan wished to return home and to receive the same level of assistance he had had prior to his admission. The only change that he wanted was more consistency in the home-care schedule and in caregivers. Both Magan and Teja had complained at the family conference
about the inconsistency of the home-care assistance Magan received. The frequent changes in caregivers resulted in each new individual having to learn about Magan’s routine and preferences as well as where everything was, which wasted a lot of time. Additionally, always having new individuals did not permit for the development of trust in relationships that were based on the provision of intimate personal care. These personnel changes combined with the limited amount of time allocated by home-care services for his care, and the inconsistent timing of their arrival meant that home-care assistance was a very stressful experience for Magan. Magan had reported this during the family conference and Teja referred to this twice in her interview. At first she described the limited care that Magan received from home care immediately following discharge.

_They were sending a caregiver for 15 minutes at a time... These ladies would come in and say “get up, get up...” you know “you gotta go to the bathroom, I got like six minutes left, brush your teeth. [unclear] six minutes... three minutes left [unclear] bye-bye.” Right? So it was very uncomfortable for him, so we had to coordinate when [home care] went there._ (Teja, Magan’s daughter)

Later in the interview she discussed that she was able to advocate for Magan to receive more care a few weeks following his discharge. Magan then received 30 minutes instead of only 15 to complete his personal care and make breakfast. _Who_ was coming each day however remained very inconsistent as did the time at which they came.

_There is a little bit better help in that it's for 30 minutes at a time visit as opposed to 15 minutes at a time. But it's still, they come and they go whenever they want. They do whatever they want. It's not, you know, you come today, she comes tomorrow, he comes the other day, she comes the next day. So, you have to train everyone again and again and again, by the time this person comes again it's been a week, they don't really know where was the toaster again. Where was the bread? You know, how do you like your coffee?... And if somebody has only 30 minutes it's not a lot of time to get somebody up and out of bed and fed breakfast if you don't know what's happening._ (Teja, Magan’s daughter)

These inconsistencies were a challenge for Magan living at home.

Teja wished for her father to move to a place where he was safe and secure, but where his safety was balanced with his happiness. When asked what was important in a home for her father from her perspective, Teja responded

_For my Dad it's security, safety. Safety, security. So I want him to feel happy in a nice pleasant environment... the definition of safety is different. To me it means having someone with him... to pick him up if he falls, or who can make a decision as in, ‘no
you need to take your medicine’. You know, that kind of safety. That being said, if...if that kind of a person was available but it would be in a down in the dumps place, I wouldn’t want that for him. So I would want to balance, and I’d probably trade off a little of the safety to get a nicer environment for him because for him that’s so very important. It is for me too, but if it wasn’t for him, I would say great piece of mind, more safety. But because it is important I would balance the two.

Teja wanted her father to be safe, but she also wanted him to be happy. She felt that safety could be sacrificed to a certain extent if it meant he would be in a place where he would be happier. Ideally, Teja wished that Magan could return home with a live-in caregiver for a year or two in order to “close out his home” as she put it, and to conclude the portion of his life lived there before moving to a place where he would receive more assistance, such as a long-term care home. In her deliberations, Teja was also concerned about financial planning for his care. She expressed that there was “a finite amount” of money. She did not know whether she should spend large amounts on a high level of care now, or if she should ration the money so as to provide for his care over the longer term.

Teja affirmed that her father would make the decisions regarding his care, because it was his money, but that she would make the arrangements on his behalf. When he expressed his wish to return home without assistance, she took him on a weekend pass to his condo. She indicated that during this time, she provided only minimal assistance because she thought that this was the best way to help her father see how much assistance he actually needed. After that weekend, he agreed to have a caregiver make regular visits to his home. Teja asserted to me that the decision regarding who would care for her father would ultimately be his, but that she would assist him with the process. Teja screened individuals to come in for an interview with her father so that he could choose his own caregiver from amongst them. In pre-selecting a short list of individuals whom she deemed best suited for the role (based on her own criteria and on those she thought mattered for her father); she thus established some of the parameters within which his decision would be made. On the surface, then, the decision was his. In practice, however, it was joint decision.

Upon discharge, Magan returned home with a caregiver who would come daily from early in the morning to the evening. On the third day, the caregiver did not show up. Magan independently performed all his self-care in the morning and went to his dialysis appointment by WheelTrans. From the appointment, he called Teja and told her what had happened. He stated
that he had proved that he did not need assistance other than the home-care visits he received. Teja felt that because her father’s money was paying for the additional care, she had to abide by his wishes dictating how much care he paid for and received. For the time being, they negotiated that he would remain at home with home-care assistance, but that if he had difficulty or his care needs changed, they would look into options for further care and assistance at that time.

5.4 Summary and conclusion to descriptions of the data

In summary, the five case studies provided different examples of circumstances in which discharge-planning processes can occur. In all cases, the older adults wished to return home. In contrast, in all cases healthcare professionals recommended the provision of 24-hour care, which may or may not have been achievable in the individuals’ homes, depending on the circumstances of the cases. In each of the five cases, the older adult played some role in discharge decision making. How much their participation was enabled, how much they saw themselves as having decisional input, and how much they influenced the decisions depended on family dynamics and the approaches taken by their family members and healthcare professionals.

The critical analysis of each case includes an examination of social and political influences on the process of discharge planning in this setting. Taking a critical bioethics perspective informed by relational autonomy theory, I approached the analysis from several different angles. Initially, I designed a set of questions based on my theoretical framework and research questions. I asked this set of questions of the data in order to examine the process across the different cases to identify discursive systems of thoughts and practices that shaped individual perspectives and behaviours in the discharge-planning process. Based on the analysis in this step, I then designed a second, and later a third set of questions and repeated the process. Throughout this process, I wrote memos of different natures (for example reflexive, conceptual or thematic). I also wrote reports at various stages in the analysis focusing on different portions of the data. I created matrices to lay out the data differently and enable the identification of similarities, patterns or contrasts. Finally, I shared my memos and reports with my advisors and consulted with them on a weekly or monthly basis. The results of this analysis are presented in the Chapter 6.
Chapter 6
The application of a relational autonomy lens: Results of the analysis

6 Introduction

In this chapter I present the findings from my analysis of the data. I begin in this introductory section with an overview of how taking a critical bioethics perspective informed by relational autonomy guided my analysis of the data. I then give a brief overview of the themes identified in the analysis. In the remainder of the chapter I address my first and second sub-questions: “How are underlying beliefs, valued approaches and conventional practices influencing older adults’, family members’ and healthcare professionals’ perceptions of their roles, duties and responsibilities in the discharge-planning process?” and “How are conventional processes, valued approaches and underlying beliefs intersecting to influence how autonomous decisions are mediated?” (The third sub question is addressed in Chapter 7.) In section 6.3 Underlying beliefs I explore underlying beliefs that were reflected in the interview data with older adult, family member, and healthcare professional participants. In section 6.4 Valued approaches to care and discharge planning I move on to examine approaches that are explicitly discussed and overtly taken by healthcare professionals. Lastly, in section 6.5 Conventions and practices I describe discharge-planning conventions and practices specific to this setting.

6.1 A critical bioethics approach to the analysis

Taking a critical approach to research in health care with older adults guided an exploration of how social and political structural attributes of the context affected, and were affected by, individual perspectives and behaviours, all of which shape the provision of healthcare. A relational approach to research about discharge planning framed individuals as socially embedded and enabled recognition of the influences of underlying beliefs and expectations, of context and role-specific norms, and of relationships and considerations for the needs of others on individual choices and behaviours. Relational autonomy theory was used in two different manners in the research. Primarily, it supported an analytical approach that looked
beyond what participants were saying to explore how systemic structures were influencing individual perspectives and behaviours, shaping the expectations of behaviour, and even determining the options for discharge. Taking this approach not only illuminated participants’ implicit and explicit beliefs, perspectives, behaviours and approaches, but it also guided an exploration of the influence of conventions and practices on the discharge-planning process. Secondarily, relational autonomy theory guided my examination of how autonomy and its exercise in decisions was understood, constructed, enacted and mediated by the various participants.

6.2 Brief overview of the analysis findings

The overarching research findings included the identification of co-constituting influences on participants’ perspectives and behaviours in discharge planning. These consisted of underlying beliefs, valued approaches and conventional practices in this setting. Specifically, two underlying beliefs influenced participants’ perspectives. The first was an underlying belief reflected in the accounts of all participants, linking aging to a loss of agency and decreased participation in decision making, and to a corollary increase in dependence on others. The second was healthcare professionals’ underlying belief about the primacy of their knowledge, expertise, and authority. This second belief was not shared by older adult and family members. Two particular approaches to care were explicitly claimed as valuable by healthcare professional participants: client-centeredness and the prioritization of safety. Client-centred approaches were claimed as valuable by healthcare professionals, but were difficult to delineate in their practices and were absent from older adult and family member participants’ accounts. Client-centeredness was considered by healthcare professionals in relation to the prioritization of safety, which was prevalent in all aspects of healthcare professional participants’ practices related to discharge planning. The value of safety was also reflected in family member participants’ intentions in discharge planning, but was not highly prioritized in older adult participants’ perspectives. Finally, context-specific conventions guided the practice of discharge planning, starting from the point of admission, and directed the process of the discharge-planning family conferences (also labelled family conference throughout the text). These local norms influenced the process and the perspectives of older adults, family members, and healthcare professionals. In this chapter, underlying beliefs, valued approaches to care and local conventions and practices are described
in turn. Their co-constitution and how their dynamic interrelationships reproduce, strengthen and further develop each is briefly considered in this chapter, and further developed in the discussion in Chapter 7.

6.3 Underlying beliefs: Aging and healthcare professional expertise

Tenets of relational autonomy theory provide an understanding of individuals’ perceptions and behaviours as influenced, among other things, by underlying beliefs and assumptions that pervade all aspects of daily life. Analogously, practices and behaviours further entrench these already pervasive beliefs and influence the development of new beliefs (or simply new aspects of existing beliefs), which in turn will be further reflected and reinforced in behaviours and practices. The identification of underlying beliefs in the perspectives of participants enabled a more nuanced interpretation of practices and approaches in discharge planning with older adults. Underlying beliefs and discourses of aging and more specifically about an expected loss of agency and a decline in participation linked to an aging process were evident in all participants’ discussions. Implicit assumptions about the primacy of healthcare professionals’ knowledge, expertise and authority were manifested in healthcare professionals’ discussions about discharge-planning goals and recommendations. These beliefs and assumptions also defined different roles in the process of discharge planning. In this section I will first examine underlying beliefs about aging and a presumed loss of agency as seen in the data from all three participant perspectives before exploring beliefs about the primacy of healthcare professionals’ expertise.

6.3.1 Perspectives on aging and autonomous decision making

The data revealed a salient expectation on the part of older adults and family members that as older adults aged they would experience a loss of agency and step back from active participation in independent decision making, relying on younger family members to assume a more prominent role in decision making with or for the older adults. Healthcare professionals reflected similar expectations, the only difference being that they assumed that older adults would defer not only to family members, but more so to them as putative experts. (Healthcare professionals also expected that family members would defer to them. Underlying beliefs related to these expectations are further discussed in the next subsection, 6.3.2 Primacy of healthcare professionals’ expertise.) In other words, the general expectation from all perspectives was that
as older adults aged, they would depart from independent autonomous decision making. As is discussed in more detail below, whether participants’ believed that older adults willingly relinquished their autonomy, that it was taken from them, or that the departure from autonomous decision making was perceived to be an inevitable consequence of loss of capacity, varied between (and to a lesser extent, within) participant groups. Nonetheless, the expectation was that older adults would increasingly rely on their children or other individuals perceived to be more able and knowledgeable, to assist in, or even to take over, decision-making practices. In relation to these assumptions, the corollary expectation was that someone, most often one or more younger family members, would respond by taking over decision making. Various aspects of these expectations were both reflected and resisted in the accounts of older adults, while the accounts of participating family members and healthcare professionals by and large only reflected, and did not resist these expectations. Individuals from all three groups of participants at times linked this expected shift in decisional control to an assumed decline in cognitive and physical capacities.

In this subsection I first explore older adult participants’ beliefs related to aging, consider how these assumptions are manifested, and examine how they influenced older adults’ expectations of their own and their children’s roles in decision making. I then describe adult children’s perspectives and expectations of their parents’ and their own decision-making roles. Finally, I examine how underlying beliefs and assumptions about aging were reflected in healthcare professionals’ accounts and how this influenced whom they approached and how in discharge planning.

**Older adult participants’ perspective on aging and decision making**

Older adult participants both reproduced and resisted notions of declining decisional control as a ‘natural’ consequence of aging. They reproduced such notions by acting in manners that exemplified the expected behaviour related to this underlying belief. The discussions and actions of three participants, Sophia, Maeve and Marion, reflected underlying expectations that as older adults age they would experience a loss of agency and were expected to relinquish decision-making power to their children, and that their children would step into the role of assisting with, or even taking over, decisions for their care.
In her interview, Sophia reinforced beliefs that as older adults age, they become more dependent on their children for their various needs and decisions, and suggested her children knew ‘better than’ her:

_E.D.: And, so, who is making the decision then for you to go to this place in [city]?
Sophia: My daughter and my son. They say you got own people, you gonna be happy. You can speak your language. And I got no choice to say no because they know better than me now, I can't do nothing without children now. Right? They take me shopping, take me to doctor. ... And I can't say nothing, just listen... I can't have nothing to say, just listen what they tell me, what to do. You know what I mean. I have to listen my children. (Sophia, older adult)_

Sophia expressed a loss of agency in comparison to the independence she implied she previously experienced. She stated that she was now dependent on her children to make decisions, to tell her what to do, and to help her with her activities of daily living. She also reflected the corollary expectation that they would take care of her, articulating that they were looking out for her well-being in telling her that she would be happy with the decisions they made. She stated that they ‘knew better’. This suggests they knew better than she did what she needed, what were possible options for her discharge and what would be the best fit. This also suggested that they knew what she wanted and what would make her happy. The tacit implication in Sophia’s account was that her children ‘knew better’ because they were younger and were therefore better qualified to obtain and or understand information to make decisions for her.

Sophia further justified her removal from decision making by insinuating that what became of her mattered less now than before because she was old, thus suggesting that there was an inverse relationship between age and the value of life.

_And I don't care [Laughs] where I go. My life is gone already, I am old already. What's (sic.) [will] be will be. (Sophia, older adult)_

In this quotation Sophia expressed she had already lived her life, therefore it did not matter where she went upon discharge. Not only was Sophia relinquishing decisional control to her children, but she was implying that because of her age, the decision itself was not important. Sophia’s account suggested she accepted notions of aging being linked to decreased participation in decision making and diminished value in the outcome of decisions for older people.

As discussed in Chapter 3, relational autonomy theory highlights that autonomous action requires trust in one’s abilities to reflect on values and preferences, to obtain and to evaluate
information in order to make informed decisions, and to act on these decisions (McLeod & Sherwin, 2000). Sophia’s trust in her own abilities in these respects had decreased and had been surpassed by her trust in her children’s abilities. Sophia did not present as unhappy about this; she seemed to both expect and accept that this was the way things should be as one aged. In Sophia’s view, it was the natural course of events that as she aged, her abilities decreased. In response, she relinquished independent autonomous decision making and allowed her children to step in to take a more active role in her care and decisions. Sophia’s acceptance and expectations of help from her children aligned with relational notions of interdependent social networks (Mackenzie & Stoljar, 2000; Sherwin, 1998, 2008; Sherwin & Winsby, 2010). In such portrayals, individuals consider the wishes and needs of others in their social networks in their choices and behaviours. Since their birth, Sophia’s children had been an important part of her social network and she of theirs. In this network, the responsibility for caring for each other had shifted between individuals and consequently, consideration of each other’s needs and wishes, and the influence these have on Sophia’s and her children’s actions had varied over time. Now that Sophia was getting older and perceived a loss of capabilities in comparison to her children, she was expecting them to consider her needs and wishes, and to take actions that would help her: to take the time to research options and help her set up her living circumstances. As such, Sophia stepped aside and both expected and allowed her children, individuals who played a significant role in her social network and whom she saw as better qualified than she, to make decisions related to her care and well-being.

It is important to note that a relational approach to decision making does not equate to individuals being excluded from decision making. Exclusion from decisions would align with a traditional account, in which individuals are expected to make decisions independently; if they are deemed incapable of doing so, decisional control is taken from them and decisions are made for them by others considered to be more capable. Relational autonomy approaches to decision making strive to achieve inclusion whereby through consideration of wishes, needs and capabilities, individualized or tailored approaches are used to enable or maximize decisional control. There are various manners in which individuals can be involved in decision making even if they are not perceived as able to make independent or final decisions. For example, as in the case of Sophia, individuals can share their wishes. Alternatively, as I describe in the examples of Maeve and Marion below, individuals may speak up against particular choices, or
may exert power in decision making in subtle ways. In the case of Sophia, through her relationship with her children and her discussions with them, she made her wishes known and trusted that they knew her needs. Her account also suggested she trusted in their capabilities to make decisions that were in her best interests more so than she trusted in her own. Trusting and knowing this, in the decision-making process, Sophia stepped away from making final decisions with the expectation that her children would make decisions for her benefit. Through her relationship and discussions (past and present) with them, however, she remained an active member of the decision-making process.

Maeve provided another example of an older individual relinquishing decisional control to her children. In the context of her interviews and of the family conference she fervently asserted that she wanted to return home, yet Maeve did not take any action towards setting up circumstances to be able to do so.

**E.D.: Do you know what is the plan for the discharge?**

*Maeve: No I don’t. No I’ve been talking with [my children to] go off somewhere else, but I don’t know, I don’t know. I have to see the kids when they come in. Because of the, the plague [infection outbreak] that was on they weren’t able to come in at all. I’m not in any contact with them either. …

**E.D.: So who do you think is looking to see what’s going to happen?**

*Maeve: Probably the three kids are, I would think. Probably they’re looking to see what is the best for me. (Maeve, older adult)*

In this excerpt, Maeve seemed disconnected from the discharge-planning process. She makes reference to an outbreak on the unit, in response to which restricted visiting practices were implemented for several days. Individuals were able to visit using infection-control precautions, however, and Maeve had a telephone and could have called her children. Despite these potential means of communication, Maeve did not take any initiative to plan her discharge either independently or in collaboration with her children. Maeve exhibited despondence in her tone when she said “Nobody knows what’ll happen to me”. Her words and actions suggested that she was not making independent decisions about her care and living circumstances, but rather was stepping back and expecting her children to make decisions for her. In this way Maeve was also reflecting expectations that as they age, individuals experience a loss of agency and rely on their children to make decisions.
In contrast to the sense of detachment I observed with Maeve, her son Tom painted a picture of his mother as a strong-willed independent matriarch. He reported that she had explicitly told him not to put her in a nursing home.

She’s one of the smartest people I know... She used to work in the nursing field. She used to work in a nursing home, so she knows behind the scenes... She told me about fifteen years ago: “Tom, don’t ever put me in a nursing home. Just shoot me”.... She’s very stubborn, and she doesn’t like to share her space. She’s been widowed since 79. So she’s basically had a house to herself. (Tom, Maeve’s son)

Tom’s impression of his mother was of a strong and independent person who in the past had expressed to him that she fervently did not want to move to a nursing home. During the discharge-planning family conference, in the face of Maeve’s discharge and the apparent detachment she was displaying, (which Tom may have felt was out of character) Tom and his sisters presented as unsure of how to proceed. Tom appeared to be feeling tension between his mother’s previously expressed wish not to move to a nursing home, and the impressions he and his sisters shared that Maeve required more help than she wanted to accept. Their impressions were strengthened by healthcare professionals’ assessments and their recommendation for Maeve to have 24-hour care. The different perspectives, how these were expressed, and the resulting tensions are described in my field note about the family conference:

Maeve did not try to integrate herself into the conversation. Maeve was very quiet. She spoke up a couple of times to say she wanted to go home and that she didn’t want anyone staying over with her. The team expressed their recommendations that Maeve would require assistance, and in fact, they were recommending 24-hour care. Maeve’s children agreed with the team that Maeve would require more help. Although everyone was aware that Maeve did not want this, no one really engaged her in a conversation addressing this. At one point [Maeve’s] son said something about long-term care, and when she didn’t respond he prodded her to say something, to which she responded that she didn’t want this. That was the only time [she was directly engaged in a dialogue]. Otherwise, the conversation about care following discharge happened around Maeve about her. She held a sort of power however because everyone was stating their recommendations or concerns, but no one was willing to override what they knew to be Maeve’s wishes. ... Maeve appears to be passive in terms of her care, deferring to her children to make decisions, but if they make a decision that she does not like, if she is asked directly or if the comment is directed at her, she speaks up and speaks her mind. Until that happens however, she tends to let people talk about her and talk around her. (Case 1 family conference field note)

This excerpt reflects the disagreement between Maeve wanting to return home with minimal assistance, her children wanting her to have more than minimal assistance, and the healthcare
professionals’ recommendations of 24-hour care. Tension is evident in the lack of discussion addressing the obvious dissonance between Maeve’s wishes and those of her children and the healthcare professionals. All parties had expressed their perspectives, but other than the one exchange between Maeve and her son where he pushed her to answer on the subject of long-term care, there was no collaborative discussion initiated by any party to resolve the conflicting opinions and wishes.

Maeve’s children and the healthcare professionals seemed to be waiting for Maeve to come to a realization that what they were suggesting was the best course of action, and for her to make a decision in alignment with their wishes and recommendations. Maeve, however, was refraining from doing so. On the surface, it may have appeared that Maeve was relinquishing full decisional control to her children. Without actively making decisions or plans for discharge however she was very much involved in the decision-making process by voicing her opposition to suggestions for options that included the provision of more care. She may have been waiting for someone else to suggest an option that matched her preferences, at which point she would have acquiesced. Despite voicing her opposition, Maeve did not offer alternatives or assert decisional control as seemed to be expected of her by the others. In the absence of Maeve making a decision, her children made the decision for her to go to long-term care. This seemed reflective of entrenched understandings and practices of revoking/denying autonomous decision-making authority when an individual is deemed incapable of making decisions and allowing other individuals, perceived as more capable, to make decisions on their behalf. While Maeve was not explicitly deemed incapable of making decisions by her children or by the healthcare professionals, they nevertheless assumed decisional power. There did not appear to be a tailored process in place at the family meeting or otherwise aimed at enabling Maeve’s more active participation in decision making, or a collaborative negotiation process aimed at identifying what was important from each perspective and/or how an outcome could be devised to maximize individual priorities. The process and outcomes were aligned with expectations that as individuals age, they experience diminished agency and become dependent on their children to make decisions for them.

Maeve appeared to have the capacities to fully participate in decision making, which included self-trust in her own capabilities to obtain and understand information, an ability to evaluate this information in light of her own values, preferences and capabilities, and an ability
to make a decision and act on it (McLeod & Sherwin, 2000; Meyers, 1987). Based on Tom’s assertions about Maeve’s previous independence, it would appear that she had had many years of opportunities to develop and express her sense of agency and the capacities required to make decisions about her own care and living circumstances. According to this history and based on the insights Maeve shared with me during her interviews, it seemed incongruous that Maeve would not have had the capacities required for autonomous choice. Maeve seemed instead to be choosing not to participate in decision making. From the accounts, her motivation for relinquishing decisional control presented more in keeping with the expectation that she, as an older person, must step back from decision making and rely on her children. It is possible that Maeve refrained from making plans for her discharge because she knew that her choices would not align with her children’s wishes and the healthcare professionals’ recommendations. Maeve’s approach to discharge decision making therefore may have been to refrain from making plans of which she knew others would not approve, and which could set up an uncomfortable situation of opposition. She displayed enough agency to voice her opposition to plans that she did not like, but not enough to make plans against others’ wishes. When, in the end, others made plans against her wishes, she abided by them but with despondence, voicing “I sure didn’t think I’d end up in a home”. It is possible that Maeve’s acquiescence did not result from linking aging with decreased agency, but rather (or as well) reflected depression or a feeling of loss of power - a kind of fatigue and giving in to all that was happening to her.

A third older adult whose discussion and actions reflected a loss of agency and less independent decision making was Marion. Marion expected her children to make decisions and to set up circumstances for her care. Marion implied this expectation in praising her son and her daughter for doing so:

Well I put him [her son David] up on a pedestal. He is absolutely wonderful. It’s hard to get a child to look after their mother. So his remark to me, he says “you looked after me when I was a kid, I say and now it’s my turn.” And Darlene’s the same way, my daughter. She’s- I’ve got two wonderful children. (Marion, older adult)

Marion took pride in her children’s expression of familial responsibility in caring for their aging mother. The implication is that, to her, it was their duty to take care of their mother. At the same time, however, Marion also stated in the interview that she had no choice in having her children make decisions for her. As she saw it, this is how it was. Marion expressed anger at the
lack of control she felt in the face of her children’s power to make decisions that she may or may not like:

_E.D.: Who’s making those decisions, about you- where you go when you leave here?_

_Marion: My son._

_E.D.: Your son?_

_Marion: Yes._

_E.D.: And what about you?_

_Marion: Well there’s some of these -decisions that I don’t like, but, I have no choice. And he has mentioned “well if you don’t want this then you’ll go into a home.” And I don’t want to hear the home. If I hear that home once more I’ll walk the streets._ *(Marion, older adult)*

Marion protested the fact that her children, her son in particular, were making decisions for her. In the excerpt above, she described an argument during which her son threatened her with long-term care. Marion resisted his threat with threats of her own to ‘walk the streets’ if it came to that. Despite her negative statements about being in a position where her son made decisions for her, Marion granted him the power to make decisions but asserted her agency in other ways. Though she verbally protested some of the decisions he made for her, she quickly accepted his decisions and shifted her complaining to something else. An example of this was that although she protested against having a live-in caregiver at the beginning of the discharge-planning family conference, by the end of the meeting 30 minutes later, Marion accepted this amount of care and shifted the argument from having one at all to how this individual’s presence was going to affect her living space. Marion thus granted her son the power to make decisions, but asserted her agency and power through her complaints and threats. In doing so, she influenced outcomes and participated in decision making, but not in the overt and traditionally expected manner of so-called independent decision making.

These three examples reflected underlying beliefs of participants that, as older adults age, they experience diminished agency and decisional control. Each of the participants in their own unique ways shifted decision-making responsibilities for their children to assist in, or even take over, decision making. There were different ways in which older adults approached this shift in power. Sophia’s interview indicated that she accepted this change. To her, this was the ‘way things were’ and she had no choice. Maeve suggested that she was more or less indifferent to this shift and Marion’s remarks reflected anger at a loss of control. Nonetheless, all three older
adults were accepting of, or resigned to, this shift and they both expected and allowed their children to take a lead role in making decisions and taking action to put in place circumstances for their care. Thus within a relational autonomy framework we can see a shift in decisional control. This does not imply that these women had ‘full’ or ‘complete’ autonomy or independence in their younger lives. Like all persons their ability to exercise autonomy was contingent on delimiting immediate circumstances and the broader social order. But what we do see in these accounts is a shifting of decisional responsibility, which is largely perceived as ‘natural’ or ‘given’ in the context of aging, even as it is resisted.

