Transitional Care Experiences Across Different Health Care Settings

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions as accepted by my examiners.

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ABSTRACT

Background: Older adults with multiple chronic conditions typically require care from numerous specialized health care providers across various different settings, making it necessary for patients to transition between these providers and settings (Institute of Medicine, 2001; Coleman, 2003). Transitions of care often result in discontinuities in care, leading to unmet patient needs, adverse events, and poor satisfaction with care, especially in patients with multiple chronic conditions, such as patients with hip fracture (Coleman & Boult, 2003; Naylor, 2000; Naylor, et al., 2009; Jaglal et al., 1996). This project aimed to understand how experiences of patients with hip fracture, family caregivers, and health care providers may differ across different points of transition.

Methods: A secondary analysis of 103 qualitative, semi-structured interview transcripts was conducted to gain an understanding of how transitional care experiences may differ across varying settings of care. The analysis was completed using emergent coding techniques according to Braun & Clarke (2006) and Lofland & colleagues (2006). The results of this analysis were presented in a focus group interview, where participants who represented various roles across the health system were asked to comment on how the secondary analysis results fit their experiences and the current context of the health system. Results of the focus group interview were similarly analyzed using emergent coding techniques (Braun & Clarke, 2006; Lofland et al., 2006).

Results: Seven key themes, each relating to various distinct transitional care settings, emerged from the secondary analysis: (1) Patients and family caregivers felt uninformed; (2) Multiple different providers contributed to patient and family caregiver confusion; (3) Transitions

increased stress in patients and family caregivers; (4) Family caregivers were not considered important in the patient's care; (5) Care was not tailored to patient needs; (6) System related issues impacted care experience; (7) Providers faced barriers in getting adequate information. The focus group interview results built upon these themes, adding an additional five related themes: (1) Enhancing knowledge and understanding in patients and family caregivers is important for safe and effective transitions; (2) Appropriate collaboration and communication between health care professionals improves transitions; (3) Consistency in health care providers can support system navigation and transitional care; (4) Development of system solutions should involve input from patients, caregivers, and front-line providers; (5) Transitional care may be improved through interventions aimed at enhancing communication and information sharing. The secondary analysis and focus group interview revealed that experiences of patients, caregivers, and health care providers vary by transition type. Specifically, transitions to other formal care settings are experienced differently from transitions to home.

Discussion: In transitions to formal care settings, similarities were largely related to feeling confused, while in transitions to home, similarities existed in regards to patients, caregivers and health care providers feeling unprepared. Interestingly, the findings of the secondary analysis related to transitions to home seem to overlap with key factors of existing transitional care interventions, many of which have been developed for transitions to home. Future research should further explore the ways in which other transition settings may impact patient, caregiver, and health care provider experience, and quality of care, for a variety of complex health conditions.

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CHAPTER 1: INTRODUCTION AND OVERVIEW

1.1 STATEMENT OF RESEARCH FOCUS

The Canadian health system is designed to provide care in response to a single ailment, which conflicts with the complex needs of patients with multimorbid conditions, for whom concerns cannot efficiently be handled in isolation (Ministry of Health and Long Term Care (MOHLTC), 2007; Primary Health Care Advisory Group, 2016). Older adults with multiple chronic conditions typically require care from numerous specialized health care providers, who often practice independently across a variety of different settings (Institute of Medicine, 2001). As such, it becomes necessary for patients managing their multiple health concerns to transition between multiple health care providers and a range of settings (Coleman, 2003). These 'handoffs' often result in discontinuities in care, frequently leading to unmet patient needs, adverse events, and poor satisfaction with care, especially in patients with multiple chronic conditions (Coleman & Boult, 2003; Naylor, 2000; Naylor, Kurtzman, Pauly, 2009).

The majority of patients with hip fracture are older adults with complicated co-morbidities (Jagal, Sherry, Schatzker, 1996; Marengoni, Rizzuto, Wang, Winblad, Fratiglioni, 2009). As a result, older adults who experience hip fracture often face a complex recovery journey involving multiple care transitions (Jaglal et al., 1996; Wells, Seabrook, Stolee, Borrie, Knoefel, 2003).