Resistance to expectations of a loss of decisional control with age was most prominent in the accounts of two participants: Magan and Rita. Magan recognized there were contextual expectations about aging and explicitly resisted a belief that he should act a certain way because of his age by saying:

*In a society a pattern is set. And once you reach that age, it becomes a belief, which I call a myth, that you got to do this [act in certain ways] {banging on table with his hand} and that and that and that. Otherwise this and this and this can... {/banging} It’s a myth. It’s a fashion... And these ideas when repeated so many times, it will take root. (Magan, older adult)*

While Magan did not qualify the roles that should be played at certain ages, he recognized that within the different layers of his social and political context, there were age-related norms for roles and behaviours. He also recognized that by abiding by these expectations, he reinforced them. By calling them ‘myths’, he indicated that he resisted these perspectives. The expectations described by Magan are discursive systems of thoughts which influence individual underlying beliefs and furthermore shape norms and expectations. All of these notions and ways of thinking influence the opportunities available to individuals, which in turn influence individual perspectives of the self and others, and affect individual behaviours and the development of capacities.

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10 Please note that despite Rita having been interviewed as a “family member” participant and not as an older adult facing discharge herself, in the analysis, her perspective aligned strongly with older adult participants’ perspectives and thus is included as such, rather than as a family member. This implies that in this analysis, there were stronger demarcations between perspectives based on the roles of older adults, *their children*, and healthcare professionals, than there were between older adults, *family members*, and healthcare professionals, as was determined during the inception of the study. Further study examining the similarities and differences between familial roles in discharge planning could be a fruitful contribution to the literature.
Aligned with his resistance to such expectations, Magan’s actions also contradicted perceptions that as older adults age they retreat from activities. He was a businessman who remained very active in his business world. He was also very involved in making decisions about his care, but accepted his daughter’s participation in these decisions. Contrary to other participants, he did not link a loss of autonomy or agency with aging. Furthermore, he was not overly concerned with the process of aging, but was more so concerned with maximizing the time he had to learn and as he put it, “to find something for inner peace”. Other than resisting perceived expectations of how one should act as one aged, Magan focussed on doing what he wished. Gender, culture and other influences undoubtedly helped shape Magan’s attitudes, however, such differences were not the focus of the study and the sample was too small to comment in a meaningful way.

In approaching discharge, Magan made it clear that he wished to return home with no more support than he had had prior to his admission. His daughter Teja worried that he could not care for himself and wanted him to have more assistance than before. Magan accepted her input and they decided jointly that he would return home with full-time daily assistance (eight hours a day). As noted, on the third day post discharge, by chance, Magan’s caregiver did not show up. Magan seized the opportunity to show Teja that he did not need help by getting himself to his dialysis appointment independently. Through both his words and his actions, Magan resisted perspectives of frailty and of dependence traditionally associated with older age. Despite not being particularly healthier than the other participants, using evidence of his capabilities and taking advantage of circumstances, he changed the decision he and his daughter had made.

Assumptions that as older adults age they should allow their children to take over decision making were also resisted by Rita and Frederik, who as a couple made joint decisions without the assistance of their children. Despite their actions, Rita made comments that reinforced assumptions that it was a natural course of events for children to become more involved in older adults care as they aged:

*I cannot imagine what people do who do not have children or somebody else. We are very lucky.* (Rita, wife of Frederick)

Rita’s comment reinforced the perspective that it was the children’s role to help their parents as they grew older, a role that in her view would leave a void if she did not have children.
A critical approach informed by relational autonomy theory illuminated underlying beliefs about the relationship between aging and a loss of agency and the manifestations of such beliefs or expectations in influencing individual behaviours. Across the accounts, older adults’ actions reflected and reinforced, as well as resisted, underlying assumptions about aging being linked to a loss of agency. They expressed their agency and exercised their autonomy in different ways that reflected different amounts of independence and/or decisional control. In some cases, older adults shared decision making with their children, or maintained the lead and accepted their children’s involvement in realizing decisions. In other cases, older adults deferred decision making to their children but participated in the process by making their wishes known in various manners, thereby influencing the process without overtly making the decision. In all cases, adult children responded to expectations that they would actively step in to take a more prominent role by doing so. Adult children’s involvement will now be explored from their own perspectives.

**Adult children’s perspectives of aging and their role in their parent’s care**

The interviews with adult children exemplified the previously described assumptions about aging being linked to a loss of agency, but further reinforced the corollary expectation that children were obliged to assume more decisional responsibility as their parents aged. The children’s perspectives were distinct from those of their older adult parents in the sense that children felt it was their duty to assume a more salient role in their aging parents’ care not only if this role was granted by the older adult, but even if their parent did not defer decision making. This assumption was both implicit and explicit in the accounts.

In the case of Sophia, her children deemed that she was relinquishing decisional power to them. Sophia’s daughter, Nancy, stated that Sophia told her and her brother to make decisions about her house as she no longer wanted to think about things.

*She said... “you and your brother do... what you want, you know, with the house, with the thing... cause I don't want to think about nothing.”* So she’s reached that point of; you know. (*Nancy, Sophia’s daughter*)

Contrary to Sophia’s assertion that she had no choice but to rely on her children now, in Nancy’s view it was Sophia’s choice to relinquish independence and decisional control. In response, Nancy and her brother stepped in to play a bigger role in making decisions and caring for Sophia. In saying “she’s reached that point”, Nancy suggested that there was a generally
understood expectation that there is a point to be reached where older adults will inevitably take
a less active role in decision making. This aligns with beliefs that older adults experience a loss
of agency linked to aging. In her perspective and her actions, Nancy was responding to this
expectation and to the expectation that children take a more active role in their parents’ care.

Similarly, Sophia’s son described his perception of his mother’s approach to discharge
planning by stating that his mother had relinquished these responsibilities to her children.

*ED: And what do you think is your mom’s role in discharge planning?*

*Peter: Well... I think she's kind of leaving it up to the kids. I think that's basically all it is.
She doesn't really have any role.*  (Peter, Sophia’s son)

Peter also felt it was his mother’s choice to leave decisions to them, which again contrasted with
Sophia’s assertion that she had no choice. In these quotations, Sophia’s children were
responding to their perception of their mother’s choice to relinquish her agency by stepping in to
make decisions for her. In doing so, they were themselves reproducing expectations that older
adults inevitably experience a loss of independence and were also reproducing the corollary
expectation that it is their duty as children to step in and to assume decisions for their aging
parent. Viewed through a relational lens Nancy and Peter were responding to their perceptions
of their mother’s actions and how best to uphold her wishes. They perceived that she was
leaving the decisions up to them, which reaffirmed underlying assumptions that individuals reach
a certain point where they no longer want to think about things and make decisions, and
therefore that they experience a loss of agency linked to aging. They were also responding to
both Sophia’s and their own self-imposed expectations that they would step in to assist her.
Nancy and Peter may also have been reacting to internalized social expectations of a filial duty.
Nonetheless, in acting on these underlying beliefs and corollary expectations, they reproduced
and reinforced them.

In some instances, assumptions that aging resulted in decreasing agency were linked
directly to an assumption that older adults were experiencing age-related cognitive decline.
Participating children of older adults believed they were better able to understand information
than their parents and as such were better placed to make decisions. From a relational
perspective in considering the abilities required for decision making, the older adults’ children
thus had higher trust in their own abilities to reflect on their parents’ values, to obtain
information, and to make and act on a reasoned decision, than they did in their parents’ abilities
to do so. This view was evident in interviews with adult children who stated that they ‘convinced’ their parent to see things their way:

We finally convinced her to go to this home. (Roy, Sophia’s son-in-law)

and similarly:

She’s come around in the past two three months, she’s realizing that she needs assistance, further assistance, but she’s very stubborn. (Tom, Maeve’s son)

These family members implied that their older parents did not understand information and/or appreciate consequences in the same way as younger individuals inevitably did. The suggestion was that older adults need more time, explanations and convincing to understand information and to see the presumed “right way” of moving forward. The implied lack of understanding and ability to process information by older adults is directly addressed in the quotation below:

I think one of the biggest and the hardest things to have done in this situation with my mom is trying to explain to her her health and where the best place is for her to go. (Peter, Sophia’s son)

Peter implied that he knew better than his mother what her health status was, what were the potential implications of her going to various discharge destinations, and that she needed Peter to explain to her these details regarding her own health and discharge plan. The assumption in all these excerpts from adult children was that older adults were experiencing a loss of cognition, which contributed to their loss of agency. Children thus perceived that their parents required assistance from them to understand situations and take over decision making, or to accept the decisions made for them by others.

While Peter implied that his mother had impaired cognition, he at the same time, indicated that he believed she was capable of making decisions:

But today was another [emphasis] exhausting [/emphasis] discussion with her... Because I think she's not fully comprehending or understanding or, there’s a lot of repeating and she’s forgetful, and you have to kind of reinforce that line of thinking to her... She’s still mentally capable to handle her own affairs, you know, so, she could, if she wanted to -In the meeting, if she turned around and said “no I'm going home”, I don't think there is there a thing that my sister and I could do. I mean I think we could say “oh well... we'll have to ask somebody to come in and find out if she's mentally capable”, right? And if they find her mentally capable, which I think they will, she can go home and do whatever she wants, right? ... Yes, it is a lot of responsibility to leave it up to me (Peter, Sophia’s son)
In this quotation, Peter expresses both that Sophia required extensive assistance to understand information, but also that she was capable of making decisions. Peter was torn between his desire to uphold his mother’s autonomous choice on the one hand, and his perceptions of her potential cognitive decline and a filial duty to assist her and to protect her from what he felt she did not understand on the other. Ultimately, Peter felt a responsibility to make decisions for his mother:

*E.D.:* Who do you think is going to end up making the decision ultimately of where she goes?

*Peter:* Me.

*E.D.:* You? Over your sister? Over [Sophia]?

*Peter:* I already have. I already told my sister... I told her what I talked to mom about.

*E.D.:* And what is the decision?

*Peter:* I told her [Nancy] to find out from [long-term care home] fill out the paperwork, give them a call, see if they have a room available next Wednesday morning. I said if they do, we’d like, I’d like, to try her [Sophia] out there. (Peter, Sophia’s son)

Peter stated that he was making the decision. His words were that he’d like to “try her out” at that particular senior’s residence, thereby suggesting Sophia had very little, if any, say in the situation.

David, Marion’s son also reinforced expectations that older adults experience decreased agency, independence and cognitive capabilities as they age. He, too, responded by enacting a filial duty to make decisions for his mother. Unlike Peter, who took on this responsibility despite expressing that his mother was capable of making decisions, David asserted that he could not allow his mother to make decisions for herself:

*ED:* And who do you think is making the decision of this is the time to go [somewhere other than home]?

*David:* That’ll be my decisions. I, I can’t allow her to make these decisions any more, she-you know like I try to discuss it with her, as you saw, um, but she gets defiant. And uh, I can just take so much of the defiant attitude, and then it’s like I have to put my foot down, it’s like she’s a child and I’m the adult now, sad as it may seem, but it is reality. (David, Marion’s son)

David attributed his mother’s lack of decisional capacity to what he described as defiant and childish behaviours. He did not explicitly link this behaviour to her aging, but a lack of capacity to understand or to make reasonable decisions due to her age was implied. David reinforced
expectations that as older adults age, they experience a loss of agency and require their children to step in and to make decisions for them.

Teja’s perspective on her responsibilities in her father’s care was more complex. Magan did not exhibit the same loss of agency as Maeve, Marion or Sophia, yet Teja felt a responsibility to take an active role in her father’s care, something he accepted. Despite feeling a need to step in and direct Magan’s care, Teja felt that because the financial resources to fund her father’s care were his, he should ultimately be making the decisions. At the same time, however, she wanted his decisions to align with her views of what he needed. As long as she felt he was not in a position of danger, she did not want to take decisional power from him. She struggled, however, because she wanted a particular outcome.

_The decision not to have assistance was his because, after all, it's his money that's being spent. So, I could have said “no no no, you have to have” but you know, how can you do that... If I thought he was in danger, I would say no... Now, the way I was able to finally convince him and persuade him to get help is to appeal to what was important to him, and let him deny the reality – reality being he needs medical care._

(Teja, Magan’s daughter)

Teja’s impression was that her father did not appreciate the risks that she perceived. She did not accept that he was willing to assume these risks whether he saw them or not and as such felt that she had to persuade him to do what was best. The assumptions underlying her actions were that her father had a decreasing understanding of his situation, but that he had a strong sense of agency, and wanted to make his own decisions. Teja linked decisional control to her father’s finances and felt that despite his limited understanding, she could not overrule his decisions unless he was in a position of significant or immediate risk.

Thus across the accounts, adult children participants explicitly stated or implicitly suggested that as their parents aged, they lost the ability to appreciate potential risks, and therefore, the ability to make appropriate decisions. In response to these beliefs, in all cases adult children stepped in to take an active role in their aging parent’s care. The older adults’ real or perceived loss of capacity led to a decrease in agency and control in decision making. The children therefore felt they were in a better position to obtain, understand and apply information, and to either assist their parent in making decisions, or to make decisions for them. They were acting to fulfill internalized expectations of their duty to care for aging parents.
As was discussed above, while older adults may in some cases have deferred the act of making a final decision, they nonetheless expressed their agency in different manners that enabled them to maintain a role in decision making. Conversely, older adults’ children responded to the older adults’ expressions of agency and enabled participation in decision making even though it may not have been perceived as such by individuals in either role. For example, although Peter may not have recognized it, his taking the time to explain his understanding of the situation to Sophia in an effort to help her understand was a manner of maximizing her strengths, minimizing her weakness in not understanding, and also giving her an opportunity to voice her questions, concerns and values. All of these served to uphold her autonomy and enable her participation in decision making. Similarly, as was discussed in Chapter 5, by pre-screening individuals for Magan to select a caregiver from a select few, Teja was also enabling his participation in decision making. She was doing some of the work that he was perhaps less able to do, and including him in manners that suited his desire and ability to participate and make decisions. Finally, by working to find a solution where Marion could stay at home rather than go to long-term care - the solution he, his sister and the healthcare professionals preferred - David allowed Marion to influence the discharge-planning decisions.

Each of these cases reflects the relational nature of decision making in different ways. By knowing their parent’s needs and values, and based on their relationship and communication practices, the children each took a unique approach tailored to their parent’s needs, values and strengths in order to enable their participation in decision making.

Healthcare professional participants’ perspectives of aging

Healthcare professionals reflected similar beliefs to those of the adult children that aging lead to a loss of agency, a decline in participation in independent decision making, and an increased need for assistance. In the data, as in the excerpt below, this assumption was reflected in offhand comments implying that it is understood that “this population” needs more assistance:

*It’s just the population I think … Like, I mean these are older people who have done really well until now, but you know a hospital admission for a 97 year old is very different than for a 60 year old.* (Monica, healthcare professional)

The implied assumption was that as people age, they have greater health needs and more complications and that as such, they require more assistance. Healthcare professionals viewed the increased need for support by older adults as not limited to assistance with their care, but as
also including assistance in making decisions about their care. Healthcare professionals also assumed that as older adults age, they experience a loss of agency and of the capacities required for decision making. The implication was therefore that older adults require younger family members or other individuals who are more capable of understanding information and of making informed choices to assist or even take over decisions. The assumption that individuals required others to step in to make decisions, and the related shift in approach, were reflected in observations of family conferences as well as in discussions of interviewed healthcare professionals.

In the family conferences, in all but one case, older adults were present but largely excluded from the discussion in which discharge plans were addressed. (Please see section 6.5.2 for more detail about the process of the family conference.) The exceptional case was that of Frederik and his wife Rita, both of whom were actively involved and contributed to the discussion pertaining to Frederik’s discharge plans. In all other cases, when the rehabilitation professionals made their recommendations for discharge, they directed the conversation towards family members and the discussion proceeded between healthcare professionals and family members. This was exemplified in the excerpt from the field note about Maeve’s family conference discussed above (p. 97), as well as in the following excerpt from the same observation:

In the discharge-planning conference, the healthcare team had a tendency to talk about Maeve in the third person, a few times bringing Maeve into the conversation, but mostly talking about her even though she was right there. (Case 1 family conference field note)

In a similar example, in her family conference, Sophia appeared to be following the discussion, but she did not speak.

[Sophia] hardly spoke during the meeting. She was engaged in the discussion, looking at the speakers and smiling, but she was not understanding what was taking place in the meeting. She knew very well what the meeting was about but she was not able to follow all the details of the discussion... Right before the end, Peter said to the team that he didn’t think his mother had understood all of this and he asked his mother in Polish if she’d understood. She said no. (Case 4 family conference field note)

To others, Sophia may have appeared on the surface to be participating by following social cues and looking at speakers while smiling, but she had not understood the discussion. Though Polish was her first language, Sophia spoke English. The speed and high number of individuals
involved in the discussion however proved to be more difficult for her to follow. Without understanding, she would most certainly have difficulty in contributing. The fact that no one was aware that she could not follow the conversation demonstrates the lack of effort to engage her and how the discussion occurred between healthcare professionals and her family members.

In their interviews, healthcare professionals reported that family members were often intensely involved in planning for discharge. Interestingly, family members’ capacity or interests in the well-being of their parent was never questioned; however, comments about older adults’ ability to make decisions or contribute to their discharge plans were almost always accompanied by questions about the older adults’ capacity to make decisions. The underlying inference was that older adults’ capacity was questionable, but that the decision-making capacity of others was presumed acceptable. Such differences reflected assumptions about putative links between aging and cognitive decline. Many of these patterns of assumptions are evident in the following quotation:

*It’s very individual with regard to how much family involvement there is. If there isn’t [any family], then obviously we’re dealing directly with the patient and, if they’re competent to make their own decisions and implement all the recommendations that we’re making, then we deal mainly with the patient. But the family is, I mean, generally here in this population- it’s an older population. Generally the family is very involved. We’re meeting them. Like, I know all of the families. They’re in often. I talk to them on the phone. We see them in the family meeting. We see them all of the time, so they are generally quite involved with discharge planning. (Julie, healthcare professional)*

Julie thus stated that in discharge planning, she relied on the older adult if the individual was capable of making all the decisions and implementing all the healthcare professionals’ recommendations. “Competence”, meaning mental capacity, was criterion for engaging the older adult in decision making. That she immediately mentioned capacity (competence) implies that there would be reason to suspect impaired capacity. In her response, she focussed on the involvement of family members, suggesting that with this population, it is taken for granted that there is a high need for family involvement.

A relational examination of influences on individual perspectives and behaviours highlights how entrenched notions of aging and accompanying decline mediated decision-making practices and processes. All participants, with the exception of two older adults (Magan and Rita), reflected an underlying belief that aging is inevitably linked to a loss of agency and a
decline in decisional capacity. In light of these anticipated changes, the expectation was that individuals become more dependent on others to assist with, or even take over, decision making. Some of the older adult participants and all of the children family members and healthcare professional participants attributed this increased need for assistance to an expectation of cognitive decline resulting from the aging process. These underlying beliefs influenced the actions of all participants in discharge-planning decision making. Some older adults resisted such beliefs and maintained the lead in making decisions (Frederik and Rita). Others accepted an overtly joint decision-making process (Magan), or found other ways to participate in decisions (Sophia, Maeve and Marion). Sophia, Maeve and Marion expected and at least overtly allowed their children to make decisions for them, but found other ways to express their agency and maintain participation in the process of decision making even if their children made the final decision. Despite their different behaviours in decision making, all older adults expected and accepted assistance from their children in some form. Older adults’ children were influenced by underlying beliefs about aging being linked to a loss of capacity for decision making and a filial duty to step in to assist their aging parents. In some cases the children implemented strategies to maximize older adults’ autonomy and agency in the process while in other cases the children took over decisions about care entirely. Healthcare professionals reflected these assumptions about aging by having less trust in older adults’ abilities to plan for their discharge and having a standard protocol of including family members in this task, at times inadvertently excluding the older adults from the decision-making process. Individuals from all three perspectives were influenced by underlying beliefs linking aging to a loss of agency and to a decrease in participation in decisions. They were also responding to expectations that as older adults retreated from active decision making, their children would step in to assist them or make decisions for them.

6.3.2 Primacy of healthcare professional expertise

A second underlying belief evident in healthcare professionals’ accounts was related to the primacy of healthcare professionals’ knowledge and their roles in discharge planning with older adults. Essentially, healthcare professionals privileged their own knowledge, expertise and authority in determining the best course of action in a given discharge situation. Related to this was the implication that older adults and family members did not have equal knowledge or
authority. This belief was co-constituted with underlying beliefs linking aging to a loss of agency and to decline in cognitive capacities. The belief that older adults inevitably experience a loss of agency and cognitive decline reinforced beliefs about the presumed superiority of healthcare professionals’ knowledge and expertise. Similarly, healthcare professionals privileged their own expertise, which further devalued the wishes, beliefs, values and capacities of older adults. This underlying belief attributing primacy to healthcare professionals’ expertise, evident in discussions with healthcare professional participants, was not shared by older adult and family members. In this subsection I first explore reflections in healthcare professionals’ interviews of underlying beliefs about the primacy of their own knowledge and expertise before examining how healthcare professional involvement in discharge planning was considered by older adults and by their family members.

**Healthcare professional participants’ perspectives**

Healthcare professionals asserted that they played the central role in making discharge decisions, and in many cases they spoke as though they had not considered older adults and family members as contributing at all. As will be further explored in the next section 6.4 *Valued approaches to care and discharge planning*, situations where older adults or their family members disagreed with healthcare professionals’ recommendations were deemed ‘disasters’. The underlying suggestion was that the assessments and subsequent recommendations by healthcare professionals were the best or only reasonable course of action and that any deviation from this plan was at least unfortunate if not dangerous. This underlying belief in the primacy of healthcare professionals’ knowledge and expertise seemed to justify the central role they attributed themselves in guiding the discharge-planning process.

A noticeable lack of older adult or family involvement in discharge planning was apparent in this excerpt from a healthcare professional’s discussion of when and by whom decisions were made.

*We meet as a team at rounds and discuss each patient, and that’s really when we talk about discharge planning formally, but we also talk about it informally all the time, amongst whomever the physio and OT are. (Rebecca, healthcare professional)*

Rebecca described that discharge decisions are made through discussions of patients during rounds and in informal conversations between involved healthcare professionals, both being
forums at which patients are not present. Similarly, when asked to describe who was involved in discharge planning, healthcare professionals described the healthcare team members:

**E.D.: Who is involved in discharge planning?**

Monica: The whole team, so physiotherapist, OTs, social work, nursing, physician, um and I guess any other team members that would be involved like SLP. Um, but primarily I think it would be like the allied health. (Monica, healthcare professional)

And again:

**E.D.: Who do you think is making those decisions about where they’re going and putting those resources? Who’s guiding it?**

Julie: For sure [the] team is guiding that. Absolutely. Our team. (Julie, healthcare professional)

There was no mention in these accounts of the older adult or of family members’ contributions to discharge plans. When asked directly what was the older adults’ role in discharge planning, one healthcare professional responded that they participated in therapy and assessments:

**E.D.: What’s the client's role in discharge planning?**

Alison: pretty much to participate in their therapy, in their assessments, bathroom, kitchen, to get stronger and see what equipment is safe for them at home. Patients generally here aren’t as involved, just they... more things are done for them, or to them, to help them. So I know in other facilities, let’s say for a walker for example, you give them a list of vendors, say “choose a vendor and go get your own walker. Here's the list.” Here I say “I have a list of vendors, but I can help you order one, do you want to go through a vendor, and here’s a list, a vendor of your choice, or would you like me to choose?” “You do it.” ... and we do it for them. So... in a lot of ways it's like a paediatric facility, you're working a lot with the caregiver around the client rather than directly with the client. Depending on cognitive level. (Alison, healthcare professional)

Older adults were seen as responsible for complying with therapy and assessments and for using the equipment that was prescribed and at times even purchased by the healthcare professionals, but were not viewed as having a role to participate in discharge decisions or even in decisions about their own purchases at times. This therapist both viewed older adults as incapable of contributing to discharge planning, but also took pride at being part of a team that provided high quality service to individuals beyond what other facilities provide. She was focussed on providing beneficent care without consideration of autonomy.

The healthcare professionals did not seem to value the contributions that older adults or their family members could make to discharge decisions as much as might be expected, given
that these decisions had such significant implications for the older adult and family members. The apparent lack of importance that health care professionals placed on older adult and their family members’ contributions may have stemmed from either a lack of awareness of their potential value, awareness but a belief that their own knowledge was superior, or other situational factors. Only one healthcare professional asserted that older adults have an influence on the discharge decision. She started by discussing the involvement of the team, moved on to indicate that older adults look to the team to make recommendations, but ended by commenting that older adults ultimately make the decisions.

**E.D.: And in discharge planning, we’ve talked about many people, who do you think has the biggest say?**

Erica: Hmm, it’s from a health team, healthcare team perspective, I think all. I think in our team at least the physical therapist and the OT have, do have a weight in terms of what we have to say as to what recommendation we will give. But I think that if we look at the whole sort of working relationship[s] at large, like including the family and clients, I think the client[s] do have a say, I mean at the end. Um, they [are not] normally the one[s] who give a lot of input... they look at us to give them, give them the direction, but...I think they are the one[s] who ultimately make the decision given that they are capable. (Erica, healthcare professional)

Erica stated that the healthcare team had a heavy influence, but that in the end, assuming that the older adult was capable of making decisions, the choice was “ultimately” the older adult’s. The implication however was that the older adult made this decision based on the healthcare team’s recommendations. From her perspective the healthcare team’s input was of primary importance in discharge-planning decisions.

The participating healthcare professionals’ belief that their knowledge and expertise gave them the authority to make important decisions was supported by their views that the role of older adults and their families was limited to implementing their recommendations. In the description below, the primacy of healthcare professionals’ knowledge and expertise was upheld in that ‘working with families’ was described as explaining in simple terms the recommendations that the healthcare team had provided for the family and the plans that needed to be implemented:

*We are talking a lot with the family and with social work around if someone needs 24-hour supervision we break it down and say “They need 24-hour care due to cognitive issues” and things like that because they’re at risk for falls. But if someone needs help with their ADLs and also IADLs we’re the ones that are making the*
recommendations so we would say “They’re gonna need help every day because they need help getting dressed in the morning, getting their groceries, they also need help with managing finances.” Whatever it is. (Julie, healthcare professional)

Thus, working ‘with’ the family from the perspective of this participant consisted of a one-sided approach explaining to the family in simpler terms what sort of help the individuals might need. This implied a team-driven approach where the family members were valued essentially in the role of providing support and putting the recommended services and equipment in place. This view was explicit in the same healthcare professional’s statement that the role of older adults or family members was to “implement all of the recommendations that we’re making”. Thus, family members were to act on the recommendations of the healthcare team but were generally not seen as holding independent knowledge or expertise worthy of consideration in decision making.

Similar views privileging the healthcare professionals’ recommendations were reflected by Carol, a manager who described a good discharge as one where the team, family and older adult all agree and where the healthcare team’s recommendations are followed.

*A good discharge would be that we have the support of the family and the client. And that all the discharge recommendations have been implemented and followed. And the discharge happened on... the recommended discharge date. That all support services that the client required to support them at home are in place, and all the equipment [is] ready and in place – that would be a good discharge.* (Carol, healthcare professional)

The implication was that the healthcare team’s recommendations were most appropriate and legitimate and would lead to the individual being safe and supported. If the family agreed with the team’s recommendations and put in place all the recommended services, then the discharge was a good one.

Underlying beliefs about the primacy of healthcare professionals’ expertise were further reflected in situations where patients did not agree with the discharge plan or with the team’s recommendations, in which case the older adult patient’s cognition and insight were questioned. This is exemplified in the excerpt below:

*When you’re making a recommendation that the patient does not agree with... either they don’t have insight, or they have just not come to the point that they’re accepting that they’re at a lower level than they really are... for example, if we- if we decide, as a team, and with the family usually, that someone needs to go to long-term care versus home because they just can’t be managed any longer at home, I mean sometimes*
there [are] issues around competency and we actually have to do the competency eval. (Julie, healthcare professional)

In this description, a discrepancy between the healthcare team’s recommendations and the older adult’s wishes meant that the older adult was either not capable of understanding their situation, or was denying the gravity of their situation. The implication was that it would be unreasonable for anyone not to follow the healthcare professionals’ recommendations, given the underlying belief that healthcare professionals are in the best position to make discharge decisions. Of note in this excerpt, the health care professional indicated that family contributions often coincided with the healthcare professionals’ recommendations, and therefore reaffirmed the primacy of healthcare professionals’ knowledge. In other cases where there was disagreement, family perspectives were challenged or overlooked.

This analysis suggests that underlying beliefs about the primacy of healthcare professionals’ knowledge, expertise and authority to determine the best plan for discharge structured professionals approaches to discharge planning with older adults. Healthcare professionals reflected a weak form of paternalism and focussed on their duties and responsibilities to help people perceived as incapable of helping themselves. In response, patients were expected to comply with professional advice. Within this model, there is little, if any, perception of the need for enabling autonomous choices of older adults. Healthcare professionals’ belief in their own expertise and their related practices reinforced beliefs that as older adults age they experience a loss of decision-making capacities. In light of these losses, older adults were perceived to be dependent on healthcare professionals, which heightened perceptions of the primacy of healthcare professionals’ expertise.

As will be discussed below in section 6.5 Conventions and practices, the way discharge planning was carried out in this setting also reinforced healthcare professionals’ underlying belief attributing primacy to their own knowledge and expertise. Such beliefs however were not reflected by older adults and their family members.

Older adult participant perspectives

The healthcare professionals’ underlying beliefs that their knowledge was of primary importance in decision making was not shared by the older adult participants. Instead, general consensus among the older adults was that healthcare professionals were not very involved in
discharge-planning decision-making processes. Older adults suggested that healthcare professionals could provide little value to discharge planning in comparison to the importance of their negotiations and discussions with their children. When asked about the healthcare team’s role, Sophia reported this is ‘not their job’ and that it is up to her and her family to plan for her discharge:

E.D.: The social worker, or the occupational therapist, or the physical therapist, [Monica] or [Stacey]?... [Diane]? What do they think about where you should go when you leave here?

Sophia: I think, I, I don't ask, only say we gonna miss you.

...

E.D.: And what does the doctor say? Has he said anything?

Sophia: Doctor? Doctor I saw last time and he says you make big progress here. Now you feel better, your blood is prepared for you now [meaning that her blood pressure had stabilized]. Pressure, everything is good he says.

E.D.: Good. And did he say where you think it would... where he thought it would be best for you?

...

Sophia: No, that's not his job. That job is now up to me and to my family where they're going to put me. What they're going to do with me. (Sophia, older adult)

Sophia saw the healthcare team as ‘nice people’ with whom she had developed relationships, and the doctor as providing information about her health. She did not see them as providing information of value to assist her with discharge decisions. Maeve similarly felt that the healthcare professionals did not have very much input into her discharge plans. When asked who was planning for her discharge, Maeve responded that it was her children. When prompted about whether or not healthcare professionals had been talking with her about discharge, she said no. Neither Sophia nor Maeve indicated that healthcare professionals had much to contribute to their discharge plans. They did not seem to be either reflecting or resisting the primacy of healthcare professionals’ knowledge, but seemed unaware of the healthcare professionals’ real or potential contributions to discharge planning.

Other older adult participants’ viewed the healthcare team as providing advice which they did not have to follow. For example, Magan saw the healthcare team’s contributions as recommendations, which he did not privilege in any way.

E.D.: And what about the people here... Are they involved at all, or no?
Magan: Well, they make recommendations. They will make recommendations, and I suppose some recommendations are valid and adaptable and some are not. (Magan, older adult)

Another example of the ‘take it or leave it’ approach older adults had to healthcare provider recommendations is in Marion’s responses below:

E.D.: And what about the therapists here and the doctor here, what are they saying about you going home?

Marion: They didn’t say too much. You mean the ones that were at the meeting?

E.D.: Yeah

Marion: Well she [the occupational therapist] gave me a list to read. I don’t go by that list. (Marion, older adult)

Magan and Marion both viewed the healthcare professionals as making recommendations, but did not feel they had to follow these, thereby indicating they did not regard the healthcare professionals’ knowledge as highly as did the healthcare professionals themselves.

Frederick and his wife Rita were the only older adults in the study who looked to the healthcare professionals to guide them, in terms of what care they might seek upon discharge, although they did not feel bound to accept all their recommendations unilaterally. They felt that healthcare professionals had provided useful information and recommendations at the family conference, but that since that meeting (two weeks prior to our interview, which was on the eve of Frederik’s discharge), much had changed and they required more information. Rita and Frederik looked to the healthcare professionals to provide guidance about the care Frederik would require upon discharge, but stated that not enough guidance was provided.

Older adult participants did not share the same underlying belief in the primacy of healthcare professionals’ knowledge and expertise, and thus, this belief did not influence their perspectives on plans for their discharge. Older adults instead considered themselves and their family members as those who were in the best place and had the responsibility to determine the discharge plan.

Adult children perspectives

Similarly to the older adults, their children did not value the healthcare professionals’ recommendations for discharge as highly as the healthcare professionals themselves. Older adults’ children either regarded healthcare professionals’ recommendations as a tool to advance
their own views with their parents, or they disregarded the healthcare professionals’ recommendations. In Sophia’s case, her son used the information and recommendations that healthcare professionals shared as a means to persuade Sophia that she required assistance. In Magan’s case, his daughter deemed the healthcare professionals’ recommendations completely unhelpful, and in Marion’s case, the healthcare professionals’ recommendations were not considered at all by her son.

Peter used the information provided by healthcare professionals in conversations with his mother Sophia to support his own view that she needed assistance:

*I kinda gave her all the input that came out of the meeting, and I told her, I said that from the meeting, the way it works out is that you need... you need a lot of help in doing a lot of things. And I said you need something like this (the rehabilitation unit’s) kind of atmosphere, and I think that you, [need] a long-term care facility, she doesn't understand.* (Peter, Sophia’s son)

In this excerpt we see that Peter used healthcare professionals’ input to convince his mother of his own parallel view that she needed help. Ultimately, however, as quoted above, Peter asserted that he alone was making decisions, and in this way, Peter’s regard of the healthcare professionals expertise aligns with Sophia’s report above that ‘this is not their job’.

In relation to healthcare professionals’ expertise and contributions to discharge planning, Magan’s daughter, Teja felt that healthcare professionals were a good source of information. In her interview she said:

*They were very good as a source of information for me, and a source of comfort for me, and I'm sure the same for Dad.* (Teja, Magan’s daughter)

However she also asserted that the recommendations shared at the family conference were not helpful at all and she was very disappointed at the suggestions the healthcare professionals provided in the meeting.

*In terms of information, I was [emphasis] extremely [/emphasis] – I'm speaking candidly – I was extremely disappointed with that meeting that you sat in on....I found it completely unhelpful, almost patronizing....the head nurse said “Oh, you [should] wear a night shirt.” And I thought that was a really good suggestion, would never thought of it. But Dad hated the suggestion. It would have been nice if they were able to discuss it for a minute, rather than the answer that we did get, which is “well I told you how to fix it, if you don't want to do it I can't force you to do it.” Which I didn't like.* (Teja, Magan’s daughter)
In Teja’s view, the healthcare professionals provided information, but did not provide useful guidance tailored to her father’s needs and preferences. Additionally, Teja’s use of the word “patronizing” might suggest that she sensed professionals’ underlying belief in the primacy of their expertise, which may have been insulting to her.

A final perspective on healthcare professionals’ contributions to discharge planning is provided by David below. This perception mirrors healthcare professionals’ view of family members (as providing support upon discharge but not as contributing to discharge decisions), but with the roles reversed. David indicated that the role of healthcare professionals was to look after his mother and to relieve his burden for a time, and then to tell him when she was being discharged so that he could prepare for it.

D: Discharge planning is that they give you notification of when they feel the patient can be discharged. And the planning is the organization that I have to take care of to make the environment um, safe um, workable, for her and [the] caregivers, it’s- if that be the case- and make sure she’s getting the proper care.

...  
E: And what role do you see the healthcare professionals playing? (Pause) if any?  
D: Looking after my mother’s well-being and taking the burden off of me. (David, Marion’s son)

David expressed that making decisions and taking care of all the arrangements for his mother’s care was up to him as her son. Healthcare professionals assisted him by giving him a break and by letting him know when his break was over.

In summary, there was a discrepancy in perspectives regarding the importance and function of healthcare providers’ knowledge and expertise in discharge-planning decision making. The healthcare professionals believed that their knowledge and expertise granted them the authority to determine what was the best course of action for discharge. The accounts suggested that healthcare professionals placed relatively little value on the knowledge that older adults and family members could contribute to discharge decisions. In contrast, older adults and family members did not value the healthcare professionals’ recommendations to the same extent, as from their perspectives, discharge decisions were the responsibility of the older adults and/or their family members, with little input from healthcare professionals.
6.3.3 Discussion of the underlying beliefs about aging and the primacy of healthcare professionals’ expertise

Underlying beliefs about aging and the primacy of healthcare professionals’ knowledge and authority influenced the perspectives and actions of individuals involved in discharge planning with older adults. With the exception of two older adults (Frederik and Rita in case 2), all participants reflected underlying beliefs linking aging to a loss of agency and increased dependence in decision making. In the accounts of older adults and family members, beliefs about aging were related to expectations that older adults would rely more heavily on their family members for assistance. Older adults expected that their children would provide assistance and children expressed a duty to assist their parents or even take over the decisions. In some cases, the relational nature of decision making was acknowledged and supported. Situations were tailored to meet the older adults’ needs and capabilities and to enable him or her to contribute to decisions without being burdened with making the final decision.

In healthcare professionals’ accounts, underlying beliefs about aging and decreasing capabilities reinforced their beliefs about the superiority of their own expertise and contributions to discharge planning. From the healthcare professionals perspectives, older adults had little, if any, role in discharge planning while family members played supporting roles to put in place healthcare professionals’ recommendations. Healthcare professionals’ saw themselves as the primary decision makers in discharge planning. If older adults or family members did not agree with the recommendations, capacity was questioned, denial was attributed, or situations were described as ‘bad’ or even ‘disaster’ discharges. Healthcare professionals’ views were consistent with, and justified by, their beliefs about age-related losses in agency and about the primacy of their knowledge and expertise. Healthcare professionals’ underlying belief about the primacy of their own expertise was reflected in their approaches and in the institution’s conventions for discharge-planning processes, as will be discussed further below.

6.4 Valued approaches to care and discharge planning: prioritization of safety and client-centred practice

Within the interviews, healthcare professional participants actively worked to establish themselves as adhering to the principles and tenets of a client-centred approach. There was variation in how participants defined a client-centred approach but understandings tended to
focus on abiding by client wishes, if and only if doing so was deemed safe. Protecting client safety was assumed to be distinct from and inherently took precedence over the promotion of client preferences. Other than the explicit statements of consideration for client preferences in a client-centred approach, practices to uphold client preferences were not visible in the accounts. Practices prioritizing safety on the other hand were explicitly stated and were evident in all discussions related to discharge planning. The promotion of safety and professed adherence to the principles of client-centeredness differed from underlying beliefs in being explicitly claimed. Underlying beliefs were revealed through participants’ interviews, but were not necessarily recognized or named. Nevertheless beliefs about the loss of capacity in aging and the primacy of expert knowledge were reflected in how healthcare professionals appeared to have operationalized client-centred care and overtly prioritized patient safety in their practices. I will first describe how client-centeredness was conceptualized and interpreted before discussing how such notions were overshadowed by the prioritization of safety and how safety was overtly promoted in discharge planning.

6.4.1 Client-centred approaches

In their accounts, healthcare professionals professed adherence to the guiding principles of a client-centred approach. Understandings of client-centeredness, however, differed between participants. According to one, a client-centered approach balanced safety with the individual’s wishes, while taking into consideration the individual’s capacity.

A good discharge plan has to involve a client, knowing their preference and their will... I feel that client-centeredness does not always mean that we go with what they want. It has to be a balance between honouring their wish but also maintaining safety... so I feel that client-centeredness has to be respected, but also with the understanding that you have to look at the person’s capability and capacity to make decisions for themselves. (Erica, healthcare professional)

In some respects Erica equated being client-centred with doing what the client wished, but she also pointed out that professionals had to consider the individual’s capacity to make decisions. Erica implied that a client-centred approach honoured patients’ wishes if they were capable, but aimed to maximize safety nonetheless.

Another healthcare professional equated client-centeredness with enabling what the client wanted “as long as it’s safe”:
ED: What do you think of this word [client-centred] and how would it apply to discharge planning?

Rebecca: I mean the first person who I meet with is the, is the client, right, is the patient, because obviously I want to hear what, what they want from their rehab stay and what they hope would be the discharge plan for them, because sometimes their kids or their grandchildren or siblings or whoever it is has a very different idea on what would be best for them. So I always like to hear what the patient wants first. I always try and be client-centred in my approach, and that’s what I do on the unit. Like I said, they’re the first people that I, that I meet and you know we have patient rounds, I, I advocate for what the patient wants as long as it’s safe. (Rebecca, healthcare professional)

Rebecca suggested that she was client-centred in her practice because she met with the patients and found out what they wanted. As with Erica above, Rebecca also highlighted safety as something that may be separate from what patients want. In her approach, Rebecca was client-centred and vouched for what the patient wanted as long as this was safe. This quotation implied that client-centred care does not necessarily ensure the promotion of safety and reaffirmed the importance of prioritizing safety. Safe practice trumped client-centred practice (here equated with honouring patients’ wishes) if the two were in opposition.

A different way of equating client-centeredness with doing what the patient wants was evident in suggestions that the healthcare team was client-centred when older adults agreed with their recommendations.

I think I am very client-centred, and I would say, you know, 90 percent of cases of discharge, the patient is in agreement with what we’re recommending. (Julie, healthcare professional)

Julie implied that in having patients agree with the recommendations, she was being client-centred. Again the implication is that healthcare professionals’ knowledge and expertise placed them in a superior position to determine the best discharge plans. She went on to discuss a different understanding of client-centred practice, however, in which she described as the inclusion or ‘involvement’ of patients in discharge planning from the beginning, even if patients did not agree with the plans being made.

Um, that it might be a discharge plan that they don’t totally agree with, but I think that they’ve, I certainly don’t think that they’re not involved along the way. I still think it’s a client centred approach. (Julie, healthcare professional)
Thus, in Julie’s view client-centeredness could diverge from patient wishes as long as patients were involved in the process from the beginning, however, it was unclear what she meant by involvement.

To be client-centred then, according to healthcare professionals, could mean different things. The most prominent understanding of a client-centred approach was that it entailed abiding by clients’ wishes. In other words, allowing patients to determine their own best interests. A second understanding included balancing patients’ wishes with their safety and capacity (to understand the situation and to make decisions). In other words, the implication was that a patient’s determination of best interests might be different from that of healthcare professionals, who would prioritize the patient’s safety, while older adults might not. Therefore, in this formulation, healthcare professionals had to balance patient’s wishes with their duty to act in a non-maleficent manner and protect patients from potential harms. An additional interpretation included keeping clients ‘involved’ throughout the process. In this interpretation, client-centeredness was equated with clients being included or informed even if they did not agree.

Part of the challenge in identifying which portions of the accounts related to client-centred care may be the multiple ways it has been defined and conceptualized in the literature and taken up by practitioners and organizations. As I further discuss in Chapter 7, descriptions of client-centred approaches vary in the literature but have in common notions of taking into consideration the patient’s perspective (Gerteis, Edgman-Levitan, Daley & Delbanco, 1993) and patient and family members’ needs and preferences (Canadian Medical Association, 2010). More robust conceptualizations include not only considerations for individual values or preferences, but an understanding of the person, their environment, relationships and social networks (see Brookman, Jakob, DiCecco and Bender (2011) for an extensive review of the literature). Such considerations were not evident in the healthcare professionals’ accounts. They however provide a strong overlap with relational approaches that consider individuals’ unique capabilities, needs and preferences, and how they are shaped by their social and political contexts (Sherwin, 1998). Furthermore, in relational approaches, individuals are understood as inextricably embedded in their social networks, and as such, their relationships influence their choices, needs and preferences (Mackenzie, 2008; Mackenzie & Stoljar, 2000; Sherwin, 1998, 2008; Sherwin & Winsby, 2010). Alignment of a client-centred approach with relational conceptualizations of
autonomy, and the potential value this could bring to clinical practice will be further explored in Chapter 7.

6.4.2 Prioritization of safety

Conceptualizations of client-centred care in the literature did not explicitly include safety; however, client-centeredness and safety were frequently linked in the data by the healthcare professional participants. In addition to its explicit mention in discussions of client-centred care, however, the promotion of safety was a prominent theme in all healthcare professionals’ discussion of their practices. Not only did healthcare professionals view safety as something to be prioritized over client preferences, but healthcare professionals viewed safety as the most important consideration in all situations of goal-setting or discharge.

In the formulation of healthcare professionals’ recommendations for discharge (with respect to the environment in which the older adult would live), safety was the most important concern over other possible considerations such as the importance of returning to one’s home, the proximity to family, familiarity with the community, or the ability to return to pre-admission activities. There was a difference between what healthcare professionals viewed as important in relation to their own home or living situations and what they saw as important for older adults’ living situations upon discharge, namely, safety. When asked what they personally saw as important in their own living situations, there was no mention of safety. Instead, they listed attributes such as being close to family:

Home to me is, um, let me think... I always think of my family and who’s living in my house, all of those things are important to me, that’s what makes my home. (Julie, healthcare professional)

or opportunities in the community:

I’m in a place where there are a lot of things around me... I want to go to Starbucks I go for a walk, I want to go to the bank, I go for a walk, so... To have things accessible, close by, I don’t have to sit in traffic for three hours to get somewhere, I think that’s important. To be close to family I think is important. (Alison, healthcare professional)

In relation to themselves, safety was not an important attribute of home. In consideration of older adults’ living situations and discharge plans, however, the prioritization of safety was pervasive across discussions of the goals of rehabilitation, in descriptions of good and bad discharges, and in the recommendations that healthcare professionals made for discharge.
When discussing discharge planning and rehabilitation on the unit, healthcare professionals described the goal of rehabilitation as aiming to maximize older adults’ functional abilities in order for them to be discharged as safely as possible. Examples of the aims of rehabilitation were:

*Helping a client to actually reach the goal to be discharged independently – well, discharged to the community as safely as possible* (Erica, healthcare professional).

and:

*Helping people maintain their maximal functional abilities in order to return home.* (Julie, healthcare professional)

The overarching aims were to maximize safety and functional abilities, however, other than this explicit mention when discussing the aims of rehabilitation, the aim of maximizing function was not mentioned or apparent in talk, practices or behaviours. The aim of maximizing safety on the other hand was further reaffirmed through discussions and behaviours related to all aspects of discharge planning. For example, in response to the question: “What is discharge planning?” a healthcare professional responded that discharge plans were:

*The plans that you make, you know, to hope that the patient’s gonna be safe at home* (Rebecca, healthcare professional).

Safety was further promoted by Carol, a manager who, when asked what was being prioritized in the team’s recommendations for discharge, answered:

*I think safety is the main thing.* (Carol, healthcare professional manager)

Being in a leadership role, Carol was proud of her team for their promotion of safety, thus reinforcing its importance.

Evidence of the prioritization of safety in healthcare professionals’ approaches further came to light in discussions of what was a ‘good’ or a ‘bad’ discharge. Whether a discharge was good or bad was closely linked to the safety of the discharge plan as defined by the healthcare team, the alignment of the final discharge outcome to the team’s recommendations, and the amount of discord between involved parties. All healthcare professionals indicated that a good discharge was a safe discharge.

*A safe discharge for me is a good discharge* (Alison, healthcare professional)

Conversely, unsafe or risky discharges were described as ‘disaster discharges’.

I mean obviously it’s people’s personal choice to live at risk... we call them disaster discharges. There’s lots of times that there are disaster discharges where the person goes to an environment that you know, I think is not optimal for them. (Julie, healthcare professional)

According to Julie, disaster discharges were those whereby individuals chose to live at risk and to not put in place the recommendations of the healthcare team - which would keep them safe. Another healthcare professional reaffirmed this idea:

Rebecca: We’ve discharged patients here and it’s been a disaster - I mean it. The discharge plan is totally not what we would have recommended or - at the end of the day what can you do? I mean unless they’re incapable and then you can deem them incapable and you know defer to the POA [power of attorney] or the substitute decision-maker.

ED: When you say that the discharge plan is a disaster, you mean like in terms of what they’ve put in place?

Rebecca: In terms of them not following our recommendations and [they] leave and we’re very anxious because we know it’s not safe but that’s what they’ve decided they want to do. (Rebecca, healthcare professional)

In these last two quotations the prioritization of safety was explicit, but also implied was the previously discussed underlying belief on the part of healthcare professionals about the primacy of their professional expertise, which thereby attributed them the authority to determine what is safe. These two notions reinforced one another since assessing safety relies on the technical expertise of the professionals, which reinforced the importance of their expertise to the exclusion of other complex factors arguably outside their purview, for example psychological security. The prioritization of physical safety was thus seen as the only logical or reasonable option. The prioritization of physical safety and the healthcare professionals’ concurrent presumption of the superiority of their knowledge reinforced their view that healthcare professionals are the primary experts in identifying what is safe and therefore the best discharge plan. These intersecting beliefs and approaches mediated behaviours and attitudes, and shaped practices that further strengthened these beliefs and approaches. In light of these practices, healthcare professionals’ perceptions of patients seemed to be reduced collections of abilities (current and declining), risks, and potential health complications. The co-constituting beliefs and practices focus perceptions on these specific attributes and overshadow consideration of other aspects of individuals. Using these particularized perceptions of older adults, healthcare professionals’ recommendations for discharge more easily elide to a prominent focus on safety,
and reinforce the authority of healthcare professionals to determine safe options. Collectively, the data suggested that the healthcare professionals believed they themselves were in the best position to know what was safe and what would be a risk, which ultimately placed them in a position to make the putatively “right” decision.

Additionally, in the above quotations, healthcare professionals implied that they did not support autonomous choices that differed from their recommendations for a safe discharge. There was no mention of consideration for patient preferences or of attempts to find a solution that might be more acceptable to all of the involved parties. This directly contradicted their own understandings of client-centeredness and the promotion of client preferences. Because professional expertise, oriented towards maintaining safety, was considered the only criterion for a good discharge, patient preferences that did not prioritize safety had little or no place in decision making. Taking a putatively client-centred approach was therefore in effect, maximizing client safety. The ranking of professional judgments above all others was reinforced and affirmed by what healthcare professionals’ considered the irrational priorities of older adults and, at times, their children.

The prioritization of safety was also evident in healthcare professionals’ practices of frequently recommending that older adults have either 24-hour supervision or 24-hour assistance upon discharge:

> I think a lot of times OTs and PTs immediately err on the side of caution, and will immediately say okay, ideally everybody needs 24-hour care almost without exception (Diane, healthcare professional)

Diane expressed that a blanket prioritization of safety often results in a recommendation for 24-hour care, which may be more of a precautionary measure than an actual need. The recommendation of 24-hour supervision or care can have significant implications for older adults and their families. Primarily, this recommendation comes at a significant financial cost if the individual is to remain in his or her own home. Family members shared that this was a consideration in their decisions. For example, Teja explicitly spoke of the financial stress resulting from this decision.

> We had hired a full-time person, which was a huge stress, financially, right? Because we had done lots of homework, [contacted] lots of agencies, private care, under the table, over the table, official, unofficial, nurse, not nurse – all sorts of options we had looked at. (Teja, Magan’s daughter)
Despite having explored all of the potential options she could find, Teja did not find an affordable option and found the provision of 24-hour care to be a financial strain. Some healthcare professionals seemed to be aware of the potential financial implications of having 24-hour supervision or assistance. Monica, for example, discussed how this might be difficult for older adults who may not have very many financial resources, and how financial constraints might determine the discharge plan.

*We’re recommending 24-7 supervision, like that’s a lot of money for someone who’s you know, 97, not working, hasn’t worked for a long time... Money makes a difference... A discharge decision may be based on that, instead of what the client wants. So resources is [sic] a big thing... I think ideally most people want to go home; it’s just if they can’t afford it, then they go to long-term care. That’s what we see a lot, you can’t put in 24-7 so long-term care is what we have to do... (Monica, healthcare professional)*

Monica acknowledged that there can be significant financial implications to a recommendation that the older adult receive 24-hour care and that this might result in an unwanted move to long-term care. Implicit in her account was that the healthcare professionals’ recommendations must be followed and that safety must be prioritized. Individuals must be safe at all costs, whether these costs be in the form of wages for a 24-hour caregiver at home, or in the form of the personal cost of moving to a long-term care facility (which could also involve significant financial costs, though these may be lessened through the sale or release of current living arrangements). A similar example implying the prioritization of healthcare professionals’ recommendations for safety at all costs was demonstrated in another healthcare professional’s description of situations where individuals go to long-term care because they cannot afford 24-hour care.

*Rebecca: If we recommend 24-7 care and the family can’t afford it, the patient usually goes to long-term care. (Rebecca, healthcare professional)*

Rebecca affirmed that at times older adults had to choose between the lesser of two evils: the financial cost of remaining at home and hiring a full-time caregiver or the emotional or functional costs associated with leaving one’s home and moving to long-term care. This perspective shows that only the options that prioritized safety were considered.

11 By functional costs I mean the decrease in function that comes with moving to a new environment and learning to navigate in this new setting. At times, the decrease in function associated with new learning is
While some of the healthcare professionals seemed to be aware of a potential financial cost associated with a recommendation of 24-hour care, healthcare professionals did not go beyond the personal physical safety and related financial considerations in their discussions of discharge. Emotional and psychological concerns pertaining to discharge were not a topic of discussion within the data. From the data gathered from healthcare professionals, the older adults seemed to be reduced to a collection of physical and medical needs that needed to be addressed. There was no apparent consideration of the cost of maximizing safety on other aspects of the older adults’ lives and identities.

Despite 24-hour care being recognized as a financially costly option, it also was considered in some respects to be a better value than hiring someone by the hour. This was explained by one healthcare professional who said:

*We send a lot of people home with caregivers... that don't really need 24 hour care, they need daytime care. But it's cheaper to have live-in care than it is to have by the hour. So that's why we make that recommendation, and we tell them that that's the distinction, so the caregivers might only work from, say, 8 to 8 or something like that to help them through the day, and then once they're settled for the night and in their pyjamas, they don't really need anybody there... we use different products like bedside commodes or overnight briefs or urinals for the men, bedpans for the women that are agile enough to dump them into a bedside potty. So there's all kinds of ways of... not requiring 24 hour help... but, it's the cost factor, it's just cheaper for them. Most of the people if they have a home, they may not have a lot of money, but they have a house. So they have more room, they can afford to... you know, that... the room and board offsets the cost of the care.* (Sharon, healthcare professional)

This healthcare professional asserted that many of the individuals who returned home with a recommendation for a 24-hour caregiver did not need it. She reported that there were many creative ways in which the need for overnight care could be mitigated by the older adult without assistance, but that the provision of room and board did not cost the older adult very much and offset a considerable portion of the caregiver’s wages. Not mentioned in Sharon’s account is that this option had what she sees as an added bonus of providing another individual in the home overnight even if their services were not required, thereby increasing safety in the discharge plan.