The care journey of older patients with hip fracture was previously investigated in the InfoRehab Transitions project. This project interviewed Canadian patients with hip fracture, their family caregivers, and health care providers at each transition point in their hip fracture care to

understand their experiences across the entire care journey. This project, however, did not explicitly investigate how experiences at each transition may have differed depending on the specific settings in which the care transition occurred. Developing an understanding of these differences may work to inform future efforts that attempt to enhance transitional care by tailoring the approach to meet the specific needs of the patient in their specific transitional setting.

1.2 Thesis Structure

This work presents an examination of the unique experiences of patients, family caregivers, and health care providers previously interviewed for the InfoRehab Transitions study at each transition point through the entire care trajectory. This project aimed to understand how experiences may differ across different points of transition by analyzing the existing InfoRehab transcriptions with careful attention to the settings in which the transition is occurring. This thesis first provides an overview of existing literature, followed by the study rationale, methods, and results. A brief discussion of the potential implications of this study is also included, along with the strengths and limitations, and conclusions.

CHAPTER 2: LITERATURE REVIEW

2.1 Aging Population and Complexity

Over the next 20 years, the population of older adults in Canada is expected to grow by 68% (CIHI, 2017). The highest users of health services in Canada are persons 60 years of age or older with various chronic conditions (Reid, Roos, MacWilliam, Frohlich, & Black, 2002). Additionally, the Canadian Institute for Health Information reports that health spending in Canada is highest for older adults (CIHI, 2017). As a result, the aging of the Canadian population is expected to have a considerable impact on the health care system (Canadian Medical Association, 2013). While older adults account for a large portion of health spending, population aging is reported as only a modest cost driver (CIHI, 2017). Instead, age-related multimorbidity and the resulting greater health service use, is thought to drive the increase in health spending (Roberts, Rao, Bennett, Loukine, Jayaraman, 2015; McPhail, 2016; Freeborn, Pope, Mullooly, McFarland, 1990). In other words, the more chronic conditions one has, the more they tend to cost the health system (McPhail, 2016).

Chronic conditions are often mismanaged in acute-focused health care systems. As Bodenheimer, Wagner, & Grumbach (2002) explain: 'frequently, the acute symptoms and concerns of the patient crowd out the less urgent need to bring chronic illness under optimal management' (p.1775). The brief and passive visits, unprepared practice teams, and under-informed patients characteristic of acute-focused health care systems are not conducive to the management of chronic conditions, and may contribute to rising health care costs (Bodenheimer et al., 2002; McPhail, 2016). One solution for containing health care cost may be to focus on improving the management complex, comorbid patients by enhancing self-management and streamlining the care process, as suggested in the Chronic Care Model (Bodenheimer et al.,

2002). The Chronic Care Model outlines six key factors for enhancing chronic disease care: community resources and policies, health care organizations, self-management support, delivery system design, decision support, and clinical information systems. A number of these factors, including delivery system re-design, aim to alter the system's current approach to managing the multiple and complex conditions faced by older adults, which presents a particularly complicated challenge (Reid et al., 2002).

2.2 Hip Fracture

The occurrence of hip fracture is largely associated with increased age, making hip fracture a major population health concern within the context of globally aging populations (Leslie et al., 2009; Jaglal et al., 1996). Patients with hip fracture provide an ideal patient case for the examination of complex health issues. Patients with hip fracture tend to be highly complex, often presenting with multiple comorbidities (Jaglal et al., 1996; Marengoni, Rizzuto, Wang, Winblad, Fratiglioni, 2009). A study assessing patterns of multimorbidity in older adults, determined that hip fracture was the least likely of the diseases assessed to occur in the absence of a comorbidity (Marengoni et al., 2009). In fact, the strongest pre-operative risk factor for hip fracture in older adults is the presence of three or more comorbid conditions (Roche, Wenn, Sahota, & Moran, 2005). The complexity of patients with hip fracture often leads to a variety of adverse outcomes including additional morbidity, permanent decline in function and independence, (Randell et al., 2000; Koval, Skovron, Aharonoff, Meadows, Zuckerman, 1995; Young, German, Brant, Kenzora, Magaziner, 1996), a decline in health-related quality of life (Zinden, Kreuter, Frandin, 2010), and increased mortality (Leslie et al., 2009).