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temporary, but in other cases, function that was possible in the previous environment may not be regained in the new environment.
In another excerpt, a healthcare professional participant emphasized safety in considering which of two discharge plans made her more ‘uncomfortable’: those where the patient was capable and made a choice to live at risk or those where individuals preferred to return home, but were pushed to prioritize safety and move to long-term care.

_If I’m making a recommendation they don’t agree with, but... because their family is on board... they go to long-term care or something like that I actually feel better about that versus the other when someone is a disaster discharge and we’re making these recommendations, they’re competent, but they’re choosing to you know, go and live at risk, and I know that they’re gonna be back in the hospital a month from now._

(Julie, healthcare professional)

For this healthcare professional, the ‘disaster’ was that safety was not prioritized. The suggestion that a family member (who in this case held power of attorney), acting in the client’s best interests, should agree with the team’s recommendations further reinforces the belief of these professionals that their recommendations are best and are to be followed if safety is to be achieved. This healthcare professional felt better about prioritizing safety at the expense of client-preferences. Such notions aligned with the understandings of client-centred practice.

### 6.4.3 Client-centeredness and safety in older adult and family member participants’ accounts

Understandings of client-centeredness were not directly explored with older adult and family member participants in the interviews. Healthcare professionals raised this notion without prompting in their accounts whereas other participants did not. The phrase ‘client- or person-centred’ may be institutional or healthcare terminology that is conceptualized under a different phrase for non-healthcare professionals. The discussions in older adults’ and family members’ accounts most closely align with concepts of client-centeredness were those related to what was important to them in a choice of discharge location. Extrapolating from these discussions, older adults prioritized being comfortable in their own space. Family members added to this consideration for the older adults’ safety by ensuring their health and personal care needs were met and ensuring the older adults had support.

In the accounts of older adults, the concept of safety was not central and seldom raised. When asked about what was important in discharge and where they lived, older adults instead spoke of the importance of being in their own space. Maeve described that she just wanted to go
home “just to be in my own place”. Magan similarly talked of the expression “There’s no place like home” and further discussed the comfort of knowing where all of one’s belongings are placed and the increased function this enables.

*The comfort of knowing where things are, what is what. It also depends how you want to live. If I want to invite you to my home for lunch, I should know where things are, my crockery, my cutlery, my coffee maker, my whatever it is. So that process of inviting people to lunch or kind of thing becomes simpler.* (Magan, older adult)

In addition to consideration for comfort, Magan discussed the freedom that is afforded to invite guests or friends when one has his or her own space. Opportunities that can be afforded in one’s home were also mentioned by Rita and Frederik who discussed the importance living in a place where they had frequent opportunities to play bridge and where they could easily visit their families. Another consideration of home was the pride that individuals took in organizing and maintaining this space. Marion expressed this pride in saying:

*That’s my castle. I have a nice home, it’s clean; it’s always clean. I looked after it.* (Marion, older adult)

And furthermore expressing:

*I will not leave my home. My home is my castle. But now I have a one-bedroom, two bathrooms, a kitchen, the washer-dryer is off the kitchen I have no stairs to walk. I’m very comfortable.* (Marion, older adult)

For Marion, the cleanliness of her home inspired pride. She was comfortable there. She hinted at consideration of her functional limitations and the implications for her safety when she mentioned that there were no stairs in her home. (Marion had difficulty going up and down on her own.) Similarly, while Sophia reported feeling pride in her garden and the cleanliness of her home, she also asserted that after her recent fall and hospitalization, she was afraid of falling and that having a home where there were no stairs was important to her. Other than these mentions, safety did not factor in older adults’ discussions about their home or where they wished to live and was therefore not a priority from the perspective of older adults.

Older adults’ children on the other hand did consider their parents’ safety. This was apparent in their discussions about discharge priorities. These were varied but centred on two main themes: their parents’ happiness and their parents’ safety. Safety included having medical and personal needs met and having others around in order to decrease possible risks. Happiness included notions such as addressing loneliness and being comfortable in the environment.
Maeve’s son Tom, Sophia’s son Peter, and Magan’s daughter Teja all expressed variations of safety and happiness in what they were prioritizing in their parent’s discharge. Tom wished for Maeve to stay home as long as possible as he believed this was what she wanted and would keep her happy. He also asserted however that he and his sisters preferred for Maeve to go to long-term care as they perceived that all of her needs (safety and happiness) would be met in that environment. Peter, Sophia’s son, expressed that he was worried about his mother being lonely and he wished for her medical and personal care needs be met.

*I think there’s a couple things that concern me [in her discharge location] ... one [is] that she wouldn’t be lonely... and one thing would be is that she gets her proper medication, that somebody is there 24 hours a day, that she’s getting proper medical care ... somebody there 24 hours a day to meet... to make sure that, you know, she needs help, that somebody'll be there for her.* (Peter, Sophia’s son)

Peter perceived that the fall that had led to Sophia’s admission to acute care and subsequently to rehabilitation had affected her ability to care for herself on her own and, while he hoped she would recover her abilities, he did not anticipate she would return to the level of functioning she experienced prior to the fall.

On her part, Teja wanted her father to be safe and secure but also be in an environment where he was happy.

*For my Dad it's security, safety. Safety, security. So I want him to feel happy in a nice pleasant environment.... I would want to balance, and I'd probably trade off a little of the safety to get a nicer environment for him because for him that's so very important. It is for me too, but if it wasn't for him, I would say great piece of mind, more safety.* (Teja, Magan’s daughter)

For Teja, her father’s physical safety and having his needs met was most important to her, but because she knew that for him it was important to be in a ‘nicer’ environment, or in other words a place where he was happy and comfortable, she wished for a balance of these two attributes.

The only family member who deviated from this pattern was Marion’s son David. David wished for his mother to go to long-term care or have 24-hour care as he was concerned that it would be too much work for him to constantly be monitoring and ensuring she was receiving the care she needed at home. David thus prioritized Marion’s physical safety and medical needs, which contributed to his own psychological comfort. For the most part, the older adults’ children’s priorities in discharge planning attempted to find a balance between their perception of their parent’s wishes and what would make their parent happy, and their own perceptions of what
would keep their parent safe and well. In most cases, this included a consideration of safety similar to the focus expressed by healthcare professionals; however, their parent’s happiness was an equally important consideration.

### 6.4.4 Conclusion to valued approaches

In summary, healthcare professionals professed an adherence to tenets of client-centred care and to the prioritization of safety. Understandings of client-centred approaches varied in the data but tended to focus on discovering client preferences and honouring these if, and only if, they aligned with their perceptions of plans that would best assure their physical safety. The value of taking a client-centred approach (as it seemed to be narrowly understood by healthcare professionals), though professed to be practiced, did not seem to result in the inclusion of older adults’ preferences in discharge-planning decision making; rather, safety was prioritized in all counts, superseding client-centred intentions. The priority placed on safety heavily influenced healthcare professionals’ practices.

This prioritization was consistent with and reinforced beliefs about the primacy of healthcare professionals’ expertise, and aging as an inevitable decline in capacity. Professional beliefs manifested in judgments of what constituted a good (i.e., safe) discharge that avoided ‘disaster’. In contrast, older adults and family members did not adhere to beliefs in the primacy of healthcare professional knowledge, and did not prioritize safety in the same way, to the same degree, or at all in the case of older adults. In their accounts, older adults and family members considered happiness and comfort in the environment as at least as important as safety. Although the term ‘client-centred’ was unsurprisingly not mentioned in older adults’ and family members accounts, their priorities for discharge reflected some of the key tenets of client-centeredness described in the literature such as taking into consideration the individuals’ context and social networks. Broader conceptions of client-centeredness delineated in the literature were not visible in healthcare professional participants’ accounts. In the data, safety considerations more or less overrode professed client-centred approaches that focussed on enabling patient choice. There seemed to be a tacit understanding of client-centeredness as an ‘ideal’ whereas safety was an ‘imperative’. The healthcare professionals’ may not have intended to discount older adults’ preferences; however, the unexamined influence of dominant professional beliefs and approaches seemed to have affected their ability to provide the client-centred approach they
purported to practice. Unexamined beliefs about the primacy of healthcare professionals’ expertise and their authority to determine what was safe were reflected in practices that did not engender consideration of older adults’ or family members’ input in decision making. The conventions in the setting promoted practices that further reflected and strengthened these beliefs and approaches. Local conventions are now considered in light of the identified underlying beliefs and valued approaches.

6.5 Conventions and practices: Discharge-planning timelines and the format of the family conference

Local conventions and accepted practices shape norms and expectations and are also shaped by norms and expectations in an iterative circle. All of these then influence individual perspectives, guide behaviours and shape policy, which further determine conventions and practices. Discharge-planning processes are context-specific and in this setting were shaped by a multitude of influences, including federal and provincial policies, mandates from the regional authority (the Local Health Integration Network (LHIN)), services offered from local Community Care Access Centres (CCACs), institutional policies, institutional culture, and healthcare disciplinary cultures among others. The intersection of all of these potential influences mediates the construction and implementation of the institutional conventions in practices. Conventions observed in this setting included a push to begin discharge planning on admission, and the structure, process and timing of the discharge-planning family conferences. These two conventions and the related experiences of participants will now be discussed.

6.5.1 Approach discharge planning from point of admission: destination triage

In this setting, typical practice included commencing discharge planning from the moment of admission. When asked to describe the process of discharge planning, all of the eight healthcare professionals interviewed made reference to the predetermined scheduling of events, which included setting the discharge date upon admission. Healthcare professionals also described that the team had to complete all of their assessments, set patient goals and come to an agreement about the recommendations for discharge circumstances prior to the discharge-planning family conference, which was also scheduled upon admission for two weeks into the patient’s stay (See figure 6.5.1 below).
The implications of considering discharge immediately from the point of admission shaped the approach taken by healthcare professionals in all of their interactions and interventions with the older adults. One participant explained that because discharge is considered immediately upon admission, the entire rehabilitation process during the patient’s stay is discharge planning.

"On this unit discharge planning starts from the minute you meet people, so it would be assessment, appropriate treatment and then putting that all together to figure out what the safest option is for this person to go home... discharge planning is a kind of process." (Monica, healthcare professional)

According to this healthcare professional, discharge planning from the moment of admission enables the identification of the safest option. The drive to plan for discharge immediately upon admission was further promoted by the administration of policies of the unit. This was evident in the following passage:

"As soon as the patient is admitted, in their initial assessment, all team members start to think about discharge planning.... usually patients get a family conference at about the mid-point, which is at week two, at the end of week two. So by the time of the end of the first week, when each health professional finishes their assessment, they need to formulate what are their rehab goals for the client, what is the recommended discharge destination." (Carol, healthcare professional manager)

Healthcare professional participants reported that they aimed to have all of their assessments completed, the recommendations for discharge identified, and their rehabilitation goals set prior to the family conference.
From the perspective of several healthcare professionals, the rush to assess and to make recommendations so early in the client’s stay, and with such a short stay in rehabilitation, meant that there was no time left for intervention. This feeling of not having time to work with individuals on rehabilitation goals was exemplified by a healthcare professional participant below:

*Discharge planning is what I do. That’s like I’d say my primary job here, cause it’s such a short length of stay with so many people with like so many things happening like physically, cognitively, family, social like there’s just so many things happening with these people and I, I actually think that I get 4 weeks to discharge plan on this unit, I don’t know that I do as much assessment, like I do a lot of assessment with the goal of a good discharge. I don’t feel like I have time to do as much intervention as I would like because there’s so, it’s so complicated.* (Monica, healthcare professional)

Thus the primary focus on discharge planning impeded the interventions that she could implement to address some of her assessment findings and to help older adults regain their abilities. A second healthcare professional reported that the average length of stay on the unit had recently decreased to four weeks, and she no longer had time to do interventions with older adults because all of her time was consumed by planning for discharge.

*I liked it more when it was a one to three month length of stay... ’cause I didn’t do discharge planning the day they came in, I really had time. I find it a big challenge now.* (Alison, Healthcare professional)

The early focus on discharge planning resulted in clinical time being spent on assessments in preparation for discharge, rather than on interventions aimed to maximizing capabilities.

Older adults and family members did not seem to have explicit expectations for the process of discharge planning. Nevertheless they were keenly aware of the professionals’ focus on discharge from the moment of admission. In some cases, this lead to individuals feeling rushed or pressured to make discharge decisions. Some were even discharged before they were prepared or before all services were put into place. In other cases, patients and their family members reported that the focus on discharge from the moment of admission gave them a clear message about the limitations of what was offered by the healthcare professionals and the rehabilitation setting, and that there was no room for individualized care or more assistance.

A feeling of being rushed to leave rehabilitation was evident in Rita’s concluding comments in her interview.
I think if you would make a note of what I started with. When you discharge people, to give them a complete way to go home you know, not to be left on your own very quickly. (Frederik and Rita, Older adult and his wife)

Rita had also opened her interview with a similar comment off-tape, when I had asked if we could discuss hers and Frederik’s experience of discharge planning. Rita felt that Frederik was being discharged without enough information to help them mitigate the transition. Their joint interview strongly conveyed Rita and Frederik’s feelings of being unprepared for discharge and somewhat abandoned.

Peter, Sophia’s son also commented about the focus on discharge from the point of admission in saying:

Well, they've already kind of filled the family in when you first come in... the maximum stay, 30 to 45 days or something like that, you know. And they said after that you're on your own, you know. So they're kind of letting you know that hey, you know, we're going to give your, your loved one the best care possible, but we can only do it for so long, right? (Peter, Sophia’s son)

It was impressed on patients and families from the point of admission that the timeline was set and that the family should prepare accordingly. This practice suggested that the process was the same for everyone and that there was no room for flexibility based on specific circumstances or individual need. This uniform approach is reminiscent of traditional conceptions of autonomy, which have been criticized as portraying individuals as generic and not considering individual situations or circumstances (Sherwin & Winsby, 2010). Although it is acknowledged that a focus on discharge and on clarifying expectations for length of stay could be helpful, none of the participants expressed this view. Family members expressed that the focus on discharge before the older adult had had a chance to recuperate or improve their functional status put pressure on them to make premature decisions and therefore provide more material supports.

Some members of the healthcare professional team were aware of these pressures. Diane makes reference to it in the following passage:

The pressure’s really on to make the discharge date, and families... you know, I know families pick up on it... the message is always very clear, and subtly communicated that that's the date, it's happening on that date, let's make sure things are in place because if things aren't in place, you're going to have a problem. That's sort of the message families hear I think.

And families are already overwhelmed, just dealing with an aging parent or sibling or spouse, dealing with, physical changes. Often dealing with residential transitions,
I mean, there's so many transitions and changes that they're coping with... and then when they're confronted with this really complex and confusing and seemingly heartless system, I think that they can become very intimidated and very frightened [of] what's going to happen, you know? We hear patients’ families, or patients say half-jokingly “you’re not going to evict me are you? You’re not going to kick me out on the street?”. But I believe, and I hear under that humour, that there's fear, that there's, you know, uncertainty, and they're already immersed in uncertainty. (Diane, healthcare professional)

In this passage, Diane showed that she has thought about the messages that patients and families might be receiving and how they might be feeling as a consequence. She recognized that families may be feeling overwhelmed with the situation of having an older family member and the multitude of potential implications of this. Diane acknowledged that the focus on discharge from the point of admission might be difficult for patients and families, but she also recognized that there is pressure on the team to meet the targeted discharge dates.

Although healthcare professionals reported that the focus on discharge from the moment of admission and short timelines hindered their abilities to provide interventions and put pressure on the older adults and family members, in general they did not question these norms. One healthcare professional (Alison) commented that it was better when the lengths of stay were longer thus permitting time for interventions, but this was the full extent of her reflection. She did not comment on why lengths of stay had been shortened, or question whether the focus on discharge from the moment of admission was the best practice, or whether this should be adjusted accordingly. Similarly, although Diane commented that the team feels pressure to meet the set discharge date, she did not state who was exerting this pressure or suggest the possibility of changing the practice. All of the healthcare professionals commented that the date for discharge was set from the moment of admission, but it was taken for granted as unalterable, and no one elaborated on why or how this had become the practice. It may be they assumed that resources were limited and that lengths of stay were dictated by multiple layers of policy against which healthcare professionals are powerless change, but this was not discussed.

To summarize, the convention of planning for discharge upon admission and the process of discharge planning shaped the entire rehabilitation process on this unit. As has been discussed, healthcare professionals’ underlying beliefs linking aging to a loss of agency and attributing superiority to their own expertise supported practice norms of prioritizing safety, resulting in healthcare professionals presumed authority to determine safe (and therefore ‘reasonable’)
recommendations for discharge. Such attitudes and practices resulted in minimal if any consideration for patients’ preferences or unique situations. Similar disregard was afforded in the adherence to the anticipated length of stay and the prioritization of discharge-planning assessments over rehabilitation interventions. The discharge-planning process consisted of: scheduling the discharge-planning family conference and the discharge date respectively two and four weeks following admission; completion of professional assessments and team consensus on recommendations for discharge in the first two weeks (prior to the discharge-planning family conference); holding a discharge-planning family conference focussed on providing professional assessment findings and discharge recommendations to older adults and their family members. (Please see figure 6.5.1 above.) Focussing on discharge from the point of admission also meant that the expected timing of events was communicated to patients and families from the moment of admission. Such a focus on discharge was stressful for older adults and their families and potential anxiety about discharge may therefore have further encouraged the prioritization of discharge planning over interventions to maximize rehabilitation outcomes.

This was a typical process, however some flexibility and possible avenues for reform were revealed in the cases. One patient (Frederik), for example, had already been in rehabilitation for four weeks prior to his family conference, which meant that his length of stay was actually six weeks. This was because although his progress was slow, his recovery was consistent and the healthcare team felt that a longer stay would further benefit his recovery than the recommended four week length of stay. Despite the professed adherence to the strict timeline, this example indicates that the conventions were not as strict as professed and provided possible openings for reconsideration of the conventions.

6.5.2 Discharge-planning family conference

An important event in the process of planning for discharge is the family conference. This family meeting had a particular structure and as a result, the behaviours of individuals in the meeting followed a specific format. As mentioned above, the discharge-planning family conference was scheduled for a time two weeks following admission and two weeks prior to discharge. Attendees to the family conference included the older adult, one or more involved family members or caregivers (caregivers could include friends or individuals who were paid to care for the older adult) if there were any, the unit’s head nurse, the social worker, occupational
therapist and physical therapist involved in the older adult’s care, as well as other healthcare professionals if they were particularly involved (e.g. the dietician, the recreation therapist etc.).

The family conference was scheduled for 30 minutes and was held in one of the meeting rooms on the unit. In the study sample, four of the five family conferences were held in a small windowless room on the unit. There was a computer in the corner on which the head nurse took notes and a large table surrounded by chairs in the centre. (Please see figure 6.5.2 below.)

Figure 6.5.2 Floor plan of the meeting room used for family conferences

Most of the time, healthcare professionals sat at the table along with the older adult. At times family members also sat at chairs at the table, but most often they sat in chairs behind the chairs at the table, along the wall, this despite encouragement from healthcare professionals to sit at the table in unoccupied chairs. This could have been a reflection of intimidation and/or an attempt on family members’ part to promote autonomous participation by the older adult. Autonomous participation, however, did not seem to be the outcome, as older adults were rarely active in the family conference discussions. The family conference for one case was held in a
larger boardroom as the usual room was booked. The seating was much the same, but the table was larger and the room had windows.

Family conferences were chaired by the social worker and followed a standard format. The meeting began with all individuals introducing themselves and naming their role in this meeting, as well as their profession in the case of the healthcare team. The social worker then read through the list of patient goals set by healthcare professionals ostensibly in collaboration with older adults. These were phrased in a factual manner, stating what the older adult “would” do upon discharge, which seemed to reflect healthcare professionals’ perspectives more so than older adults. An example of such a goal is taken from Maeve’s family conference field note.

The goal read to the older adult during the family conference was

“When you go home, you will need contact assist, so someone touching you, to walk with a walker – [then to PT] how many wheels does the walker have? – [To Maeve] so with the two-wheeled walker like you’ve been using (Case 1 family conference field note)

This goal was written using healthcare professionals’ language (contact assist) and was read to Maeve as if she did not know herself what type of walker she was using (and had used to walk into the meeting room).

In all the family conferences I attended (other than Frederik’s), the reading of the statement of the goals was the only time where the conversation was consistently and explicitly directed at the older adult. Following the reading of goals, healthcare professionals reported on the findings of their assessments and shared their recommendations for discharge. There was then a time for discussion and questions from the family and older adult. At this point, family members usually asked for further clarification about assessment findings and about options for discharge. For the most part, the exchanges were didactic. Healthcare professionals provided information and families were expected to absorb the information being provided. Very few questions were posed to the family or the older adult and if they were, they were administrative questions about, for example, an address or the name of a family doctor. Prior to closing the meeting, the social worker would clearly restate the discharge date and time.

Below is an excerpt from my field notes following the observations of a family conference that outlines the standard practice on this unit. The notes are from Case 1, at which Maeve, two of her adult children, the social worker, occupational therapist and physiotherapist were present.
Melissa explained that the purpose of the meeting was to discuss the plans for discharge on (date). Melissa first read through Maeve’s goals and then had Alison and Monica report about their assessment findings and Maeve’s function on the unit. There was a discussion about what sort of care the healthcare professionals felt Maeve would require upon leaving [rehabilitation]. Maeve’s children were trying to persuade her to accept care in her home while she just said that wishes to be home alone. There was not really a back and forth discussion with Maeve. There did not appear to be resolution around what the discharge plan would be. Eventually Melissa brought up the discharge date, which seemed to be the process of how these meetings are run [here], but which in light of having no consensus about Maeve’s care or a discharge plan, seemed somewhat odd... and not client-centred or relevant to the discussion? Melissa gave them the date and said that Maeve has to be out by 10 [am] on that day in order for them [the facility] to prepare the bed for someone else. The conference lasted about 30 minutes. Melissa also spoke at the end about making long-term care choices and briefly mentioned the Home First program, but did not explain these. (Field note, case 1 family conference)

This meeting reflected the standard practice of family conferences in this setting. Although there was a discussion about Maeve’s possible care needs, what services might support this care, and what possible barriers her home presented, there was no consensus about a discharge plan. Despite this lack of a plan, the meeting was abruptly closed with a reaffirmation of the discharge date and the social worker highlighting that Maeve needed to be out by 10am that day. There was no mention of follow-up plans for further assistance about discharge or to come to a decision. Not all of the five family conferences ended with a lack of resolution. Three of the care conferences ended with a specific plan about discharge living circumstances for the older adult.

All care conferences shared this format. The process was standardized in that each individual had a specific role and was “allowed” to speak at the designated time in the process in order to convey specific pieces of information or to ask questions. Healthcare professionals usually made up half or more of the individuals in the room, which meant that with so many individuals observing the standard process, older adults and family members followed their lead and listened to the presentation of goals and recommendations, waiting until they were presented with an opportunity to ask questions. The conventional structure of the meeting and the behaviours of healthcare professionals during the meeting did not invite participation by older adults and family members, aside from when, after the healthcare professionals had shared their information, they were asked if they had any questions.
Healthcare professionals’ viewed the family conference as a forum to communicate with the family members and collaboratively determine a discharge plan that aligned with professionals’ recommendations.

*Each client has a chance of getting a half an hour, so team conference, where client family will be on board, the whole team, the representative of the teams, like the disciplines would be on board. So we would actually talk about our goals, our take in terms of the person’s discharge challenge, and again, involving family sort of to come up with a plan that’s feasible in terms of after rehab, where the person would go to.* (Erica, healthcare professional)

Erica described the family conference as a collaborative forum to share information and to discuss the individual’s circumstances in order to get the family ‘on board’ and to come up with a plan (that implicitly met the healthcare team’s recommendations). Another healthcare professional focussed more on the didactic aspect of the meeting when she discussed the family meeting as a means of ‘involving’ the family and of informing them about what care the healthcare team feels the older adult would require.

*I’d say the involvement happens more after the family meeting so the therapists will decide what we actually need and use our clinical judgement to decide how long this person needs to stay and what we think they’ll be able to do by the time they go home. We kind of present this at the family meeting, then there’s discussion.* (Monica, healthcare professional)

In this quotation, Monica explains how the family conference is a chance for the team to share the findings of their assessments and their recommendations for discharge with the older adult and his or her family members. From a healthcare professional perspective, the discharge-planning family conference was understood as being a medium to inform patients. This provision of information was characterized as ‘involvement’ of the older adult and their family members, despite its unidirectionality.

The family conference was discussed by family members as more or less helpful. Some older adults and family members felt that the meeting was helpful in providing information, but they also felt that more information would be required at a later point in the rehabilitation stay. This feeling was expressed by Frederik’s wife Rita.

*Rita: We had last Wednesday a very good meeting with everybody who is looking after him took part with physiotherapist and the other people and it was very good, but from then on, what we would like to have and that’s what I would expect, have another
meeting where they tell us exactly what to do when he goes home. (Frederik and Rita, older adult and his wife)

This excerpt illustrates that Rita felt the family conference was ‘very good’; however, she also felt that she would need more information before Frederik was discharged. The family conference did not meet all her information needs. Teja however felt that the conference was not helpful at all in preparing for discharge. Her comments about the conference included the following:

I found it completely unhelpful, almost patronizing. And completely opposite to all my dealings with them so far. And I found it interesting from a group dynamic perspective – I had dealt with every one of them individually face to face during my visits or on the phone during many conversations. They were very different in the group environment, it was almost, like, let me see what the head nurse says before I speak, and let me see what this person says before I speak. And it was just not helpful... I found it very not worthwhile. I thought the logistics of it weren't good in terms of, a 30 minute meeting to discuss, you know, a big thing with 5 people – that's not a lot of time for anyone to share their thoughts... I just found it was very “here’s what we've said. It may not pertain to you, or it may pertain to you because it pertains to everyone and on to the next patient.” That's the feeling I got which was very atypical of the feeling I got any other time I spoke to anyone at [institution]. Because they were very illuminating, very understanding, very good in every other instance. So I had high hopes for this meeting. I thought it would be the most useful meeting, the best advice I could get for Dad, and it was so anticlimactic, it was so disappointing. (Teja, Magan’s daughter)

Teja’s perspective reflected that healthcare professionals took on particular roles during the meeting that impeded individual contributions. She felt that the meeting format and expected roles and behaviours in the conference impeded a genuine exchange of information. Teja commented that she had had many conversations with the healthcare professionals individually, but that in the group process during the meeting, they behaved differently and the differences were not helpful. Teja felt that the idea of the meeting was a good one but that the meeting did not fulfil its promise to clarify and to help with the discharge-planning process.

The family conference was an integral part of the discharge-planning process in this setting. Healthcare professional participants’ accounts suggested that this meeting was a channel to inform family members of the healthcare team’s assessment findings as well as the recommendations for discharge and the goals related to this recommendation. This meeting was also viewed by some healthcare professionals as a forum to engage family members in the discussion about discharge planning and to involve them in various actions that the team felt
might be required from them. Family members’ involvement however was understood as healthcare professionals informing them of their recommendations and guiding them to realize these. From a family perspective, the intention of the meeting to exchange information was good, but the process and outcomes of the meeting did not meet their information needs. Some family members suggested that the format of the family conference interfered with the potential for a genuine exchange of information and an approach to providing helpful solutions for discharge.

The family conference provides an additional example of how intersecting beliefs, approaches and practices rely on and promote healthcare professionals authority to determine the only safe and therefore reasonable discharge plan. This forum also further reinforced links between aging, and decreasing agency and cognitive capacities, by speaking to (rather than with) older adults in reading them what was ostensibly their own goals, by excluding older adults from the discussion about the discharge plan, and by refraining from asking any questions. These conventions, in line with the formal roles played by healthcare professionals in the meeting reinforced the primacy of healthcare professionals’ knowledge and expertise, and further precluded the involvement of older adults in their own decision-making process. The intersection of all of these reinforced and reproduced underlying beliefs and approaches, thus further entrenching the conventions for the family conference itself.

6.5.3 Conclusion to conventions and practices

Conventions of discharge-planning processes that were evident in this setting included a focus on discharge from the point of admission. This practice structured the content of the older adults’ entire time on the unit, placing an emphasis on discharge and precluding interventions aimed at rehabilitation. The second prominent convention was in the structure and format of family conferences. Both of these conventions seemed to be well-understood and largely accepted by healthcare professionals, but seemed to be less helpful to older adults and family-members.

Summary

Discharge-planning processes and individual behaviours in this setting were influenced by particular structural contextual elements including dominant discourses of aging-as-decline,
beliefs in the primacy of healthcare professionals’ expertise, valued approaches that prioritized safety and professed to be client-centred as well as local practices and conventions. Perceptions about aging influenced the actions of older adults, family members and healthcare professionals. These were linked to assumptions about a loss of agency and capacities due to the aging process. Healthcare professionals’ accounts reflected deeply held assumptions that safety outweighs any other consideration, that clients and families should also be focussed primarily on safety, and that because of their professional expertise healthcare professionals’ assessments and recommendations should take precedence over other perspectives and concerns. Moreover the accounts revealed that other concerns such as financial or psychosocial implications were either not considered or were given little weight in relation to safety. Patient preferences were sought out and honoured only when they met the criteria of safety and more or less paralleled professional advice. ‘Client-centred care,’ was understood as seeking and honouring patient preferences. This understanding sometimes conflicted with the overarching safety goal, which was honoured by reformulating client-centred care broadly to include safety. In the latter case client-centred care was personally defined by professionals to involve a balancing of supporting autonomous choice within the context of ensuring safety. Conventions for discharge planning shaped the process of discharge for all individuals. The co-construction and intersection of the underlying beliefs, approaches and conventions ultimately influenced choices, perspectives and behaviours, which shaped discharge processes and outcomes for older adults and their families. These will be further explored in Chapter 7.
Chapter 7
Discussion

7 Introduction

A critical social science perspective informed by relational autonomy theory portrays individuals as indivisible from their social and political contexts, and as influenced by various discursive elements and practices embedded in their environments. By taking such a perspective in the analysis, I was able to identify underlying beliefs, valued approaches, and local conventions guiding discharge-planning processes and outcomes in this setting. The primary findings indicated these beliefs, approaches, and conventions intersected to promote practices and attitudes that inherently marginalized older adults in the discharge-planning process. Such marginalization excluded older adults from discharge planning and inherently disallowed them from making what were perceived by the involved healthcare professionals to be risky choices. The intersection of these same influences also prioritized assessments and interventions geared towards discharge, at the expense of interventions aiming to maximize function; however, maximizing function is a stated aim of rehabilitation services both locally and in rehabilitation more broadly (World Health Organization, 2011, p.95). In the research setting, through a lack of interventions aimed towards this end, older adults were not being enabled to maximize their potential to return home as independently, and safely, as might be possible. Through the practices of making recommendations for discharge early in the inpatient stay and of prioritizing safety, healthcare professionals made frequent recommendations of 24-hour care, even in instances where such recommendations may not be appropriate. Discourses of aging focussed on a loss of agency were reinforced though practices that essentially excluded older adults from decision making and disallowed decisions deemed to be risky. Pervasive beliefs about older adults invariably experiencing functional decline were realized since older adults were not provided with sufficient opportunities to recuperate and maximize their functional status before their discharge, and as such, were frequently recommended to have 24-hour care, even in instances when such recommendations may not have been warranted. Through these practices and processes, ageism was evident and replicated, and older adults’ autonomy was compromised in that they were denied the same personal freedoms available to other citizens.
In this chapter, I first discuss in section 7.1 the beliefs, approaches and conventions identified in the analysis that contributed to the marginalization of older adults during the discharge-planning process. I examine how these intersected and reinforced each other, shaping behaviours and practices that undermined the agency and participation of older adults and their family members in discharge planning, thus impeding healthcare professionals’ intended commitment to client-centred care. Furthermore, I explore how these co-constituting beliefs, approaches and conventions promote attitudes and procedures that disallow older adults from making choices that were deemed to be risky. In section 7.2 I examine how the orientation toward safety and the early discharge imperative hindered the provision of interventions to maximize individuals’ rehabilitation potential, thereby turning the promised process of rehabilitation into a process of discharge triage. Section 7.3 considers the practice and implications of making 24-hour recommendations, which reflect an understanding of older adults’ best interests as the promotion of their physical and medical safety at the expense of other aspects of their lives important to older adults and their families. All of these discussions address the third sub-question: How are conventional processes, valued approaches and underlying beliefs intersecting to influence decisions and outcomes of discharge planning with older adults in inpatient rehabilitation settings?

7.1 Synergetic influences and competing aims marginalize older adults in discharge planning and disallow “risky” choices

The data analysis illuminated various implicit and explicit influences that shaped participants’ perspectives, behaviours, and expectations of each other’s roles in discharge planning. These included underlying beliefs, valued approaches, and conventions in the discharge-planning process. Underlying beliefs differed from valued approaches and conventions in that these were not explicitly stated or necessarily recognized by participants, but were revealed in their discussions, commitments, priorities, and observed behaviours. Two pervasive underlying beliefs were identified across the data. The first of these, represented in all participants’ accounts, was the belief that an individual’s agency and capacity for participation in decision making declined as a result of aging. The second underlying belief was unique to the accounts of healthcare professionals and attributed primacy to health professionals’ knowledge and expertise in discharge-planning decision making. Two approaches were explicitly identified
as guiding health professionals’ practices: the prioritization of safety, and client-centred care. One local convention apparent in the data was that the discharge-planning process structured the entire rehabilitation admission. A second convention was the timing, structure and format of the family conference. While purposeful and expedient in terms of the organization’s needs, these two local conventions may have limited the older adults’ achievement of higher functional levels prior to discharge, and restricted possibilities for collaborative decision making among health care professionals, older adults and their family members. The combination of these beliefs, approaches and conventions seemed to marginalize older adults from the discharge-planning process and prevent them from making discharge choices deemed by others to be “risky”.

**Beliefs linking aging to a decline in decision-making agency and privileging healthcare professionals’ expertise**

A prominent underlying belief reflected by all participants was that older adults experience a loss of agency and retreat from participation in activities and decision making as they age, and thereby become more dependent on others. This belief was accompanied by a corollary expectation that older adults’ family members\(^\text{12}\) would assume a more active role in decision making with, and more often for, the older adult. These beliefs were reflected and reproduced in all of the participant’s accounts but were also resisted by older adults. How a loss of decisional control was manifested and enabled (or not) varied across the accounts. As was discussed in section 6.3.1, participants’ differing perceptions included that older adults willingly relinquished control, had it taken from them, or that loss or control was an inevitable result of declining capabilities. Participants from all three perspectives also linked aging to presumed declines in cognitive capabilities required for decision making.

The belief that older adults would and perhaps should give up their agency held among participants in this study can be seen as having been influenced by social and political discourses. In contemporary culture, aging as decline is a dominant discourse (Butler, 1989; 2009). Disparaging images of older adults and the process of aging are portrayed in various

\(^{12}\) Please note that in the study, in all cases family members who assisted older adult participants were adult children (and Frederick’s wife), however, in my experience as an occupational therapist, nieces, nephews or cousins also take on this role. Family members other than children tended to step in if older adults either did not have children, or their children were estranged.
media, particularly in the form of humour depicting an inevitable decline of bodily function and cognitive capabilities. Stereotypes pervade various forms of culture such as newspaper comics and comic books, novelty items (such as greeting cards and coffee mugs for example), advertising (including among others ads on billboards, public transportation, radio, television or in magazines), news reporting, television shows and movies, stage productions and literary works (Gullette 1997; Nelson 2005; Twigg 2006). These pervasive images undeniably influence everyday perceptions of older adults and may promote beliefs that older adults become incapable and require assistance to make decisions. Such discourses may influence individuals of all ages as well as specific sectors in a society, such as family caregivers and health professionals, corporations and consumers, and organizational and public policy-makers, whether or not their own perceptions align with, or resist, prevailing views. Underlying beliefs linking aging to a loss of agency, to decreased participation in activities and decision making, and to declining cognitive capacities remain prevalent in institutional healthcare contexts. These beliefs persist despite aims in institutions and education programs to overcome such discrimination (Estes et al., 2008; Brown, Kother & Wielandt, 2011; Higashi, Tillack, Steinman, Harper & Johnston, 2012; Klein & Liu, 2010).

Relational autonomy theory portrays individuals as indivisible from their social and political contexts and considers how persons are shaped, and continue to be influenced by, contextual opportunities and relationships. Older adults, their family members and healthcare professionals thus are viewed as indivisible from their social and political contexts, and as influenced by the discourses and relationships in these unique contexts. Applying a relational lens to explore the interactions between the participants enabled a nuanced exploration of how pervasive beliefs enabled or impeded participation in decision making.

From the perspective of older adults, an expected loss of agency was visible not only in explicit comments that they had ‘no choice’ except to listen to their children, but were also exemplified in their behaviours in relation to discharge decision making. Older adults reflected expectations that as they aged their children would step in to make decisions and ensure their needs were met. Similar results were found by Huby and her colleagues (2004; 2007) who found that older adults both expected decreased participation in decisions and left decisions and negotiations with healthcare professionals to younger members of their family. In the data, children reflected a complementary duty to care for their aging parents whose capabilities were,
or were expected to be, waning. These expectations however did not mean that older adults willingly and/or entirely stepped away from discharge decisions. Older adults expressed their agency in different ways, including expressions of their values, preferences, and/or clear opposition to undesired options, as well as threats of extreme actions (such as ‘walking the streets’ or not returning home) should such undesired options come to fruition. Through these expressions, power relations were played out and choices were negotiated according to individual family dynamics. These expressions of agency did not necessarily result in older adults realizing their preferences, but did enable contributions to decisions. Such interactions did not rely on traditional all-or-none determinations of decisional capacity as may be portrayed in traditional accounts of autonomy, which consider decision making in terms of a binary questions of capacity or incapacity\(^\text{13}\). Decisions were made based on long-standing relationships between parents and children that permitted depths of knowledge about each others’ values, preferences and needs. These practices reflected the relational nature of decision making and functioned to enable or disable older adults’ decisional capacities. This is not to say the practices resulted in the best possible outcomes, but only to say that autonomous choice, as observed in these cases, is more complicated than a single ‘capable’ individual making a unitary choice as traditional views of autonomy\(^\text{13}\) suggest.

In the data, healthcare professionals also reflected expectations that older adults will decrease their participation in active decision making and often linked these expectations to assumptions that older adults inevitably experience cognitive decline. Such notions aligned with healthcare professionals’ beliefs that as experts they were optimally qualified to determine the best plan for discharge and that their knowledge and expertise superseded the potential contributions of older adults and family members in discharge planning. For healthcare professionals, the two underlying beliefs intersected to reinforce each other. Perceptions of older adults as necessarily in decline suggested that older adult input was of limited value and therefore indicated a heightened need for expert professional assistance (more so than for assistance from family members who like the older adults were perceived to also lack expertise).

\(^\text{13}\) In applied consent practices, even though persons deemed incapable might still have a say (assent/dissent), a capable substitute decision maker would take decisional control from the older adult to make decisions for them. Autonomy and capacity are viewed as all or none atomistic attributes of an individual that do not admit the relational aspects of choice and multiple capacities between and amongst persons.
These views differed from those of older adults and family members in the healthcare professionals’ assumption that older adults and their families would look to healthcare professionals to make decisions for discharge. Given the organizational expectations for length of stay and the strong focus on discharge from the point of admission, these expectations were reflected in practices that did not encourage autonomous decision making on the part of older adults or joint decisions by older adults and their family members.

The decision-making behaviours of older adults, their children and healthcare professionals, and the expectations each had of each other reproduced perceptions of an expected decline in participation in decision making linked to aging. With the exception of Frederik and Rita, older adults expected to require more help and their children expected to offer more assistance. The dynamics between older adults and their family members suggest that older adults do not themselves experience a loss of agency but more so a change in how their agency is expressed or mediated. In the eyes of healthcare professionals, however, older adults experience a loss of agency and thereby need the healthcare professionals to make expert decisions and recommendations to keep them safe.

**The prioritization of safety**

The prioritization of safety was evident in healthcare professionals’ discussions of all aspects of discharge planning. Evidence of the value of promoting safety in discharges included statements such as “A safe discharge is a good discharge”, or conversely the labelling of unsafe discharges as “disaster discharges”. The importance of safety in healthcare professionals’ approaches in this setting aligned with research from Canada, the United States and Australia in which healthcare professionals prioritized safety in discharge planning (Moats & Doble, 2006; Crennan & MacCrae, 2010; Denson et al., 2013). The drive to promote and maximize patient safety is also prominent in Canadian healthcare and best practice literature (Baker et al., 2004; National Steering Committee on Patient Safety, 2002; World Health Organization, 2009) as well as in the mandates of various professional colleges and associations (Canadian Association of Occupational Therapists, 2011; Canadian Physiotherapy Association, 2012; College of Nurses of Ontario, 2011, College of Physicians and Surgeons of Ontario (2013). These prevalent structural drivers both reflect the prioritization of safety and are reaffirmed in the institutional practices of the study setting.
The practice of prioritizing safety intersected with healthcare professionals’ beliefs in the primacy of their expertise to further reinforce underlying beliefs about older adults’ declining agency and capacities for decision making, particularly if the older adults’ wishes differed from what was being recommended by healthcare professionals. The implication was that if older adults disagreed, they must not have the capacity to understand. This implication and reinforcement of underlying beliefs about aging as decline were exemplified in healthcare professionals’ questioning older adults’ cognitive capacities whenever they mentioned older adults’ possible contributions to discharge-planning decision making. Assumptions about decreasing cognitive capacities were linked to decreased safety for the older adults if they were left without supervision or assistance. Similar notions linking aging to decreasing cognition and safety have been discussed by Sherwin and Winsby (2010) who argue that underlying beliefs linking decreased cognition with aging can lead to situations where healthcare is paternalistically aimed at compensating for presumed losses in capacities. They suggest that individuals with impaired capacity may be provided care in instances where assistance is not required, and may not be offered opportunities to exercise autonomy when they could. As per Sherwin and Winsby’s arguments, there are circuitous and reinforcing interrelationships between discourses of aging as decline, underlying beliefs about the primacy of healthcare professionals’ expertise and the practice of prioritizing safety. How these intersections functioned to mediate discharge planning and choices were revealed in the practices and conventions observed in this study setting.

**Conventions structuring the format of the family conference**

An important element in the discharge-planning process was the family conference. The family conference was seen as a means of engaging older adults and family member in discharge planning both in this study and in the literature (Efraimsson et al., 2006; Griffith et al., 2004). Despite this objective, the conventions guiding the process of the discharge-planning family conference in this setting discouraged patient and family contributions to the discharge-planning discussion. First of all, the meeting was scheduled to last 30 minutes, after which time the discussion was cut off and the discharge date and time were reinforced even if no consensus had been reached to determine a discharge plan. Secondly, the meeting structure prioritized information sharing from the healthcare professionals, thereby highlighting their authority and
allowing time for discussion if any remained. Thirdly, the setup of the meeting room most often had the healthcare professionals sitting together opposite the older adult, with family members sitting behind the older adult and the head nurse taking notes on a computer. This setup was more akin to a court than a collaborative meeting and suggested power imbalances between the different individuals. Additionally, healthcare professionals tended to speak to family members about the older adults to inform them of how they could prepare for discharge, further exemplifying attitudes linking aging to declining agency and capabilities. In fulfilling these conventions, during the meeting, healthcare professionals took on roles that promoted their expertise and authority and discouraged particularly older adults’ as well as families’ involvement in the planning and decision-making discussion. These findings support research by Efraimsson and her colleagues (2006), who discussed discharge-planning family conferences and specifically individuals portraying and conducting themselves in manners expected of their roles. These researchers also found that such conventions precluded collaboration between older adults, families, and healthcare professionals (Efraimsson et al., 2006). In the present study, underlying beliefs about the primacy of healthcare professionals’ expertise in conjunction with the structure of the family conference limited the opportunity for older adults’ and family members’ meaningful participation in discharge planning.

**Client-centred approaches**

In their interviews, healthcare professionals explicitly promoted the value of client-centred care and asserted that they took a client-centred approach to discharge planning with older adults. Descriptions of client-centred practice in the data varied but tended to focus on finding a balance between upholding patients’ wishes in consideration of their capacity and maintaining their safety. Despite such descriptions, consideration for clients’ wishes or behaviours that would have engendered client input in decision making were largely absent in the data. Instead, professional approaches prioritizing safety took precedence over clients’ preferences. Wishes that did not align with healthcare professional recommendations (which were considered safe) were not supported. Thus, considerations of clients’ best interests and taking a client-centred approach in the data became akin to maximizing client safety.

In the literature there is much variability both in terminology and conceptions of client-centred approaches. In a large scale Health Canada-funded review of the literature about client-
centred care, Brookman and her colleagues (2011) suggest that person-, client- or patient-centred approaches are based on “developing an understanding of the individual, their environment, values, relationships and social world” (p.22). Additionally, the Canadian Medical Association states that patient-centred care ‘takes into consideration the individual needs and preferences of the patient and his/her family” (p.6). Similarly, the Canadian Association of Occupational Therapy denotes client centred practice as a collaborative approach that involves clients in decision making to meet their needs while recognizing their experiences and knowledge (Law, Polatajko, Baptiste & Townsend, 1997). In an earlier seminal text defining concepts of patient-centred care, Gerteis and her colleagues (1993) suggest a patient-centred approach is one that “consciously adopts the patient’s perspective” (p.5). These authors further elaborate seven dimensions of patient-centred care: 1. Respect for patients’ values, preferences, and expressed needs; 2. Coordination and integration of care; 3. Information, communication, and education; 4. Physical comfort; 5. Emotional support and alleviation of fear and anxiety; 6. Involvement of family and friends; and 7. Transition and continuity (p.5-11). This multi-dimensionality contrasts professional participants’ narrowly conceived descriptions of client-centeredness as following the patients’ wishes if and only if assessed as safe. Conceptualizations of client-centeredness in the literature focus on developing an understanding of patients’ values and contexts in order to consider these in healthcare decision making. Safety is not mentioned. Conceptualizations of client-centeredness in the literature overlap with the descriptions in the data in their common concern for patients’ values. Conceptions in the literature however promote the inclusion of patient values and preferences in the determination of care plans while practices and behaviours to honour patient values and preferences do not appear in the data.

Practices that would support the tenets of client-centred care would not easily fit within the kind of ‘triage model’ of discharge planning identified in this research (discussed below in section 7.2). Identifying individuals’ preferences, values, strengths, weaknesses and specific circumstances, and elaborating a customized plan might be at the root of client-centred care, but may take more time than healthcare professionals are afforded with each client. Additionally, individuals’ unique values, strengths and preferences may be ambiguous and may not easily fit into existing frameworks such as protecting from harm and prioritizing safety, or addressing physical illness or injury, or into a theoretical framework aiming to guide “client-centred” practice. As such, practices to identify and integrate unique client values and preferences into
intervention and discharge plans take time and may be overshadowed by practices that focus narrowly on older adult patients as objects of care who need to be kept safe and have their healthcare needs met. Such practices are arguably simpler as only physical safety is being considered rather than the breadth of personal, physical, psychological, emotional (and other) safety, needs or preferences. Similar observations were made by Huby and her colleagues who asked whether risk management and patient participation in discharge planning were compatible aims (Huby et al., 2004). As is discussed more thoroughly below, considering the unique set of client preferences, values, needs, strengths, resources and circumstances may take longer than current practice is affording. Though considering these may be healthcare professionals’ intent, it may not be the practice to which they resort in light of shorter lengths of stay and higher caseloads, as is the trend in current healthcare climates (Bull & Roberts, 2001; Connolly, et al., 2009; Efraimsson et al., 2006; Huby et al., 2004; Kane, 2011; Moats, 2006; Mor & Besdine, 2011; Pethybridge, 2004; Watts et al., 2005; Wells et al., 2002). Thus, while there is a systemic push to provide client-centred care and an intrinsic pull towards it for healthcare professionals based on their training and ethics, systemic policies regulating the amount of time that healthcare professionals have to provide care and make discharge plans limit the potential for client-centred care to be realized.

**Conclusion: older adults are marginalized in discharge planning and are not permitted to make “risky” choices**

Beliefs, practices and conventions in this setting combined to result in processes that marginalized older adults in discharge planning. Individuals reflected and reproduced underlying beliefs linking aging to decreased agency in decision making. Older adults and their family members mediated decision making in manners that enabled older adults’ participation in discharge planning. Such approaches were not shared by healthcare professionals, who primarily demonstrated confidence in their authority to determine what was safe and therefore should be the discharge plan, thereby excluding older adults from discharge planning. This exclusion was in opposition to the aspect of healthcare professionals’ stated understandings of client-centeredness that included consideration of patient preferences in the determination of care. Conventions of the discharge-planning family conference aimed to enable collaboration, but in practice discouraged older adult and family participation. In light of the intersecting and
reinforcing underlying beliefs and behaviours by all participants, the approaches taken by healthcare professionals, and the limitations presented by conventions structuring the discharge-planning family conference, older adults were marginalized in discharge decision-making processes. Furthermore, they were not permitted to make decisions that reflected their wishes to return home, as these were considered to be “risky” choices. For older adults to return home without help was deemed to be unsafe in the case studies as they may have been at physical risk of falling or being harmed. The World Health Organization (WHO) reports the incidence of falls to be one per year for every three older adults over the age of 65 (WHO, n.d.). Statistics show that hospital admissions rates for motor vehicle collisions are almost the same as those for unintentional falls (CIHI, 2012a), however, every day millions of Canadians enter motor-vehicles. Similarly, participation in winter sports results in a high incidence of injury and hospital admissions (CIHI, 2012b) but is nonetheless encouraged in Canada. Looking at the rates of injury per capita and in relation to the amount of time spent doing an activity, reveals that participation in winter sports is much more dangerous than older adults living at home. Individuals are permitted to play hockey, go skydiving or even smoke cigarettes, which are activities that undoubtedly put their safety at risk, and yet there are no restrictions related to such activities other than age-of-majority regulations. Older adults, however, are not permitted to make the decision to return to their home without substantial assistance, as this is deemed to be unsafe. The intersection of discourses of aging as decline and of practices prioritizing safety further the historical marginalization and oppression of older adults and do not enable client-centred care.

7.2 Rehabilitation as a process of destination triage

Healthcare professionals described the goals of rehabilitation as aiming to maximize individual function and safety. Other than in statements delineating these aims, the data did not reflect practices that maximized individual function; indeed healthcare professional participants complained that they had little time for actual interventions. Healthcare professionals were influenced by conventions of considering discharge from the point of admission and of scheduling the discharge planning family conference for two weeks into the admission. Such conventions limited the amount of time healthcare professionals had to complete their assessments and interventions to inform the creation and implementation of a safe discharge plan. The push to prioritize safety may have promoted a focus on putting in place a safe
discharge plan rather than on interventions to maximize function. Looming discharge dates also put pressure on older adults and their family members, thus causing them to pressure healthcare professionals into focusing on discharge. Underlying policies, practices and conventions in the research setting shaped the rehabilitation and discharge planning processes into a process of destination triage rather than the restorative provision of healthcare aiming to maximize individual function as these services were promised to be.

**Aims of rehabilitation and discharge planning: function or safety?**

As was described in Chapter 6, when healthcare professionals described the aims of rehabilitation, they reported that these were to maximize function and safety in the discharge setting. The aim of maximizing function (and not of promoting safety) was also included in the facility’s literature describing the aim of the program as helping “patients attain maximum physical, communicative and cognitive functioning, while addressing emotional, social and spiritual needs to help them return to living in the community as independently as possible”. This aim aligns with the dominant rehabilitation rhetoric, (Bauer et al., 2009; Baycrest, 2013; Dal Bello-Haas & Tryssenaar, 2009; Jewish Rehabilitation Hospital (n.d.); Providence Healthcare, 2013; St-Joseph’s Health Care London, n.d.; Toronto Rehabilitation Institute, 2013) which centres on overcoming the challenges presented by illness, injury or age-related health complications in order to maximize independence and function. Other than the explicit mentions by healthcare professionals, however, the data revealed that in practice very little, if any, intervention to realize these aims was possible.

**Influence of early consideration of discharge, shortened lengths of stay and prioritization of safety**

In the research setting, all healthcare professional participants adhered to a standardized timeline in which the process of planning for discharge began on admission. The early focus on discharge aligns with Wells’ (1997) findings describing the same practice. Briefly, in the setting of study, the scheduling of the discharge-planning family conference for two weeks following admission directed healthcare professionals to spend the first two weeks working on assessments to devise their recommendations for discharge, and the subsequent two weeks putting services and equipment in place to realize the plan. The early emphasis on discharge impeded healthcare
professionals from engaging clients in interventions or therapy geared towards individuals’ rehabilitation.

The heavy focus on prioritizing safety in the research setting further pushed healthcare professionals to focus their intervention time on assessing and preparing for discharge at the expense of interventions to maximize function. While it may be argued that interventions aiming to maximize individual function could also increase individual safety, spending time making plans for discharge, which would more immediately appear to maximize older adults’ safety, took precedence. Conventional practices focusing on discharge early, and a focus on prioritizing safety resulted in practices that conflicted with the explicitly stated aim of maximizing function, which in turn further reinforced the perceived need to prioritize safety.

Pressure to prepare for discharge may also have come from family members who reported feeling anxious with respect to the set discharge date. The immediate focus on discharge and the push to make decisions early may have surprised the older adults and their families, who were instead expecting time to regain and maximize function before making discharge decisions. Awareness that family members felt pressured was confirmed by healthcare professionals’ reports. They stated that they tried to diminish this pressure but did not elaborate. Such efforts may have included the prioritization of interventions linked to discharge plans over spending time on interventions to maximize independence and function that may not be of apparent benefit in the shorter term.