Due to their complexity, the average patient with hip fracture has three or more transitions throughout their recovery (Hung & Morrison, 2011; Boockvar et al., 2004). These

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transitions can occur in a variety of settings, including acute care, inpatient rehabilitation, complex continuing care, long term care, convalescent care, and home care (Toscan, Manderson, Santi, Stolee, 2013).

2.3 Care Transitions

A care transition can be defined as the movement of a patient between health care settings during the course of their care (Coleman, 2003). Care transitions are often unplanned, occurring suddenly and leaving patients and family caregivers unprepared (Coleman, Mahoney, Parry, 2005). It is thought that these fast and unexpected transitions are a result of our acute-focused health care system, where care is provided quickly, for singular conditions, in siloed settings (McWilliam & Sangster, 1994; Institute of Medicine, 2001). Abrupt transitions leave little time for care planning and care coordination, resulting in confusion and disorganization, insufficient communication, and ultimately substandard care (McWilliam & Sangster, 1994; Schultz, Carayon, Hundt, Springman, 2007). Poorly executed care transitions compromise patient safety and quality of care, which can lead to avoidable functional loss, pain, anxiety, delirium, and eventual re-hospitalization (Coleman, Mahoney, Parry, 2005).

With health settings operating in silos, providers are often under-informed and lack knowledge about "the problems addressed, services provided, medications prescribed, or preferences expressed in previous settings" (Institute of Medicine, 2001; Anderson, Helms, 1995). This fragmentation is thought to further contribute to poor communication between health care providers, and ultimately, 'chaotic and unsystematic transitions' (Davis, Devoe, Kansagara, Nicolaidis, Englander, 2012). Further complicating health care provider communication is the tendency for complex patients to receive care from a number of different care providers, increasing the size of their circle of care (McLeod, McMurray, Walker, Heckman, Stolee, 2011).

As a patient transitions through different care settings, multiple additional care providers become involved in the patient's recovery (Coleman, Berenson, 2004). However, health care providers rarely coordinate the patient's care after discharge, and often fail to communicate with providers in the patient's next setting (Coleman, 2003). Previous work has indicated that providers rarely have an understanding of their own roles, let alone that of other providers across transitions or within different settings (Toscan, Mairs, Hinton, Stolee, The InfoRehab Team, 2012). Communication breakdown between health care providers is thought to contribute to poor patient outcomes and dissatisfaction with care (Kripalani et al., 2007, Davis et al., 2012). This lack of coordination and communication ultimately impacts the continuity of care experienced by the patient.

Patients and caregivers are the common thread across transitions of care. As such, Coleman and colleagues (2004) have suggested an approach to decreasing the fragmentation across transitions that centers on enhancing patient and caregiver self-management. Self-management incorporates aspects of knowledge, beliefs, and self-regulation in order to enhance the management of chronic disease through skill development and behaviour change (Ryan & Sawin, 2009). In this way, self-management extends beyond the concept of self-care and patient education, which center on the independent completion of activities of daily living and the provision of information to increase knowledge, satisfaction, and readiness, respectively (Ryan & Sawin, 2009). It is thought that "patients that are knowledgeable about their condition and its management and who are able to communicate effectively with care providers are more likely to have their needs met during the series of transitions following hospitalization" (Parry, Kramer & Coleman, 2006, p.40). Therefore, a self-management approach to transitional care aims to alleviate issues related to insufficient provider communication and reduce poor transitions by

providing patients and caregivers with the tools needed to play a more active role in their care journey (Coleman et al., 2004). Self-management approaches have been demonstrated to promote better health outcomes in patients with chronic conditions (Barlow, Wright, Sheasby, Turner, Hainsworth, 2002), and have been reported to improve the patient's perception of the continuity and engagement across the transition (Parry, Kramer, Coleman, 2006). However, patients and caregivers must be enabled to manage their own care through health care provider initiated education, coaching, and instruction (Coleman et al., 2004).

2.3.1 CARE TRANSITION PROGRAMS AND INTERVENTIONS

In Canada, care transitions have been widely identified as an opportunity for improvement at a health system level (Registered Nurses' Association Ontario (RNAO), 2014; Canadian Institute for Health Information (CIHI), 2017; Canadian Nurses Association (CNA), n.d.; Health Quality Ontario (HQO), 2013). In support of improvement efforts, and to address the lack of continuity in patient care, numerous interventions focused on improving care transitions have been developed and tested in practice. One review of existing care transitions models listed six well-researched models that have commonly been applied in practice: Transitional Care Model, Care Transitions Intervention, Project BOOST, Project RED, The Chronic Care Model, and INTERACT (Enderlin et al., 2013). The Transitional Care Model, Care Transitions Intervention, Project BOOST, Project RED, and INTERACT are all clearly defined interventions that provide tools and resources to enhance transitional care. In contrast, the Chronic Care Model outlines a system-perspective to enhancing safe and effective care for chronically ill people, and has been applied as a model of transitional care in transitions to outpatient settings ((Bodenheimer et al., 2002; MacColl Institute for Healthcare Innovation, 2006, as cited in Enderlin et al., 2013). This review concluded that the Transitional Care Model,

Care Transitions Intervention, Project BOOST, and Project RED were superior to the Chronic

Care Model and INTERACT in managing transitional care because of their inclusion of specific

components important to enhancing transitional care, such as the development of a discharge

plan (Enderlin et al., 2013). These four superior models, outlined in **Table 1**, were additionally

identified in a 2016 review by Rochester-Eyeguokan, Pincus, Patel & Reitz that identified the

existing transitional care models commonly used in the United States.

      In a review of existing transitional care models, the components of each of these four

models were compared against a list of 14 factors suggested by Burke and colleagues and the

Transitions of Care Consensus Conference (TOCCC) for ideal services in transitional care

(Burke et al., 2015 & Snow et al., 2009). The factors, and the results of this comparison, are

included in **Table 1**. Through this review, Rochester-Eyeguokan and colleagues (2016)

determined that these four interventions were the most promising of the existing models due to

their continuous approach to care, and their provision of pre- and post-transition services in

home and outpatient settings. It should be noted that, while these four interventions are

commonly cited as the most promising method of improving care transition quality, none of

them satisfy all 14 of the factors for successful transitions of care (Rochester-Eyeguokan et al.,

2016).

TABLE 1 COMMON CARE TRANSITION INTERVENTIONS

Name of Intervention	Description of Intervention	Transitional Settings	Factors Met	
Transitional Care Model (Naylor & Van Cleave, 2010)	Provides high-risk, high-cost patients with comprehensive discharge plan and at home follow-up care coordinated through a Transitional Care Nurse (TCN) who follows the patient and provides continuous care across the transition.	Hospital to Home	1) inpatient interdisciplinary rounds	
			2) transition record	
			3) transmission of discharge summary	
			4) pharmacist involvement	
			5) educating patients and promoting self-management	x
			6) a tool for plan of care	
			7) enlisting the help of social and community supports	x
			8) advanced care planning	
			9) coordinating care among members	x
			10) monitoring and managing symptoms after discharge	x
			11) follow-up with outpatient providers	x
			12) accountable point provider during all points of care transition	x
			13) quality improvement of intervention	
			14) outcomes	x
Care Transitions Intervention (Coleman, Parry, Chalmers, Min,	Providing patients and family caregivers with the resources to actively participate in their own transitional care through improved medication	Hospital to Home	1) inpatient interdisciplinary rounds	
			2) transition record	
			3) transmission of discharge summary	x
			4) pharmacist involvement	x