Increasingly shortened lengths of stay may have contributed to the convention of focusing on discharge from the moment of admission at the expense of interventions to maximize function. One healthcare professional participant indicated that lengths of stay had shortened, remarking that when lengths of stay were three months, she did not focus on discharge from the point of admission but actually had time to do interventions to maximize recovery and function. Her assertion implied that shorter lengths of stays limited the amount of time spent on therapeutic interventions. Such shortening aligns with trends of reducing healthcare lengths of stay in developed countries (Bull & Roberts, 2001; Connolly et al., 2009; Efraimsson et al., 2006; Huby et al., 2004; Kane, 2011; Moats, 2006; Mor & Besdine, 2011; Pethybridge, 2004; Watts et al., 2005; Wells et al., 2002). Focusing on discharge planning from the moment of admission in conjunction with shortened lengths of stay in this setting resulted in assessments
and preparation for discharge being the focus of therapy time at the expense of time being spent on interventions aimed at maximizing individual rehabilitation and recovery of capabilities.

In not providing time for interventions to promote rehabilitation and to maximize function and independence, the structure of this rehabilitation setting does not allow healthcare professionals and patients to meet the expected aims of this program. Decreasing lengths of stay may allow healthcare settings to serve more patients, but may be hindering healthcare professionals, older adults and family members from focusing on rehabilitation before the discharge.

**Conclusion to rehabilitation as a process of destination triage**

In summary, the early focus on discharge planning focussed the inpatient rehabilitation on safety and planning for discharge at the expense of interventions to maximize individual function, the stated aim of rehabilitation. Primarily, in the research setting, discharge planning began on the day of admission by scheduling of the family conference and the date of discharge respectively two and four weeks following admission. Healthcare professionals reported that adherence to this timeline incited a focus on assessments and interventions geared towards discharge. Interventions aiming to maximize function may show limited progress in the short term and may therefore have seemed a less valuable use of the limited time afforded by shortened lengths of stay, in comparison to spending time putting services or equipment in place for discharge. Additionally, the looming discharge and reality of care needs resulted in family members feeling pressured, thereby increasing the impetus of healthcare professionals to focus on discharge. The intersection of these constraints and considerations turned the process of rehabilitation into one of destination triage, focusing the inpatient rehabilitation stay on planning for discharge and prioritizing safety. These foci overshadowed rehabilitation and the aim of maximizing function, which were the professed aims of the program.

**7.3 Discharge practices do not meet anyone’s needs**

The outcome of the process of destination triage was often a recommendation of 24-hour care. Such recommendation could have significant implications for older adults, their family members, and the healthcare system. At least one case in the study demonstrated that such recommendations can be made unnecessarily, thus potentially needlessly disrupting older adults’ and their families’ lives and incurring avoidable financial costs for them as well as the healthcare
Various influences intersected to promote recommendations for 24-hour care. Primarily, the conventional timing of the discharge process in this setting incited healthcare professionals to complete all of their assessments and determine their discharge recommendations in the first two weeks of the inpatient stay, at a time where older adults may still have been in the early stages of recovery and may not have given an accurate picture of their potential recovery. Secondly, such recommendations may have been guided by the lack of options for care in the community, thereby reducing the choice of possible recommendations and inciting more frequent recommendations of 24-hour care. The practice of making frequent recommendations of 24-hour care suggests that upholding older adults’ best interests is being equated with the maintenance of their physical safety, which may not be meeting older adults’ needs.

**Example of “unnecessary” 24-hour care recommendation from the data**

In the data, healthcare professionals reported erring on the side of safety and making frequent recommendations of 24-hour care. Examples from both the data and the literature (Clemens, 1995) suggest that there are instances where recommendations of 24-hour care were not necessary. As described previously, the case of Magan provides an example from the data in which early recommendations were overprotective and did not align with his care needs upon discharge. A similar case was reported in Clemens (1995) whereby an individual was asked to sign documents to move to long-term care early in her acute care stay. This individual refused and ended up returning home to live independently with minimal supports. While such cases may be unique, it is important to note that in this research, recommendations for 24-hour care were made in all five cases, despite being contrary to what older adults wished (thereby demonstrating the previously argued outcome of older adults having little, if any, input into discharge planning). It is difficult to ascertain to what extent the recommendations in the other four cases were overprotective because I have no information regarding how those individuals fared following their discharge. Nonetheless, healthcare professionals reported that they tended to err on the side of maximizing safety and made these recommendations more often than not. As has been shown in the previous sections in this chapter, such practices risk neglecting the potential for recovery of abilities and resulting in recommendations that are generic and not tailored to the specific circumstances, needs, resources and abilities of the individual being
discharged. Recommendations for 24-hour care may have further implications for the various involved stakeholders.

Implications of 24-hour care recommendations

From the perspective of older adults facing discharge and their involved family members or caregivers, a recommendation for 24-hour care had potential financial as well as psychological costs. From a financial perspective, the costs of hiring private caregivers to provide 24 hours of care per day were significant and in many cases may have been prohibitive. A more affordable option would have been a move to long-term care. Alternatively, a live-in caregiver could be hired. This individual could provide 44 hours of paid care per week, but also could be reasonably expected to provide a presence during the remainder of the time. The cost would be significantly less, but it would require space for the caregiver’s room and would mean having someone live in their home.

In the study, three of the older adults chose to afford privately funded care in the home and a fourth chose to move to a senior’s residence (where she was supervised and had the option of hiring a caregiver for several hours per day.) The older adult participants’ accounts suggested that a move to a new environment would have been difficult, and was anticipated to be such by the older adult who was going to a senior’s residence. Several scholars also suggest that the loss of their home can be emotionally and logistically difficult for older adults and their families (Dupuis & Thorns, 1996, 1998; McCullough et al., 1993; Moats, 2006; Potthoff et al., 1997; Wise, 2000).

14 According to the Ontario Ministry of Labour (n.d.), caregivers must be paid the minimum wage, which in Ontario at this time is $10.25. A gross calculation of the cost of minimum wage for 24 hours per day and 365 days per year suggests the cost of such recommendations is $89 790. Such calculations do not include the additional and legally required costs of overtime should it be required or of providing vacation, which requires hiring another caregiver to replace the one on vacation. Note also that such calculations are based on having a minimum of 4 different caregivers as legally, employees are not permitted to work more than 48 hours per week for the same employer.

15 In Ontario, the monthly co-payment for basic accommodation in long-term care can be as low as $1707.59, (Ontario Ministry of Health and Long-Term Care, n.d.) which amounts to an annual cost of $20 491.08.

16 The cost of having a caregiver providing 44 hours of care at minimum wage (Ontario Ministry of Labour, n.d.) was $23 453 annually. According to the Ministry of Labour (n.d.), the cost that can be deducted for room and board is $3.25 per week, thus reducing the total cost by $4328 annually per live-in caregiver. The net cost of having a live-in caregiver who provided 44 hours of work per week would therefore be $19 108.96. This calculation does not include the cost of that caregiver’s vacation time, which necessitates hiring a replacement caregiver.
From a healthcare system perspective, there is evidence to suggest that in more than 37% of cases of individuals on the waiting list for a long-term care bed, providing care at home would be more cost-effective (Williams et al., 2009). Recommendations for 24-hour care may thus have significant implications for older adults and their families, and may incur high costs for the healthcare system. Situations where these recommendations are unnecessary would therefore cause unnecessary challenges and financial costs.

**Frequent recommendation of 24-hour care**

Such financial and psychological implications have repercussions for older adults and their families, but have little impact on healthcare professionals. This is not to say that healthcare professionals are inconsiderate of the needs and perspectives of others, but merely to say that healthcare professionals may not be as aware of these implications as they are of other influences promoting their 24-hour care recommendations. Taking a critical social science perspective and applying a lens informed by relational autonomy theory incites examination of systemic structures that may be influencing and guiding behaviours (Eakin, Robertson, Poland, Coburn, & Edwards, 1996; Harvey, 2013; Mackenzie & Stoljar, 2000; Sherwin, 2008). In doing so, I argue that healthcare professionals’ recommendations of 24-hour care were guided by the convention of making recommendations early in the process, by a lack of time to provide interventions aimed at rehabilitation and maximizing function, and by a focus on the prioritization of safety. Additionally, such recommendations were shaped by contextually-determined limitations in options for care upon discharge.

Evidence shows that individuals are now being discharged from acute care services earlier in their recovery (CIHI, 2013; Brown, 1995; Clemens 1995; Moats, 2006; Potthoff et al., 1997). Subsequently, individuals are admitted to inpatient rehabilitation services when they may still have high medical needs and when they may not yet have recovered enough strength, endurance, or other capabilities required for participation in rehabilitation. As was discussed above, in this setting the two-week period immediately following admission to inpatient rehabilitation services was the time during which healthcare professionals completed the majority of their assessments to inform a prognosis of recovery of function and what may be potential needs upon discharge. As is suggested by Wells (1997), the practice of completing assessments and formulating recommendations early in the patients’ stay may set up a situation where it is more difficult to
determine an accurate prognosis of the individual’s anticipated function. In conjunction with the strong focus on prioritizing safety, such a practice may therefore promote recommendations that are aimed towards a lower level of function than patients will have upon discharge. In the case of Magan in the data and the example by Clemens (1995) in the literature, making recommendations early in the admission seemed to promote recommendations that were prematurely overprotective.

Such recommendations also arise in light of the previously argued lack of time to work on interventions to maximize individual function upon discharge. Healthcare professional participants may therefore have felt a need to compensate for this neglect by further promoting individual safety in discharge plans. By maximizing safety, they were lessening the impact of not having provided interventions aiming to maximize function upon discharge.

Limitations in the availability of publicly funded or affordable supportive services in the community set up a situation where healthcare professionals had little choice but to make a recommendation for 24-hour care. Options for care upon discharge included publicly funded home care support, which at this time in Ontario, is provided by community care access centres (CCACs) (Williams et al., 2009). In my experience working as an occupational therapist in older adult inpatient rehabilitation, there was a tacit understanding among clinicians that these services were minimal and were geared to addressing very specific medical and relatively acute needs. If individuals did not require specific medical services, they would not qualify for publicly funded care or would be placed on long waiting lists (Ontario Health Coalition, 2011) thereby not receiving services and being at risk of harm without services in the meantime. Other options included family member involvement and privately hired services. In the data, however, assistance from family members was rarely included in discharge recommendations made by healthcare professionals. It is not clear if this omission was because healthcare professionals assumed family members might be unreliable in the long-term or might be unavailable or unwilling to provide the recommended care, or because healthcare professionals did not wish to burden family members with caregiving responsibilities; nonetheless, informal family care giving was rarely brought up as a long-term discharge option. The option of hiring privately funded care was reported by participants in the study as being expensive, particularly if individuals required several hours of assistance daily. Healthcare professional participants reported that it was more affordable to hire a live-in caregiver than to hire individuals for a few
hours per day. Both hiring a long-term caregiver and moving to long-term care seemed more affordable to healthcare professionals than hiring an individual for several hours a day. Recommendations for 24-hour care were thus guided by a lack of options for care and a concern for the cost of private care.

**Conclusion: Practices and priorities are not meeting needs**

In summary, the practice of prioritizing safety and of making recommendations early in the inpatient stay in conjunction with a lack of time to work on rehabilitation interventions, limited options for care upon discharge and the previously argued lack of older adult input in discharge plans guided the frequent recommendation of 24-hour care in this setting. Such intersections reduced the consideration of older adults’ best interests to a limited focus on protecting their physical safety, thus neglecting psychological, emotional, cognitive and all other forms of safety, or all other aspects of identity. Recommendations for 24-hour care additionally have significant implications not only for older adults and family members, but also to the healthcare system in terms of cost efficiency. Such recommendations may not always be the best use of limited funds, and may not be meeting older adults’ and needs or be the most cost-efficient practice for healthcare systems.

**7.4 Summary of Discussion**

Underlying beliefs, valued approaches and conventions in this setting intersected to create and reinforce discourses and practices that marginalized older adults in planning for their discharge. Such practices promoted ageism and oppression and disallowed older adults from making decisions that were deemed by healthcare professional experts to be risky. In conjunction with the practice of considering discharge from the point of admission the intersection of beliefs, approaches and conventions led to a process of rehabilitation that contradicted the explicitly stated aim of rehabilitation to maximize patient function. It instead resulted in a process I have labelled ‘destination triage’. Discharge-planning recommendations were based on early assessments, which may have underestimated older adults’ potential function and recovery, were guided by the prioritization of safety, were limited by the options for available care and the financial implications of each, and were not informed by the older adults’ and their families’ contributions. Such recommendations did not align with older adults’ wishes
and may be financially costly for all involved stakeholders and the system. The intersection of all these practices and beliefs resulted older adults’ best interests being reduced to the explicit prioritization of their safety in discharge planning, and that did not consider other aspects of their lives.
Chapter 8
Conclusions, implications and limitations

8 Introduction

In this research I have demonstrated the value of taking a critical bioethics perspective informed by relational autonomy theory to examine discharge planning with older adults. Taking such an approach in my research and data analysis enabled not only an in-depth examination of the discharge planning process, but also of social and political, discursive and institutional influences shaping individual perspectives, behaviours and practices. Throughout the research the application of a relational autonomy lens guided my examination of how autonomy and its exercise was understood, manifested, enabled or impeded in discharge-planning decisions in this setting. In this chapter I begin with a summary of the findings before discussing some of the ethical issues that are implied by these findings. I then explore the clinical implications of applying a relational autonomy lens to discharge planning. In so doing I discuss how a relational approach to discharge planning is similar and different to a client-centred approach. I also consider how a relational approach might support and promote further development of client-centred approaches to address some of the issues uncovered in the findings, and make suggestions about how such an approach might translate into discharge planning and rehabilitation practices and processes. I then move to explore the methodological strengths and limitations of taking a critical bioethics perspective informed by relational autonomy theory in this research.

8.1 Summary of the findings: Synergistic influences and competing aims result in ethical challenges

Taking a critical bioethics perspective informed by relational autonomy theory to examine discharge planning with older adults brought to light how the intersection of discursive elements, valued approaches and conventional practices affected discharge planning and subsequently, the provision of healthcare for older adults and their families. In doing so, I have identified co-constructing beliefs, approaches and local conventions, all of which guide, shape and influence discharge planning perspectives, processes and outcomes. The intersection of these elements
promoted attitudes and practices that contributed to three different issues or conflicts in the outcomes of discharge planning processes:

Primarily, **older adults were marginalized in the discharge planning process.** Underlying beliefs about aging as decline and attributing primacy to healthcare professionals’ knowledge intersected with practices that discouraged older adults’ and families’ contributions in discharge planning. The combination of such beliefs and approaches promoted attitudes and practices that did not uphold older adults’ autonomy and rather precluded their participation in discharge planning. Paternalistic approaches aimed at beneficently protecting older adults’ physical safety overshadowed considerations for other aspects of their well-being. Older adults were furthermore disallowed from making decisions such as going home that were deemed to be “risky” by healthcare professionals, but that may seem to be benign in light of other socially-accepted decisions made by younger individuals (to participate in extreme sports for example). Such exclusion and denial of choice thereby promoted the oppression of older adults as equal citizens.

Secondly, **institutional priorities limited the provision of rehabilitation interventions and reduced the process of rehabilitation to ‘destination triage’**. The intersection of the local conventions guiding an early focus on discharge with the practice of prioritizing safety contributed to the discharge planning process overshadowing the rehabilitation process. Planning for discharge took precedence at the expense of interventions aiming to maximize function, which is the stated aim of rehabilitation. Rehabilitation was thereby reduced to a process of destination triage from the moment of admission. This raises questions of accountability as the purported aims of serving older adults by assisting them to maximize their function are not being met at the expense of planning for their discharge. Such a process is not meeting the needs of older adults who are expecting time and interventions to maximize their function, or the expectations of the program that individuals will have higher function and therefore lower healthcare needs upon discharge.

Finally, **frequent recommendations of 24-hour care may not be meeting older adults’ needs or be the most cost-efficient practice for healthcare systems.** Early discharge recommendations combined with limited ‘safe’ home and community care options often resulted in recommendations for 24-hour care. Such recommendations at times were unnecessarily
precautionary. A recommendation of 24-hour care could easily result in a move to long-term care, which has significant implications for older adults, their families as well as for the healthcare system. The actions taken based on these recommendations could not always be reversed and may therefore unnecessarily change the lives of older adults and their family members, and result in unnecessarily high healthcare costs for the healthcare system. This finding again brings up questions of accountability in suggesting that the practice of making frequent recommendations for 24-hour care may not be meeting the expectations of improved well-being for the older adult clients and their families, nor of maximizing the efficiency of all healthcare services.

Taking a critical bioethics perspective informed by relational autonomy theory to the research enabled the illumination of conflicts between the organization’s valued approaches, the conventions practiced in this setting, and the explicit aims of older adult inpatient rehabilitation services. Additionally, this approach enabled a deeper analysis of participants’ underlying beliefs and consideration of how these were shaping perspectives and behaviours in discharge planning, and furthermore, how they were influencing and reinforcing conventional approaches and practices. While further work is needed, the findings suggest various modifications to policies and practices that may address the identified conflicts and enable healthcare professionals, and the sum of their services – the healthcare system – to better meet older adults needs’ and those of their families and healthcare professionals assisting older adults in discharge planning. Such suggestions will now be explored.

8.2 Clinical implications - A relational approach to understanding unique needs, strengths and resources in discharge planning

There are strong conceptual parallels between descriptions of client-centred care in the literature and an approach guided by relational autonomy theory. In this section I first briefly review descriptions of client-centred care from the literature and the tenets of relational autonomy theory to discuss how they are similar and different. I then discuss how the consideration of relational autonomy theory enabled the depiction of relational aspects of decision-making in the practices of older adults, their family members’ and healthcare professionals. Finally I outline some potential recommendations informed by relational autonomy that could strengthen the alignment of clinical practice with the aims of a client-centred approach.
As was discussed in Chapter 7, although conceptualizations of client- patient- and family-centred care vary in the literature, they share a common focus on understanding individuals’ perspectives and values and considering individuals within their environments and social context (Brookman et al., 2011; Canadian Medical Association, n.d). Some descriptions promote consideration of individuals in the context of their healthcare journey and discharge(s). Such descriptions include concern for how the current provision of care fits with the previous interventions individuals have received and of how they will transition to a different healthcare service or environment when the current provision is no longer appropriate (Gerteis et al., 1993). Concepts of client-centeredness therefore include a focus akin to discharge planning.

In relational autonomy theory and approaches to care advanced in its name, individuals are similarly considered within their contexts. More broadly, however, relational autonomy is a philosophical stance outlining the inherent interrelatedness of human beings. Relational autonomy theory portrays individuals as unique and inextricably embedded in their social and political contexts; as such, individuals are considered to have been shaped, and to continuously be influenced, by individuals, relationships, beliefs, practices and norms prevalent in these contexts (Friedman, 2000; MacKenzie & Stoljar, 2000; MacKenzie, 2008; Sherwin, 1998; Sherwin & Winsby, 2010). As indivisible from their social networks, individuals are considered in relation to others and the influence of their relationships is also considered. Additionally, in relational accounts, individuals are considered to be in unique situations, having unique sets of capabilities, needs, preferences, strengths and resources. These intersections may result in individuals having differing levels of the capacities required for decision-making, thereby necessitating individualized approaches. The application of relational autonomy theory to the analysis enabled a broader understanding of the relational nature of decision-making and of the social and political influences on perspectives, behaviours and approaches to discharge-planning decision making.

In their decision-making practices, older adults and their family members interacted in manners that were based on long-standing relationships and a depth of knowledge about each other. Older adults and their family members demonstrated consideration for each other’s unique intersections of strengths, needs, and circumstances and worked together to maximize and complement each other’s strengths. Such collaboration was exemplified in joint decision-making practices that enabled older adults to express their agency and participate in discharge-
planning decision making even if they were not explicitly making the decision. From the perspective of older adults and family members, they were acting in ways that were ‘natural’ to them based on their long-standing familial relationships and the expectations they had of each other. Such behaviours however demonstrated a unique approach to decision-making, thereby exemplifying the relational nature of decision-making.

In contrast, healthcare professionals had difficulty adhering to their espoused commitment to client-centred care and implementing their services in ways that aligned with the relational nature of decision making. The healthcare professionals’ practices were more consistent with a narrow and conditional interpretation of client-centeredness, for example, promoting client preferences if they aligned with what the healthcare professionals perceived to be safe. Despite their stated intents, the case studies reveal that regardless of any personal commitments to client-centeredness or initiatives acknowledging and promoting client preferences, healthcare professionals’ ideals were subordinated to their prioritization of safety in the discharge planning process. Healthcare professionals acknowledged that the prioritization of safety at times did not align with patient preferences, but did not go so far as to acknowledge the ethical issues related to this prioritization taking precedence over older adults’ or family members’ contributions to discharge planning. They reconciled the dissonance between patient preferences and their recommendations by focusing on the perceived importance and value of promoting safety, which did not align with conceptions of client-centred care in the literature.

At the same time, it could be argued that healthcare professionals’ inclusion of family members in the implementation of discharge plans aligned with the tenets of client-centred care described in the literature that promote consideration of individuals within their social context. As I have outlined in Chapters 6 and 7, however, the inclusion of family members in the implementation of discharge plans by healthcare participants in this study was primarily guided by perceptions of older adults’ declining cognitive capacities and increasing reliance on family members. The approach of including family members in the realization of discharge plans was not identified by healthcare professionals as being client-centred and did little to support client-, patient- or family-centred care in discharge planning.

One of the clinical contributions of this research is in highlighting the disconnection between definitions of client-centred care in the literature and healthcare professionals’
understandings of the concept. Moreover there is a wider gap between the definitions of client-centred practice and the lack of evidence of such in healthcare professionals’ accounts. These findings align with those of Crennan and MacRae (2010) who found that some clinicians had a difficult time implementing client-centred approaches to discharge planning, particularly in situations with cognitively-impaired patients where families were involved in decisions. The findings of Crennan and MacRae and of the present study suggest the need for further research exploring how client-centred care is understood, what influences are preventing its practice and how client-centred approaches can be enabled in discharge planning.

Although relational autonomy is not explicitly linked to client-centeredness in the literature they share some common tenets. Both consider individuals as embedded in their contexts and share a focus on identifying individuals’ values, strengths and preferences in order to provide tailored care plans meeting their needs at different points in their lives. Relational autonomy theory further states however that individual choices and behaviours are shaped by their contexts which determine available options, and enable development or inhibition of particular skills and values. Furthermore, relational autonomy theory incites examination of the social, political and institutional structures and consideration of what influence these may have on individuals’ identities, perspectives, strengths and capabilities (MacKenzie & Stoljar, 2000; Sherwin, 1998; Sherwin & Winsby, 2010). Applying a relational autonomy lens to practice could thereby promote approaches that better align with intended client-centred practice.

The findings of the present study cannot possibly inform how and when relational autonomy theory should be incorporated into practice. Further research would be required to answer questions regarding whether it would be most beneficial, for example, for relational autonomy to be discussed in clinical education programs with all developing clinicians and/or at a policy level in order to inform the development of policy to guide practice, or in other forums. Nonetheless, the findings of this study suggest that conflicts exist between the stated aims of rehabilitation and the process and outcomes of discharge planning, as well as between concepts of client-centred practice as described in the literature and the approaches and practices of healthcare professionals in the research setting. I argue that several of these conflicts could be mitigated through the application of the tenets of relational autonomy theory to approaches and practices in the rehabilitation setting.
A second clinical contribution to this work is to suggest how a relational approach to practice could engender attitudes and practices that would enable older adults and their family members to participate in a collaborative manner with healthcare professionals. Such collaboration would enable the identification of a discharge plan that reconciles older adult and family member preferences with healthcare professional recommendations, thereby enabling a client-centered approach within the limitations of available services. Such an approach could theoretically uphold older adults’ agency, autonomy and wellbeing while also meeting professional and institutional aims of maximizing older adults’ function. The achievement of rehabilitation goals aiming to maximize function could furthermore reduce readmission rates and the overall demand for limited healthcare resources. In what follows I sketch out changes in practice that might be suggested by a relational approach to discharge planning and more broadly to the provision of health care. As I discussed above, the relational approach I outline has some overlaps with client-centred care and since this is a more familiar framework for professionals, I make reference to these overlaps while at the same time reframing its parameters.\footnote{It is acknowledged that the term ‘client-centered’ can be perceived to be contrary to the tenets of relational autonomy theory in that the terminology is suggestive of having \emph{one} individual client and does not suggest a relational conception of individuals. While some disciplines such as occupational therapy (Townsend et al., 2007) make the effort of defining the client as potentially including more than one individual (for example a family, group or community), such connotations are not readily apparent in this terminology. A more thorough discussion regarding phrasing of this concept is reserved for a forum other than this thesis.}

**Changing processes to maximize participation in discharge planning**

Primarily, a relational approach to discharge planning would involve the formulation of processes that maximize older adult and family participation and input in discharge planning. Healthcare professionals reported being client-centred in considering older adults’ preferences but then also reported working mainly with families instead of the older adults. At the same time, they reported their recommendations to be the determining factor in discharge planning and family involvement was reduced to carrying out the healthcare professionals’ recommendations. On the other hand, older adults and their families felt that they, as older adults facing discharge in conjunction with their family members, made decisions for discharge and healthcare professionals at best provided advice that older adults and their families could choose to incorporate or ignore. All of these reports suggested disagreements in perceptions of the process, which indicated that not all individuals are provided with opportunities to contribute their
knowledge and expertise, and not all individuals who are being provided with opportunities are being heard.

From a relational perspective, individuals have been shaped by prior opportunities and may be seen to hold their own areas of expertise. Through a process of collaboration, individuals could be enabled to contribute their expertise and collectively identify discharge plans that are more accurately tailored to individuals’ unique intersections of needs, preferences, strengths and resources. The collaborative determination of such a plan is supported in the literature (Pearson et al., 2004) and would also align with by client-centered approaches. Opportunities to maximize older adult and family involvement could, for example, include changes to the format of the discharge planning family conference, which is intended to be the main forum for collaboration between all of the involved individuals. Examples of such changes might include having chairs around the room with a coffee table rather than a meeting table that separates healthcare professionals from other individuals. Setting up the room in this or a similar manner would suggest that all individuals are bringing valuable expertise to the meeting. Other changes could include eliciting from older adults and family members their goals and expectations of rehabilitation and for discharge prior to having healthcare professionals provide their assessment results and recommendations. Additionally, as has been outlined above, older adults and family members tended to practice joint decision making. Healthcare professionals could tailor their approach not only to enable collaboration with older adult and their families in discharge planning, but to work with the relational components inherent in older adults and family members deliberations. This may change the approach healthcare professionals take in their assessment practices or in their communication habits with older adults and family members. Such suggestions would be supported by the client-centred approach suggested in the seminal text edited by Gerteis and her colleagues (1993). The text promotes methods to include patients in the determination of care (p.19-44) and explores various considerations for communicating with patients in different healthcare situations (p. 72-95).

There are recent calls for further research to enable more collaboration between healthcare professionals, older adults and family members in planning for discharge (Efraimsson, 2006; Foss & Hofoss, 2011) and for a related shift in focus away from institutionally-driven values and towards older adults’ needs and well-being (Pearson, 2004). The practices suggested above are but some suggestions that would reflect a relational approach and would include the client as an
important collaborator in the discharge planning process, thereby reducing (or even eradicating) older adults’ marginalization in discharge planning.