2006)	self-management, a patient-centred record, timely follow-up, and a list of 'red-flags' and instructions on how to respond to them.		5) educating patients and promoting self-management	x
			6) a tool for plan of care	x
			7) enlisting the help of social and community supports	
			8) advanced care planning	
			9) coordinating care among members	
			10) monitoring and managing symptoms after discharge	x
			11) follow-up with outpatient providers	x
			12) accountable point provider during all points of care transition	x
			13) quality improvement of intervention	
			14) outcomes	x
Project BOOST (Li, Williams, Young, 2015)	Improves transitional care through a focus on interdisciplinary collaboration and the use of a comprehensive suite of interventions and tools to address discharge and follow-up, including a risk assessment tool to evaluate persons at risk of dangerous transitions.	Hospital to Home (or other Post-Acute Settings)	1) inpatient interdisciplinary rounds	
			2) transition record	
			3) transmission of discharge summary	
			4) pharmacist involvement	
			5) educating patients and promoting self-management	x
			6) a tool for plan of care	x
			7) enlisting the help of social and community supports	x
			8) advanced care planning	
			9) coordinating care among members	x
			10) monitoring and managing symptoms after discharge	x

			11) follow-up with outpatient providers	x
			12) accountable point provider during all points of care transition	
			13) quality improvement of intervention	x
			14) outcomes	x
Project RED (Jack et al., 2008)	Avoids adverse events, particularly medication errors, by educating the patient, making follow-up appointments, discussing results and providing a person to contact, organizing post-discharge services, confirming the medication plan, assessing the patient's understanding, and providing written discharge plans and telephone reinforcement.	Hospital to Home	1) inpatient interdisciplinary rounds	
			2) transition record	
			3) transmission of discharge summary	x
			4) pharmacist involvement	x
			5) educating patients and promoting self-management	x
			6) a tool for plan of care	x
			7) enlisting the help of social and community supports	x
			8) advanced care planning	
			9) coordinating care among members	x
			10) monitoring and managing symptoms after discharge	x
			11) follow-up with outpatient providers	x
			12) accountable point provider during all points of care transition	
			13) quality improvement of intervention	
			14) outcomes	x

The Transitional Care Model is aimed at improving care for older adults while enhancing patient and caregiver outcomes, and reducing costs (Hirschman, Shaid, McCauley, Pauly, Naylor, 2015). This model focuses on the patient's health related goals to develop a personal and streamlined care plan that enhances continuity of care (Hirschman et al., 2015). The Transitional Care Model delivers care through an advanced practice registered nurse who collaborates with patients, their caregivers, and multidisciplinary providers to ensure continuous care as the patient transitions between settings (Naylor, 2012). The model works through nine core concepts: (1) Screening to target high risk adults transitioning from hospital to home; (2) Staffing of the advanced practice registered nurses; (3) Maintaining relationships with the patient and their caregivers; (4) Engaging patients and caregivers in the design and implementation of their care plan to ensure it matches their care goals and preferences; (5) Assessing/managing risks and symptoms that are priorities for each patient; (6) Educating/promoting self-management through encouraging the patient and caregiver to identify and respond to worsening symptoms; (7) Collaborating to ensure consensus on the care plan between the patient and members of the care team; (8) Promoting continuity through the work of a consistent clinician across transition; and (9) Fostering coordination between hospital and community health care providers (Hirschman et al., 2015). Multiple clinical trials have demonstrated that, in comparison to regular care, this intervention can result in reductions in rehospitalisation and total health care costs, even after accounting for the additional cost of the intervention (Naylor et al., 1994; Naylor et al., 1999; Naylor et al. 2004).