**Managing safety**

In their accounts, healthcare professionals highly prioritized safety in all aspects of healthcare and discharge planning, which came at the expense of other considerations important to older adults. Unsurprisingly, there were contradictions between older adults’ wishes for discharge, which were focussed on returning home and having their own space, and healthcare professionals’ recommendations, which focussed on their perceived interpretation of best interests, which they equated to protecting older adults’ safety. Healthcare professionals’ professed to be aiming to practice in a client-centred manner, however, their understanding of client-centeredness was limited to upholding patient preferences and this was overshadowed by the prioritization of safety and beliefs that they were acting beneficently in protecting older adults. This conflict relates to the dignity of risk. In her commentary, Nay (2002) recognizes healthcare professionals’ tendency to maximize physical safety at the expense of all other considerations, and that this is often linked to protecting the hospital from potential liability. She argues however that removing the freedom to take physical risks does not uphold older adults’ autonomy and can engender psychological harm. Kane and Levin (1998) discuss risk-taking in home and community care and suggest an approach that includes collaborative contracts to “manage risks”. This approach is somewhat akin to informed consent; however it promotes collaboration and empowerment in order to identify solutions of compromise and does not suggest the ‘abandonment’ that at times accompanies informed decisions that do not align with healthcare providers’ recommendations. A relational and more collaborative approach to discharge planning suggests the determination of discharge plans that both uphold older adults’ preferences and align with professional values of protecting older adults’ physical safety while also providing a good fit between older adults’ abilities, needs and resources. Such plans align with definitions of client-centeredness in the literature (Brookman et al., 2011; Gerteis et al., 1993).

**Shifting the primary focus back to rehabilitation**

A relational approach in rehabilitation would mean helping individuals to articulate their rehabilitation goals if assistance is required, and providing interventions directed at meeting
these to maximize recovery and function upon discharge. This aspect of a relational approach fits directly with the stated aims of the rehabilitation unit in this setting and with dominant contemporary rehabilitation rhetoric (Bauer et al., 2009; Baycrest, 2013; Dal Bello-Haas & Tryssenaar, 2009; Jewish Rehabilitation Hospital (n.d.); Providence Healthcare, 2013; St-Joseph’s Health Care London, n.d.; Toronto Rehabilitation Institute, 2013). The findings indicated that in this setting, the early focus on discharge planning and the high focus on prioritizing safety reduced the rehabilitation process to a process of destination triage rather than one where the focus was on maximizing function and quality of life upon discharge. Time was spent on assessments to inform recommendations for discharge before interventions to maximize function could occur. Individuals were therefore not being given a chance to work on rehabilitation and maximizing their function in preparation for discharge. Several limitations, practices and processes contributed to this reduction. The primary contributing factors in this setting included a set length of stay, the convention of focusing on discharge from the point of admission and the practice of identifying discharge recommendations and plans within two weeks of admission to rehabilitation. These could be modified and rectified using a relational approach as I now describe.

**Tailored length of stay**

In this setting, there was a set length of stay, which was primarily determined by funding formulas. Similar conventions and funding formulas exist in other rehabilitation centres in the same city. The application of a blanket four-week length of stay inhibited the aim of maximizing function. Both relational and client-centred approaches would suggest a rehabilitation focus on identifying individuals’ unique needs in relation to their strengths, resources and circumstances in order to identify their goals and maximize individual function and that was tailored to their circumstances. With respect to lengths of stay, such approaches could include flexible lengths of stay enabling individuals to recover based on their own needs and capabilities rather than a predetermined timeline. Increased function may not only improve older adults quality of life, and therefore that of their family members, but it may also reduce the amount of care required by older adults upon discharge and may reduce the number of readmissions following discharge. It is acknowledged that lengths of stay are determined by policies at various levels and are restricted by limited resources; however, shortened lengths of stay limit rehabilitation potential
and may be contributing to future increased healthcare demand through readmissions or care that could otherwise not have been needed. Further research is required to determine the financial impact to the healthcare system on the whole of having shortened lengths of stay. Such research would inform policy changes to recommended lengths of stay and to changes in the healthcare systems’ intended delivery of care to better meet the needs of older adults as well as resource-limited healthcare systems.

**Scheduling the family conference and determining discharge recommendations later in the inpatient rehabilitation stay**

In this setting, on the day of admission the discharge planning family conference and discharge date were scheduled. This scheduling meant that healthcare professionals were rushed to complete their assessments and determine discharge recommendations early on at the expense of spending time working on interventions aimed at increasing rehabilitation, recovery and ultimately functional abilities. Furthermore, recommendations made by healthcare professionals during this time were based on a prognosis made at a time when individuals may not have recovered a level of function enabling them to fully participate in either assessment or rehabilitation. The findings indicated that the practice of making discharge recommendations early often resulted in recommendations for 24-hour care, even in instances where outcomes showed this was overly precautionary and ended up being unnecessary. Forcing individuals to make discharge plans early in admission and often prior to a time when a more accurate prognosis can be made, may ensure a faster turnover of individuals in rehabilitation, but may also result in discharge plans based on a lower level of function than they will eventually achieve. This is an impediment to autonomous choices as not all of the information is available to individuals when forced to make a decision. Older adults’ needs are therefore being overshadowed by institutional and financial priorities. Such practices conflict with both client-centred and relational approaches. It is understood that healthcare services are offered within the limitations of available resources and particularly in a limited timeframe; however, different options could be considered to postpone discharge decision-making to a time when individuals have had sufficient time to recover and a more realistic prognosis could be made.

Taking a client-centred and relational approach incite the scheduling of discharge planning recommendations to be made following interventions to provide rehabilitation and maximize
function, and at a time that would provide a more accurate picture of individuals’ capabilities and needs upon discharge. While delaying discharge decisions may leave less time to set up discharge services, the benefits of taking a relational approach and identifying a better fit between the individuals’ needs and discharge plans may outweigh the costs of the instances where the discharge is delayed due to a short period of time in which to set up discharge circumstances. Other suggestions to delay longer term discharge plans could include such programs as a Home First\textsuperscript{18} program such as that implemented by the North East Local Health Integration Network of Ontario (NE LHIN, 2011), however, further research is required to inform the implementation of such services and programs.

**Increasing discharge care options**

As has been discussed, in the data healthcare professionals frequently made the recommendation for older adults to receive 24-hour care upon discharge. Healthcare professionals reported that this recommendation was encouraged by the prioritization of safety as well as limitations in publicly-funded home and community care services, which promoted live-in or long-term care as more affordable options. A relational approach suggests consideration of how political and institutional structures limit or enable options for choice and behaviours. While it was not the focus of this research to examine the structure, efficiency or financial costs associated with healthcare services, the limited options for care upon discharge and the costs associated with these were found to influence discharge planning perspectives, behaviours and recommendations. Further research would again be required to determine the impact of community healthcare services on demands for inpatient care and patient transitions between the two.

**Attitudes about aging**

A final consideration in taking a relational approach to discharge planning with older adults is that of addressing underlying beliefs related to aging identified in this work. Various

\textsuperscript{18} The Home First program was designed to send individuals awaiting long-term care placement home with maximal publicly-funded assistance until they were found a place in long-term care. The costs of waiting for placement at home are less than would be incurred in acute care (NELHIN, 2011). If individuals were permitted to go home to convalesce with full services for a period of time they may be able to begin rehabilitation later in their recovery. Literature describing this program outlined that healthcare provided through this program could include physicians, nurses and allied health professionals, however how much care was provided was not indicated.
assumptions linking aging to a loss of agency, to decreased participation in activities and to declining cognitive capacities were reproduced or resisted by all participants. While individuals may experience changes related to aging, these are unique to each person and should not be assumed. Assumptions about older adults as inevitably in decline are contrary to both client-centred and relational approaches. Nonetheless, such assumptions influenced recommendations and behaviours in discharge planning. A relational approach to discharge planning would explore older adult’s capabilities, strength and resources and have these instead of stereotypical assumptions guiding the discharge plan. In the broader context of rehabilitation education, advocacy and research, it also suggests the need to explore contextual drivers of such beliefs and assumptions, as well as efforts to change these perceptions. One such existing project is the work of the National Institute for the Care of the Elderly (NICE) in Canada. A project was launched by this group in October 2012 to highlight one picture per day on the internet and to tag it with terms related to aging in order to challenge negative perceptions of aging and present a more realistic view of the experience of aging (NICE, 2013; http://www.engaged.is/). These images are being selected by a specific group of individuals who are promoting their own discourses of aging, which could potentially have as many issues as the ones I am contesting in this text; however, by portraying a different perspective and inviting discussion through workshops and social media, the site challenges current assumptions and incites others to challenge those for themselves.

The suggested changes to practice together sketch out a relational approach to discharge with older adults that works to uphold older adults’ unique perspectives, values and preferences in discharge planning and address their marginalization. Additionally, these changes would uphold the stated aim of rehabilitation to maximize function.

8.3 Theoretical and methodological implications and limitations, and avenues for future research

In the study, the critical bioethics perspective informed by relational autonomy theory complemented the use of microethnographic case study methodology (Willis, 2007). Microethnographic case studies enable the examination of a phenomenon within a specific context and through a focus on the experiences, perspectives and behaviours of one or a small number of individuals (Willis, 2007). Critical bioethical approaches engender the examination of social and political influences on phenomena through the lens of a bioethical theory.
Relational autonomy theories are based on the idea that individuals are socially embedded within, and are indivisible from, the different layers of their contexts (MacKenzie & Stoljar, 2000; Sherwin 1998). The use of this perspective, methodology and specific theory enabled an in-depth examination of the discharge planning process within the social, political and institutional context and allowed for an exploration of various influences on the individual behaviours and perspectives of older adults, family members and clinicians.

The strength my critical perspective was how it enabled the excavation of underlying beliefs, valued approaches and local conventions that were influencing discharge planning processes. The approach further incited an exploration of how these influences co-constituted one another to reinforce and reproduce each other. This approach brought to light how the intersection of the various systems of thoughts, norms and expectations influenced interpersonal dynamics that shaped the discharge planning process itself, as well as the experience and outcomes of the process for older adults, their family members and healthcare professionals. This approach enabled the examination of how discourses and conventional processes promoted attitudes and practices that encouraged the marginalization and oppression of older adults and the prioritization of systemic and institutional values over the values, needs and preferences of the older adults the healthcare system purports to serve. Research taking a critical bioethics perspective informed by relational autonomy to discharge planning has not been conducted before and therefore this study makes a unique contribution to knowledge.

The use of a microethnographic approach with multiple data sources for each case in conjunction with a critical bioethics perspective enabled an in-depth examination of the different influences on individual perspectives, choices and behaviours and how these manifested in dynamics and interactions in discharge planning to shape outcomes. A better understanding of such dynamics can inform healthcare approaches and practices that better promote older adults agency and participation in discharge planning and uphold relational approaches as taken by older adults and their family members.

A final contribution of this work is in providing an example of empirical critical bioethics research using a relational approach. To date, no empirical studies have been identified that take a relational approach to research with older adults and only one empirical study (Moser et al., 2010) was found that examined the implications for clinical practice with older adults. Other
research and scholarship in the area of relational autonomy has been theoretical in nature or has used ‘relational autonomy’ to mean merely family involvement. The present study therefore presents a novel methodology for conducting research with older adults.

Like all ethnographies, this study was limited to one institutional setting in one urban centre in Canada. Further research to examine discharge planning in different healthcare institutions, urban/rural areas, and provinces would enable comparison to determine if the findings of this study have similarities with other settings. An examination of the similarities and differences would provide more information about how the discharge planning process and related decision-making practices are approached, perceived and experienced by the various individuals involved within the Canadian healthcare system. Research including different settings could more soundly inform the formulation of processes and policies to meet the varied individual needs of all stakeholders involved or invested in discharge planning processes. Such processes could then both shape and adapt to conventions in their settings depending on the needs of individuals and of particular settings.

The study participants were generally from a higher socio-economic status. The affluence of older adult patients in the research setting may also have affected the types of recommendations made by healthcare professionals. In my experience working as an occupational therapist in an older adult inpatient rehabilitation setting, because individuals seldom were able to afford 24-hour care, our team infrequently made this recommendation and opted for less costly options and higher family support. Research in a different healthcare setting and with individuals having varied socioeconomic statuses would again provide more information about individual expectations, perspectives and behaviours in the process and could provide information that may be informative in different settings and populations.

A third limitation of the study is that while the five older adult participants were all of different cultural backgrounds and I attempted to recruit a balanced number of male and female older adult and family member participants, (I had less freedom in the recruitment of the healthcare professionals) the sample was too small to evaluate gender and cultural influences, roles or expectations. Although an examination of cultural or gender influences in discharge planning was not a goal of the study, discharge planning is the phenomenon of deciding what will be an individual’s home and living circumstances; one’s expectations of the physical and
social home environment are at least in part influenced by cultural or gender roles and expectations, as are expectations of the roles and living situations of family members. Future research about discharge planning that included the role of gender and culture would thus make a valuable contribution to the growing body of research in this area.

A final limitation relates to the window of time on which the research was focussed. While my research was focussed on the process of making decisions and could as such inform policies and practices to guide a more relational approach, information about how discharge plans turn out, which decisions were helpful and which were overturned would further inform the process. Future research linking process to outcomes would also be valuable.

8.4 Conclusion

The use of a critical bioethics perspective informed by relational autonomy theory has illuminated contextual-specific beliefs and practices that influence the perceptions and behaviours, and ultimately the outcomes of the complex process of discharge planning with older adults. In this research I have identified and explored underlying beliefs about the primacy of healthcare professionals’ knowledge and authority to determine the best course of action. Moreover, I have uncovered assumptions from the perspectives of all participants linking aging to a decline in cognitive abilities, to decreased participation in activities and to a loss of agency and related increase in dependence on younger family members. Explicitly valued approaches guiding healthcare professional behaviours and recommendations included the prioritization of safety and a largely unrealized professed aim to take a client-centred approach. Setting-specific conventions and practices influencing the experience and outcomes of the process included consideration of discharge from the moment of admission and a strict adherence to a specified timeline in consequence of a set discharge date, as well as norms for the process of the discharge planning family conference. The intersection of these varied elements resulted in discharge planning recommendations that prioritized institutional and societal norms of expediency in healthcare and the prioritization of safety at the expense of rehabilitation processes aimed at maximizing function and tailored discharge plans made in collaboration with older adults’ and their families aimed to uphold their preferences and maximize quality of life. Taking a relational approach to research and clinical practice challenges us to look closely at the social, political and institutional structures that may have become invisible but that mediate the beliefs and practices
of professionals and clients, and to consider individuals in their unique contexts in order to determine a discharge plan to meet their unique capacities and needs.

Going back to my experience at L’Arche, while the power differentials could not be eliminated, relational interactions were evident in all aspects of daily life. Individuals’ agency was upheld and their strengths and contributions were valued and promoted. I acknowledge that the L’Arche model may not fit all aspects of the health care we attempt to provide, however, the people at L’Arche may provide a fine example of relational care after which healthcare systems could be modelled.
References


Kane, R. (2011). Finding the right level of post hospital care “We didn’t realize there was any other option for him”. *Journal of American Medical Association, 305*(3), 284-293.


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Appendices

Appendix 1 – Letter of information for older adult patients at Institution

[Institution letterhead]

Participant Information
Older adult patients at Institution

Before agreeing to participate in this research study, it is important that you read and understand this research consent form. This form provides all the information we think you will need to know in order to decide whether you wish to participate in the study. If you have any questions after you read through this form, I can answer your questions. You should not sign this form until you are sure you understand everything on this form. You may also wish to discuss your participation in this study with a family member or close friend.

**Title of Study:** Discharge planning with older adults: The influence of social, cultural and political systems and practices

**Principal Investigator:**
Evelyne Durocher, PhD candidate, Graduate Department of Rehabilitation Sciences, University of Toronto, (416) 946-3953 evelyne.durocher@utoronto.ca

**Student supervisors:**
Dr. Barbara Gibson, PT, PhD, Department of Physical Therapy, University of Toronto
Dr. Susan Rappolt, OT Reg. (Ont.), PhD Department of Occupational Science and Occupational Therapy, University of Toronto

**Contact at Institution:**
[Name] Program Director, Rehabilitation and Geriatric Assessment, Institution
[Contact information]

**Purpose of the Study**
In this study I want to find out what is influencing decisions in the process of discharge planning with older adults who are preparing to leave inpatient rehabilitation. Many individuals are involved in the discharge-planning process. Most commonly, these include the older adult preparing for discharge, his or her family members, and the healthcare providers. Each of these individuals may have a different perspective on what is the “best” plan for discharge. The goal of this study is to explore what opinions, values, ideas and concerns are guiding decision making.
**Description of the research and your role in the study**

As part of your care here at [Institution], you, your family members and your healthcare team are going to have a meeting to plan for your discharge from [Institution]. If you participate in this study, I will silently observe this meeting. After that, only in relation to the study, I will interview you, one or two of your family members who were at the meeting and one or two members of your healthcare team. I will ask questions about what is important to each person in this process of planning for discharge and planning to leave the hospital; what is important to have in the place where you will go after you leave inpatient care; and how you feel about what your family members and the healthcare professionals were saying during the meeting. You can skip any of the questions that you do not want to answer and we can stop at any time. The interview will take about 30-60 minutes. It will be audio-recorded and later typed out word for word so that I have a record of what you said. What you say in the interview is completely confidential and no one except myself and the researcher team will know what you have said. How we protect your confidentiality is described in more detail below.

Participation in this study would in no way affect your care here at [Institution].

**Potential benefits**

Although you will not directly benefit from participation in this study, you will have the opportunity to contribute to the development of ethical guidelines for discharge-planning processes. Facilitating and improving discharge-planning processes can benefit individuals who will be experiencing discharge planning in the future and can help to ease the demand on our healthcare systems.

**Potential harms and discomforts**

There are no known harms associated with participation in this study. However, talking about your personal life can sometimes make people feel discouraged or down. It’s a good idea to have someone, like a close friend or family member, to talk to after your interview. There is a small chance that being in the study will be very upsetting. If you feel troubled at any time during or after the study, please tell me. We can take a break, schedule a follow-up interview or stop altogether. I will provide you with suggestions for support if you want, or help to arrange for a referral for counselling. You can choose to skip any of the interviews questions. You can drop out of the study at any time.

**Confidentiality**

Confidentiality will be respected and no information that discloses your identity or your family will be released or published without consent unless required by law.

Only the investigator team will have access to your personal information. The typed notes from your interview will not include your name or any other identifying information.
The digital recording of your interview will be stored on a secured computer and no one will have access to it except the research team.

Nothing that reveals your identity will be shown to anyone without your permission except if required by law. These laws include things such as suspected abuse or risk of suicide. In these cases, research documents may be ordered by a court of law, or researchers may be required to report information to the police or other authorities.

**Publication of results**
No information that identifies you will appear in any report or publication of the results of the study.

**Participation and withdrawal**
Your participation in this study is voluntary. If you choose not to participate, you will continue to have access to customary care at [Institution]. If you choose to participate in this study, you can withdraw at any time. You can choose not to answer any questions. If you do withdraw from the study you will have the option of having any or all of the information you shared up to that point excluded from the study.

In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

An information sheet with a summary of the results of the study can be sent to you upon completion of the study if you wish. In this case, we would be required to keep a record of your name and contact information. This would be kept in a file separate from the data and would not link you to the data.

**Honorarium**
In recognition of your time and contribution you will receive a $10 gift card at the completion of your interview.

**Questions**
Please feel free to ask any questions. You may contact Evelyne Durocher at 416-946-3953, evelyne.durocher@utoronto.ca.

If you have questions about your rights as a research participant you may contact [Name], Chair of the Research Ethics Board at [Institution] [contact information]
CONSENT FORM

This study has been explained to me. I have read the study information sheet and all of my questions have been answered. I know that I can ask questions about this study after I sign this form and that they will be answered. A copy of this form will be provided to me.

I understand what this study is about.

I understand the potential risks and benefits of participating in this study.

I understand that my confidentiality will be maintained.

I understand that my interview will be digitally audio-recorded.

I understand that I may drop out of the study at any time.

I agree to participate in this study.

I would like a summary of the results upon study completion □yes □no

I have been given a copy of this signed consent form.

Participant’s Name (please print) __________________________ Signature __________________________ Date ____________

Witness (if participant cannot sign) (please print) __________________________ Signature __________________________ Date ____________

Name of person obtaining consent __________________________ Signature __________________________ Date ____________
Appendix 2 – Letter of information for family members at [Institution]

[Institution letterhead]

Participant Information
Family members

Before agreeing to participate in this research study, it is important that you read and understand this research consent form. This form provides all the information we think you will need to know in order to decide whether you wish to participate in the study. If you have any questions after you read through this form, I can answer your questions; you should not sign this form until you are sure you understand everything on this form. You may also wish to discuss your participation in this study with a family member or close friend.

**Title of Study:** Discharge planning with older adults: The influence of social, cultural and political systems and practices

**Principal Investigator:**
Evelyne Durocher, PhD candidate, Graduate Department of Rehabilitation Sciences, University of Toronto, (416) 946-3953, evelyne.durocher@utoronto.ca

**Student supervisors:**
Dr. Barbara Gibson, PT, PhD, Department of Physical Therapy, University of Toronto
Dr. Susan Rappolt, OT Reg. (Ont.), PhD Department of Occupational Science and Occupational Therapy, University of Toronto

**Contact at Institution:**
[Name] Program Director, Rehabilitation and Geriatric Assessment, Institution
[Contact information]

**Purpose of the Study**
In this study I want to find out what is influencing decisions in the process of discharge planning with older adults who are preparing to leave inpatient rehabilitation. Many individuals are involved in the discharge-planning process. Most commonly, these include the older adult preparing for discharge, his or her family members, and the healthcare providers. Each of these individuals may have a different perspective on what is the “best” plan for discharge. The goal of this study is to explore what opinions, values, ideas and concerns are guiding decision making.
Description of the research and your role in the study
As part of your family member’s care here at [Institution], you, your family member and your healthcare team are going to have a meeting to plan for your discharge from [Institution]. If you participate in this study, I will silently observe this meeting. After that, only in relation to the study, I will interview you, your family member here at [Institution], maybe one other of your family members who was at the meeting, as well as one or two members of the healthcare team caring for your family member here at [Institution]. I will ask questions about what is important to each person in this process of planning for your family member’s discharge from [Institution]; what is important to have in the place where your family member will go after he or she leaves inpatient care; and how you feel about what your family members and the healthcare professionals were saying during the meeting. You can skip any of the questions that you do not want to answer and we can stop at any time. The interview will take about 30-60 minutes. It will be audio-recorded and later typed out word for word so that I have a record of what you said. What you say in the interview is completely confidential and no one except me and the researcher team will know what you have said. How we protect your confidentiality is described in more detail below.
Participation in this study would in no way affect your family member’s care here at [Institution].

Potential benefits
Although you will not directly benefit from participation in this study, you will have the opportunity to contribute to the development of ethical guidelines for discharge-planning processes. Facilitating and improving discharge-planning processes can benefit individuals who will be experiencing discharge planning in the future and can help to ease the demand on our healthcare systems.

Potential harms and discomforts
There are no known harms associated with participation in this study. However, talking about your personal life can sometimes make people feel discouraged or down. It’s a good idea to have someone, like a close friend or family member, to talk to after your interview. There is a small chance that being in the study will be very upsetting. If you feel troubled at any time during or after the study, please tell me. We can take a break, schedule a follow-up interview or stop altogether. I will provide you with suggestions for support if you want, or help to arrange for a referral for counselling. You can choose to skip any of the interviews questions. You can drop out of the study at any time.

Confidentiality
Confidentiality will be respected and no information that discloses your identity or your family will be released or published without consent unless required by law.
Only the investigator team will have access to your personal information. The typed notes from your interview will not include your name or any other identifying information. The digital recording of your interview will be stored on a secured computer and no one will have access to it except the research team.

Nothing that reveals your identity will be shown to anyone without your permission except if required by law. These laws include things such as suspected abuse or risk of suicide. In these cases, research documents may be ordered by a court of law, or researchers may be required to report information to the police or other authorities.

**Publication of results**
No information that identifies you will appear in any report or publication of the results of the study.

**Participation and withdrawal**
Your participation in this study is voluntary. If you choose not to participate, you will continue to have access to customary care at [Institution]. If you choose to participate in this study, you can withdraw at any time. You can choose not to answer any questions. If you do withdraw from the study you will have the option of having any or all of the information you shared up to that point excluded from the study.

In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

An information sheet with a summary of the results of the study can be sent to you upon completion of the study if you wish. In this case, we would be required to keep a record of your name and contact information. This would be kept in a file separate from the data and would not link you to the data.

**Honorarium**
In recognition of your time and contribution you will receive a $10 gift card at the completion of your interview.

**Questions**
Please feel free to ask any questions. You may contact Evelyne Durocher at 416-946-3953, evelyne.durocher@utoronto.ca.

If you have questions about your rights as a research participant you may contact [Name], Chair of the Research Ethics Board at [Institution].
CONSENT FORM

This study has been explained to me. I have read the study information sheet and all of my questions have been answered. I know that I can ask questions about this study after I sign this form and that they will be answered. A copy of this form will be provided to me.

I understand what this study is about.

I understand the potential risks and benefits of participating in this study.

I understand that my confidentiality will be maintained.

I understand that my interview will be digitally audio-recorded.

I understand that I may drop out of the study at any time.

I agree to participate in this study.

I would like a summary of the results upon study completion □yes □ no

I have been given a copy of this signed consent form.

_____________________________  ______________________  ____________
Participant’s Name (please print)  Signature  Date

_____________________________  ______________________  ____________
Witness (if participant cannot sign) (please print)  Signature  Date

_____________________________  ______________________  ____________
Name of person obtaining consent  Signature  Date
Appendix 3 – Letter of information for healthcare professionals at [Institution]

[Institution letterhead]

Participant Information
Healthcare Providers at [Institution]

Before agreeing to participate in this research study, it is important that you read and understand this research consent form. This form provides all the information we think you will need to know in order to decide whether you wish to participate in the study. If you have any questions after you read through this form, I can answer your questions. You should not sign this form until you are sure you understand everything on this form. You may also wish to discuss your participation in this study with a family member or close friend.

**Title of Study:** Discharge planning with older adults: The influence of social, cultural and political systems and practices

**Principal Investigator:**
Evelyne Durocher, PhD candidate, Graduate Department of Rehabilitation Sciences, University of Toronto, (416) 946-3953, evelyne.durocher@utoronto.ca

**Student supervisors:**
Dr. Barbara Gibson, PT, PhD, Department of Physical Therapy, University of Toronto
Dr. Susan Rappolt, OT Reg. (Ont.), PhD Department of Occupational Science and Occupational Therapy, University of Toronto

**Contact at Institution:**
[Name] Program Director, Rehabilitation and Geriatric Assessment, Institution
[Contact information]

**Purpose of the Study**
In this study I want to find out what is influencing decisions in the process of discharge planning with older adults who are preparing to leave inpatient rehabilitation. Many individuals are involved in the discharge-planning process. Most commonly, these include the older adult preparing for discharge, his or her family members, and the healthcare providers. Each of these individuals may have a different perspective on what is the “best” plan for discharge. The goal of this study is to explore what opinions, values, ideas and concerns are guiding decision making.
Description of the research and your role in the study
As part of your provision of care here at [Institution], you participate in discharge-planning conferences. If you participate in this study, I will silently observe this meeting. After that, only in relation to the study, I will interview you, the older adult, one or two of the older adult’s family members and potentially one other member of the healthcare team. I will ask questions about what is important to each person in this process of planning for discharge and planning to leave the hospital; what is important to have in the place where the older adult will go after leaving inpatient care; and how you feel about what the older adult, his or her family members and the other healthcare professionals were saying during the meeting. You can skip any of the questions that you don’t want to answer or we can stop at any time. The interview will take about 30-60 minutes. It will be audio-recorded and later typed out word for word so that I have a record of what you said. What you say in the interview is completely confidential and no one except myself and the researcher team will know what you have said. How we protect your confidentiality is described in more detail below.

Potential benefits
Although you will not directly benefit from participation in this study, you will have the opportunity to contribute to the development of ethical guidelines for discharge-planning processes. Facilitating and improving discharge-planning processes can benefit individuals who will be experiencing discharge planning in the future and can help to ease the demand on our healthcare systems.

Potential harms and discomforts
There are no known harms associated with participation in this study. However, talking about your personal life can sometimes make people feel discouraged or down. It’s a good idea to have someone, like a close friend or family member, to talk to after your interview. There is a small chance that being in the study will be very upsetting. If you feel troubled at any time during or after the study, please tell me. We can take a break, schedule a follow-up interview or stop altogether. I will provide you with suggestions for support if you want, or help to arrange for a referral for counselling. You can choose to skip any of the interviews questions. You can drop out of the study at any time.

Confidentiality
Confidentiality will be respected and no information that discloses the identity of the subject will be released or published without consent unless required by law.

Only the investigator team will have access to your personal information. The typed notes from your interview will not include your name or any other identifying information. The digital recording of your interview will be stored on a secured computer and no one will have access to it except the research team.
Nothing that reveals your identity will be shown to anyone without your permission except if required by law. These laws include things such as suspected abuse or risk of suicide. In these cases, research documents may be ordered by a court of law, or researchers may be required to report information to the police or other authorities.

**Publication of results**
No information that identifies you will appear in any report or publication of the results of the study.

**Participation and withdrawal**
Your participation in this study is voluntary. If you choose not to participate, you will continue to have access to customary care at [Institution]. If you choose to participate in this study, you can withdraw at any time. You can choose not to answer any questions. If you do withdraw from the study you will have the option of having any or all of the information you shared up to that point excluded from the study.

In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

An information sheet with a summary of the results of the study can be sent to you upon completion of the study if you wish. In this case, we would be required to keep a record of your name and contact information. This would be kept in a file separate from the data and would not link you to the data.

**Honorarium**
In recognition of your time and contribution you will receive a $10 gift card at the completion of your interview.

**Questions**
Please feel free to ask any questions. You may contact Evelyne Durocher at 416-946-3953, evelyne.durocher@utoronto.ca.

If you have questions about your rights as a research participant you may contact [Name], Chair of the Research Ethics Board at [Institution] [contact information]
CONSENT FORM

This study has been explained to me. I have read the study information sheet and all of my questions have been answered. I know that I can ask questions about this study after I sign this form and that they will be answered. A copy of this form will be provided to me.

I understand what this study is about.

I understand the potential risks and benefits of participating in this study.

I understand that my confidentiality will be maintained.

I understand that my interview will be digitally audio-recorded.

I understand that I may drop out of the study at any time.

I agree to participate in this study.

I would like a summary of the results upon study completion □yes □no

I have been given a copy of this signed consent form.

__________________________________________________________________________  ____________________________________________________________________________  ___________
Participant’s Name (please print)  Signature  Date

__________________________________________________________________________  ____________________________________________________________________________  ___________
Witness (if participant cannot sign) (please print)  Signature  Date

__________________________________________________________________________  ____________________________________________________________________________  ___________
Name of person obtaining consent  Signature  Date
Appendix 4 – Recruitment script

Recruitment script to be read by the [Institution] healthcare team member appointed to assist with recruitment:

I am visiting you today on behalf of a graduate student at U of T who is conducting a research study about the process of discharge planning. The purpose of this study is to explore the different perspectives of individuals in discharge planning, so the views of the older adult being discharged, one or two of his or her family members and one or two of his or her healthcare professionals, in the hopes of gaining a better understanding of what each person is bringing to the table. The results of this study could help to improve discharge-planning processes in the future.

She is wondering if she could come visit you to describe her project and ask if you would be interested in participating.

Your participation is entirely voluntary and whether or not you choose to participate will not affect your care here at [Institution] or anywhere else.

She can explain to you more what your participation would entail, but essentially, she would like to attend the family conference we are having on Wednesday, and then she would come to interview you about what was decided during the meeting. She would also talk to one or two of your family members who come to the meeting and to one or two of us on the team.

Would it be okay with you for her to talk to you about her project? This doesn’t mean that you have to participate, only that she will come talk to you about the project.

Again, whether you say yes or no will make no difference at all to the care you receive.
Appendix 5 – Data collection form for participants

Case study number:
Date of family conference:

For older adults
Name: Pseudonym:
Gender: Year of birth:
Length of time since initial admission:
Reason for admission:
Primary diagnosis:
Secondary diagnosis:
Ethnocultural group:
Religion:
Name of involved family member:
Name of second involved family member if applicable:
Name of involved healthcare professional:
Name of second involved healthcare professional if applicable:

For family members:
Name: Pseudonym:
Contact information:
Relationship to older adult:

For healthcare professionals:
Name: Pseudonym:
Contact information:
Profession:
Years of experience in this profession:
Role in discharge planning:
Length of time caring for this older adult:
Appendix 6 - Interview guide for older adult patient

Hello, it’s nice to see you again. It seems busy here today (or some comment about the weather or flowers in their room or something to open conversation).

I’m here today to ask you a few questions about the meeting with your family and the healthcare team yesterday. I’m hoping to find out a bit more about what is behind the decision to go to (discharge location) for you. Is that okay with you?

I just want you to know that this is completely voluntary and if at any point you feel uncomfortable or you want to stop, that’s perfectly fine.

I also want you to know that what we discuss today is completely confidential. I will not be going and reporting anything that you say to your family or to the doctors or nurses or anyone else. I will be using this information for my research project, but there will not be any way to identify you in my work. I will be changing names and ages and small details to make sure there is no way to guess who is involved.

Is it okay then if we start talking?

In preparing to leave rehab, you have likely heard the phrase “discharge planning”, what does this mean to you?

Can you tell me about your experience of discharge planning?

Probes –Who has been involved in this process?

- What did each person do?
- Did they help? Why or why not? How?
- Do you feel you have been involved?

How did you feel about the discharge-planning family meeting yesterday?

Do you think that the decision made at the meeting was a good one? Why or why not?

- How do you feel about that?

There were several options discussed. What did you think of that option?

Why is (discharge location) decided as the best place to go?

When you think about going to (discharge location), how does it make you feel?

Probe more – What part of it is more (whatever they said)?

(If different than what they wanted) You said that you wanted (what they wanted). Can you tell me more about that?

What is it about going to (what they wanted) that is so important to you?


When you think about (other option), how does that make you feel?

Where one lives affects who is around them (for example do they live alone or with family, who are the neighbours and so on), what one has to do during the day (so does one have to go up stairs? Is there an upstairs? Does one have to do laundry? Make food? Get dressed on their own or is someone there to help?) and how those things get done (so again, is someone making the food or are you making it?) What would be things that are important to you where you live?
Your (family member) was saying (what they were saying). How do you feel about that?
The (healthcare provider) was saying (what they were saying). What did you think about that?
   How did that make you feel?
Ask if there is something that we haven’t covered that they might want to add or that they might
   think could be helpful to me in this research project.
Ask if they have any questions for me,
Ask demographic information
Thank them!
Appendix 7 - Interview guide for patient’s family member

Hello, it’s nice to see you again. How are you today?
I’m here today to ask you a few questions about the meeting with your (family member) and the healthcare team yesterday. I’m hoping to find out a bit more of what is behind the decision to go to (discharge location). Is that okay with you?
I just want you to know that this is completely voluntary and if at any point you feel uncomfortable or you want to stop, that’s perfectly fine.
I also want you to know that what we discuss today is completely confidential. I will not be going and reporting anything that you say to your (family member) or to the doctors or nurses or anyone else. I will be using this information for my research project, but there will not be any way to identify you in my work. I will be changing names and ages and small details to make sure there is no way to guess who is involved.
Is it okay then if we start talking about the plan for your (family member) to go (discharge location)?
In preparing for your (family member) to leave rehab, you have likely heard the phrase “discharge planning”, what does this mean to you?
Can you tell me about your experience of discharge planning for your (family member)?
Probes – Who has been involved in this process?
- What did each person do? How did they help?
- How do you feel you have been involved?
- How do you feel your (family member) has been involved?
In the discharge-planning family meeting yesterday it was decided that your (family member) is going to go to (discharge location), how do you feel about that?
Why is that the best place for (family member) to go?
When you think about your (family member) going to (discharge location), how does it make you feel?
Probe more – What part of it is more (whatever they said)?
(If different than what they wanted) You said that you wanted (what they wanted). Can you tell me more about that?
What is it about your (family member) going to (what they wanted) that is so important to you?
When you think about (other option), how does that make you feel?
Where one lives affects who is around them (for example do they live alone or with family, who are the neighbours and so on), what one has to do during the day (so does one have to go up stairs? Is there an upstairs? Does one have to do laundry? Make food? Get dressed on their own or is someone there to help?) and how those things get done (so again, is someone making the food or are you making it?) What would be things that are important to you where you live?
What would be things that are important to you about where your (family member) lives?
Your (family member) was saying (what they were saying). How do you feel about that?
The (healthcare provider) was saying (what they were saying). What did you think about that?
Ask if there is something that we haven’t covered that they might want to add or that they might think could be helpful to me in this research project.

Ask if they have any questions for me,

Ask demographic information

Thank them!
Appendix 8 - Interview guide for healthcare professional

Hello, how are you today?

I’m here today to ask you a few questions about the discharge-planning conference with (patient and family) yesterday. I’m hoping to find out a bit more of what is behind the decision to go to (discharge location). Is that okay with you?

I just want you to know that this is completely voluntary and if at any point you feel uncomfortable or you want to stop, that’s perfectly fine.

I also want you to know that what we discuss today is completely confidential. I will not be going and reporting anything that you say to your (family member) or to the doctors or nurses or anyone else. I will be using this information for my research project, but there will not be any way to identify you in my work. I will be changing names and ages and small details to make sure there is no way to guess who is involved.

Is it okay then if we start?

What does discharge planning mean to you?

How does the process work here?

- What is your role in discharge planning?
- What are other people’s roles?
  - How do you feel (the patient) has been involved?
  - How do you feel (the patient’s family member) has been involved?

Good discharge/bad discharge

In the discharge-planning conference yesterday it was decided that (patient) is going to go to (discharge location), how do you feel about that?

Why is that the best place for (patient) to go?

(If different than what they recommended) You said that you were recommending (what they recommended). Can you tell me more about that?

What do you think about (other options)?

Where one lives affects who is around them (for example do they live alone or with family, who are the neighbours and so on), what one has to do during the day (so does one have to go up stairs? Is there an upstairs? Does one have to do laundry? Make food? Get dressed on their own or is someone there to help?) and how those things get done (so again, is someone making the food or are you making it?) What would be things that are important to you where you live?

What would be things that are important for (patient)?

(Patient) was saying (what they were saying). How do you feel about that?

The (family member) was saying (what they were saying). What did you think about that?

- Do you feel there are reasons why certain decisions get made over others that may not be related to the patient’s welfare?
  Important in a home for them

Client-centred care
Ethical issues
Ask if there is anything they would like to add that we haven’t covered or that they think would be helpful to me in this research project?
Ask if they have any questions for me.
Ask healthcare provider specific background information.
Thank them!
Appendix 9 – Questions guiding the analysis

A) Questions guiding narrative case reports

1. Summary of the case
2. Data matrix (included in Appendix 10)
3. Answers to questions asked of data
   3.1 What is the discharge plan in this case study? Why was this chosen? What was guiding this decision?
   3.2 What was, and what was guiding (social issues, values, assumptions, material issues, other), each person’s perspective?
   3.3 If with anyone’s, with whose perspective did the discharge plan most closely align?
   3.4 What was each person’s level of involvement in discharge planning? How does each person perceive their own role and that of others in this case?
   3.6 Are discourses depicted in each person’s perspective? If so, what are they and how are they represented?
   3.7 How are processes or practices guiding the discharge-planning process in this case?
   3.8 What power relations are at play? How are these visible? How do these intersect in the decision-making process?
   3.9 Did any of the participants experience ethical conflict? If so, what was the nature and root of the conflict?
4. Discussion of “themes” in this case
5. Memos written in this case
6. Things I wish I’d done differently in this case

B) First set of questions asked of the data across cases

1. Decision-making process
   a. Who thinks who is making the decision
   b. Tension between expressed wishes?
      i. The older adult may express one thing but act in another
   1. Not knowing anything about potential discharge locations, only knowing one’s home
2. Power relations? Not feeling like they should be making the decision?

3. Feeling of helplessness?

   ii. Family members may feel competing wishes/demands (own wishes for mom, own family demands, own limitations on how much help can offer, mom’s wishes, hcp recommendations etc.)

      1. Family members may have difficulty proceeding if their spouse/parent isn’t seeming to move on their wishes
      2. The family member’s wish may not match the older adult’s
      3. Guilt at having own wishes that are different than mom’s/dad’s

   iii. Power relations – hard for children to accept responsibility for decisions? Especially if decisions are different than older adult’s expressed wishes?

   iv. Differences between hcp recommendations and older adults’ or family members’ wishes

      1. How HCPs react to differences – paternalism? Disapproval?
      2. How family members or older adults react to HCPs’s recommendations
      3. Power relations between HCPs and older adults or family members

   c. Who is the patient? Whose needs are to be considered? Whose opinions? Reports of information?

   d. There is only a decision-making process if there are differences of opinion

   e. How tensions are resolved in decision-making process – How a happy medium is found (if it is found or if there is a process to try to find it)

      i. Presentation of selected options
      ii. Presentation of selected information in a specific manner

   f. Financial considerations in decision making

      i. Who is paying
      ii. Long term planning with unpredictable needs/cost/duration

C) Second set of questions asked across cases (focus on relational autonomy)

1. Decision-making process

   a. Who thinks who is making the decision? Influence on each?

   b. How is autonomy being mediated by each of the different stakeholders (older adults, family members, healthcare professionals) in light of the tension between expressed wishes? What assumptions can be depicted in the interactions/accounts?

      1. Power relations between the different individuals, how are these visible?
      2. How are older adults and children making decisions? How is older adult’s autonomy being mediated... or is it?
3. How are healthcare professionals mediating joint-decision-making autonomy and practice of older adults and family members... or jointly with healthcare professionals?
4. Differences between hcp recommendations and older adults’ or family members’ wishes – how does this influence interactions, perspectives on decisions/wishes/choices?
5. Feeling of helplessness, hopelessness?
6. Feelings of empowerment
7. What are visible role expectations (as a child, healthcare professional, older adult, etc.)
8. Are external factors also influencing assumptions?
   c. There is only a decision-making process if there are differences of opinion

2. Process
   a. How the approach of thinking about DCP right from admission affects healthcare professionals – practices, perspectives?
   b. How thinking about DCP right from admission may affect older adults or family members (i.e. pressure to make a decision) – discourses? Roles? Power? Pressure?
   c. Implications on discharge decision and outcome
   d. How did this influence the assumptions identified in section 1?
   e. Family conference
      i. Roles
      ii. Process or conventional structure
      iii. Set up
      iv. Contribution to dcp?
      v. Interactions, discussions, different players/audiences

3. Discourses – Pull together what is discussed in section one; how are these reinforced/reproduced/changed? In practices and explicit processes?
   a. Aging
   b. Medical model, roles and expectations (including of patients, families etc.)
   c. Risk and safety
   d. Notion of client-centeredness
   e. Long term care
## Appendix 10 – Role ordered data analysis matrices

<table>
<thead>
<tr>
<th>Case Number</th>
<th>Wish for DCP</th>
<th>What is important in DCP for this person</th>
<th>Self-perceived role in DCP</th>
<th>Perception of others’ roles in DCP</th>
<th>Who is making decisions about discharge</th>
<th>Pre-admission social and physical living circumstances</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Older adult Maeve</strong></td>
<td>To return home to her house. She knows she has difficulty “getting around” and that this makes parts of her home inaccessible to her. She feels she would be fine living on one floor only.</td>
<td>To be in her own space</td>
<td>She has voiced her wish to return home but asserts that her children are doing everything.</td>
<td>She asserts her children are making all decisions. When asked, she reports they are not communicating much about the decisions or the process. She also reports HCPs are not talking to her about discharge.</td>
<td>Her children.</td>
<td>Maeve has lived alone for 33 years since her husband passed away. She was living in the two-storey house where she has been lived for over 40 years.</td>
</tr>
<tr>
<td><strong>Family member Tom, Maeve’s son</strong></td>
<td>For his mother to go home as in previous discussions he had with her, she has asserted she does not want to go to long-term care.</td>
<td>To honour his mother’s wishes and for her to be comfortable</td>
<td>In conjunction with his sisters, he makes decisions for his mother’s care. He also plans on supporting her by helping with IADLs upon her discharge.</td>
<td>He states his mother makes the decision and he and his siblings put care and services in place to support her. He sees the HCPs as assisting while she’s in inpatient care, but he picks and chooses what recommendations he will take from the HCPs.</td>
<td>He and his sisters</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare professional, (occupational therapist Monica)</strong></td>
<td>Maeve should go somewhere with 24 hour care. She feels Maeve has cognitive and mobility impairments, which impede her ability to be safe and care for herself at home without significant assistance.</td>
<td>Maeve’s safety.</td>
<td>To “be the bad guy” and assess and inform about cognitive changes. To make recommendations for discharge.</td>
<td>The older adult is expressing her wishes, but because of cognitive impairment, this is not reliable. The children are very involved and preparing the home and putting services in place.</td>
<td>Maeve and her children</td>
<td></td>
</tr>
<tr>
<td><strong>Outcome of DCP</strong></td>
<td>At first Maeve was to return home with CCAC and some hired assistance. Then the children changed their minds and she was going to go to long-term care. In the end Maeve had a medical complication and returned to acute care. It is not clear where she went after that.</td>
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</tbody>
</table>

Table 12.1 – Case One data matrix
<table>
<thead>
<tr>
<th>Case Number 2</th>
<th>Wish for DCP</th>
<th>What is important in DCP for this person</th>
<th>Self-perceived role in DCP</th>
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<tr>
<td><strong>Older adult Frederik</strong></td>
<td>To return home with his wife Rita. Is amenable to having live in care</td>
<td>To go home with his wife as soon as is feasible</td>
<td>He perceives himself as one who makes decisions along with Rita.</td>
<td>He seems to perceive his wife and step-daughters as the one putting services in place for him to return home with his wife. HCPs provide information about services.</td>
<td>Frederik, his wife, his stepdaughters.</td>
<td>Lived with his wife. Sees his stepdaughters and their families who also live in the city weekly. Lived in a two-bedroom condo in an accessible building. There are no steps to go up or down.</td>
</tr>
<tr>
<td><strong>Family member Rita, Frederik’s wife</strong></td>
<td>For her husband to come home with her.</td>
<td>For her husband to be with her and for all his care needs to be met.</td>
<td>She is asking many questions and is trying to ensure that Frederik’s needs will be met upon discharge by a combination of herself and private and CCAC assistance.</td>
<td>She states her daughters are taking all required actions with respect to putting services in place.</td>
<td>Mainly Frederik, and herself but her daughters are making decisions relevant to putting services in place.</td>
<td>-</td>
</tr>
<tr>
<td><strong>Healthcare professional: Social Worker Rebecca</strong></td>
<td>For Frederik to go somewhere where he will have 24 hour assistance, whether this be home or LTC.</td>
<td>For his care needs to be met 24 hours a day.</td>
<td>To liaise with the therapists to make recommendations to the family.</td>
<td>The therapists have their own realms of expertise to assess and make recommendations. The family have their responsibility to put care in place.</td>
<td>The team is making recommendations that Frederik, his wife and family are following.</td>
<td>-</td>
</tr>
<tr>
<td><strong>Healthcare professional: occupational therapist Julie</strong></td>
<td>For Frederik to go somewhere where he will have 24 hour assistance, whether this be home or LTC.</td>
<td>For his care needs to be met 24 hours a day.</td>
<td>To provide assessment and recommendations for patients to return to live safely.</td>
<td>The family listen to the recommendations and put services in place.</td>
<td>The team</td>
<td>-</td>
</tr>
<tr>
<td><strong>Outcome of DCP</strong></td>
<td>Frederik will return home to live with his wife. They will have a live-in caregiver for the time being.</td>
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</tr>
</tbody>
</table>

Table 12.2 – Case Two data matrix
<table>
<thead>
<tr>
<th>Case Number 3</th>
<th>Wish for DCP</th>
<th>What is important in DCP for this person</th>
<th>Self-perceived role in DCP</th>
<th>Perception of others' roles in DCP</th>
<th>Who is making decisions about discharge</th>
<th>Pre-admission social and physical living circumstances</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older adult Mrs. Marion</td>
<td>To go home with some assistance. Would prefer someone to come in daily rather than have someone live with her, but is accepting of having someone live with her as long as they don’t disturb her den.</td>
<td>To be in her own space as “her home is her castle”</td>
<td>Not involved; her children are making all the decisions</td>
<td>The health professionals don’t talk to her about it. They make recommendations but she doesn’t buy them. Her children will make all the decisions.</td>
<td>Her children</td>
<td>She lived alone in an apartment. She has two grown children, a son who lives in the same city and a daughter who lives 1.5 hours away. Main floor apartment. Accessible for her mobility but would need to have furniture changes to accommodate a live-in caregiver to have a bed.</td>
</tr>
<tr>
<td>Family member (son Allen)</td>
<td>For his mom to be in long-term care as this would be easiest for him, but he knows she does not want this so he wants her to have live-in help.</td>
<td>For his mom to have someone looking after her. For him not to have to worry about always replacing caregivers.</td>
<td>Is the primary decision-maker. His sister is involved, but he is the key individual as he is the one who lives close by.</td>
<td>He seems to allow his mother a little bit of a role in working with her to go home and have care there. He sister is a support for him and his mother. The healthcare professionals are there to inform him and his family, and their recommendations match his wishes, therefore he uses their information in making decisions. If they didn’t match his own impressions or wishes, I wonder how he would use them.</td>
<td>He asserts that it is himself, but he also states that he'd prefer his mother go to long-term care and this is not where she is going. This indicates to me that Mrs. Marion is also contributing to this decision.</td>
<td></td>
</tr>
<tr>
<td>Healthcare professional, (occupational therapist Erica)</td>
<td>For Mrs. Marion to have 24-hour care, whether this be in the home or in long-term care</td>
<td>safety</td>
<td>As one who assesses and informs the family of the amount of care that Mrs. Marion needs.</td>
<td>The children are there to support their mother and help convince her to accept more help.</td>
<td>The client and family have the ultimate decision. She seems to perceive this as a joint decision in this case.</td>
<td></td>
</tr>
<tr>
<td>Outcome of DCP</td>
<td>home with live-in caregiver 7 days a week.</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 12.3 – Case Three data matrix
### Case Number 4: Wish for DCP

**Self-perceived role in DCP**
- She has no role in making decisions. Her role is to do what her children decide and to try to make the best of it.

**Perception of others' roles in DCP**
- Her children are investigating different places and making the judgement of what would be best for her. She doesn’t feel the healthcare providers are saying much or having much of a role.

**Who is making decisions about discharge**
- Her children Nancy and Peter

**Pre-admission social and physical living circumstances**
- Sophia has lived in a two storey home for close to 50 years and has been living alone since her husband died 15 years ago. Her children each live about one hour away but visit weekly.

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**Older adult Sophia**
- Wishes to return home but also realizes she has difficulty going up and down stairs and so her home is not accessible with respect to her abilities. Wishes to be safe and not have stairs.

**Family member Nancy, Sophia’s daughter**
- For Sophia to go to the Polish retirement home for the 30 day trial period
  - For her mom to be safe and secure; for someone to be looking in on her for supervision, and also companionship for her mom to be able to speak polish with others of her culture
  - She is organizing many of the details for visits and finding out about pricing and availability

**Family member Roy, Sophia’s son-in-law, Nancy’s husband**
- For Sophia to go to long-term care
  - For Sophia to have a lot of care as “more care is better”. For the government to ensure no one is left unprepared

**Family member Peter, Sophia’s son**
- For his mom to try the Polish retirement home for the 30 day trial period
  - For his mom to be happy and receive the care and social and physical support she needs, but for him and his sister not to be overburdened.

**Healthcare professional: Social Worker Diane**
- For Sophia to go to the Polish retirement home for the 30 day trial period
  - For Sophia to be in an environment that is socially and culturally supportive and free of physical challenges
  - To provide the information about options. The family will make a decision based on this.

**Outcome of DCP**
- Sophia went to the Polish retirement community for a trial of 30 days.

### Table 12.4 – Case Four data matrix
<table>
<thead>
<tr>
<th>Case Number 5</th>
<th>Wish for DCP</th>
<th>What is important in DCP for this person</th>
<th>Self-perceived role in DCP</th>
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<th>Who is making decisions about discharge</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Older adult Magan</strong></td>
<td>To return to his condo.</td>
<td>Inner peace, to be able to host guests</td>
<td>He is making decisions</td>
<td>His daughter is involved… he doesn’t really say how. HCPs are making recommendations, some that are “valid and adaptable but some that are not”</td>
<td>Magan and Teja… later he says himself</td>
<td>He lived alone in a condo but had CCAC coming in twice a day. He also had a secretary spending a few hours daily at his house. His daughter speaks with him and visits weekly.</td>
</tr>
<tr>
<td><strong>Family member Teja, Magan’s daughter</strong></td>
<td>For her father to go somewhere where he will be happy and safe, in that order. Ideally she would want him to go home with help until he needs more help, at which time he could move to LTC or wherever was appropriate.</td>
<td>For her father to be happy and safe.</td>
<td>To collect information and assist her father in making a decision.</td>
<td>The healthcare providers did not do very much. They provided very generic advice.</td>
<td>Magan</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare professional Alison, physiotherapist</strong></td>
<td>For Magan to return home as that’s where he wants to go, but with a lot of support safety</td>
<td>To assess what is safe and make recommendations based on that.</td>
<td>Family prepares for safety of discharge. Older adult lets things happen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare professional Diane, social worker</strong></td>
<td>For Magan to return home with a live-in caregiver who could meet his needs both for care and leisure and productivity Safety and support, but also preventing an emergency placement</td>
<td>To support Magan’s wishes as he is competent and secondarily to support his daughter and her anxieties</td>
<td>The other healthcare professionals fulfil their respective roles in assessment, intervention and recommendations. The daughter assists Magan with his wishes and support for discharge.</td>
<td></td>
<td>Magan</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare professional Monica, occupational therapist</strong></td>
<td>For Magan to go to a senior’s home where he would have independence as well as support and structure Safety first and secondly Magan’s happiness</td>
<td>To support Magan and his daughter</td>
<td>His daughter’s role is to support her father</td>
<td></td>
<td>Magan</td>
<td></td>
</tr>
<tr>
<td><strong>Outcome of DCP</strong></td>
<td>Magan will return home to his condo with assistance from CCAC and a private caregiver who will come in several hours a day.</td>
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</tr>
</tbody>
</table>

Table 12.5 – Case Five data matrix