The Care Transitions Intervention was developed with the goal to improve care transitions from hospital to home through knowledge and self-management (Parry, Coleman, Smith, Frank, Kramer, 2003). The model is focused on improving transitions through four

pillars, or conceptual areas: (1) Medication self-management through enhancing patient knowledge and providing a medication management system; (2) Use of a dynamic patient-centered record that is managed by the patient or their caregiver, and which works to facilitate communication and continuity of the patient's care plan across providers and settings; (3) Primary care and specialist follow-up schedules and empowerment of the patient to become an active member of their care; and (4) Knowledge of red flags so that the patient understands when their condition is declining and how they should respond (Parry et al., 2003). These pillars are actioned through the personal health record and a nurse Transition Coach, both of which work to educate and empower the patient (Parry et al., 2003). The personal health record allows patients to update and track their own records, ultimately improving the flow of information as the patient transfers between health settings and professionals (Parry et al., 2003). The Transition Coach facilitates interdisciplinary communication and collaboration as patients transfer between settings, and helps to develop and operationalize the patient's care plan (Parry et al., 2003). Clinical trials have demonstrated that this intervention can reduce rehospitalisation and health care costs when compared to regular care patients (Coleman, Parry, Chalmers, Min, 2006). Additionally, patients receiving the Care Transitions Intervention have reported an enhanced confidence in obtaining information that allowed them to manage their own conditions, better communicate with their health care providers, and increase their understanding of their medical regime (Coleman et al., 2004).

Project BOOST, or Better Outcomes by Optimizing Safe Transitions, is an intervention that has been implemented in over 180 hospital systems (Coffey, Greenwald, Budnitz, Williams, 2013). Project BOOST provides a platform on which various tools and interventions can be layered (Coffey et al., 2013). The program focuses on increasing knowledge and understanding

of transitional care, and how it functions within a particular institution. Project BOOST tools and interventions include: the 8P Risk Assessment, the Generalized Assessment of Preparedness, the Teach Back approach, patient-centered discharge instruction, timely follow-up appointments, standardized communication with primary and post-acute care providers, and a 48-72 hour follow-up call for high risk patients (Li et al., 2015). Understanding the successes and failures of the current state of transitional care allows institutions to tailor their approach through the selection of particular tools that best fit their context (Coffey et al., 2013). Project BOOST begins with ensuring the support of the institution, followed by the assembly of a Project BOOST team, the clarification of stakeholders and an approval process, a survey of previous or ongoing efforts, the development of SMART goals, and the selection of metrics and a measurement plan (Coffey et al., 2013). The selected intervention is then trialed in a carefully selected hospital care unit (Coffey et al., 2013). Project BOOST encourages the implementation of a 'comprehensive transition plan' that aims to streamline transitions through patient risk assessment, medication reconciliation, patient- and family-centered education, timely sharing of information, and timely follow-up (Li et al., 2015). An evaluation of the Project BOOST intervention demonstrated an associated decrease in hospital readmission, but did not show any significant change in length of stay (Hansen et al., 2013). The observed reduction in readmission seems consistent across a variety of diverse acute care settings, and was accomplished in settings where funds were limited (Hansen et al., 2013).

Project RED, or Re-Engineered Discharge, developed a series of key components for safe and effective discharge through engineering methods, such as process mapping, failure mode effect analysis, and probabilistic risk assessment (Jack & Bickmore, 2011). The resulting key components were: (1) Educate the patient about diagnosis throughout their hospital stay; (2)

Make appointments for follow-up with input from the patient; (3) Discuss tests not completed in hospital with the patient; (4) Organize post-discharge services; (5) Confirm the medication plan; (6) Reconcile the discharge plan with national guidelines and critical pathways; (7) Review with the patient the appropriate steps for action in the event that a problem arises; (8) Expedite transmission of the discharge summary to clinicians accepting care of the patient; (9) Assess the patient's understanding of the plan; (10) Give the patient a written copy of the discharge plan; and (11) Call the patient 2-3 days after discharge (Jack & Bickmore, 2011). These components where used to inform the RED Toolbox which provides a training manual and checklist for use by a discharge nurse, as well as an individualized 'After-Hospital Care Plan' for the patient (Jack et al., 2008). When delivered by a nurse in acute care hospitals, Project RED decreased hospital utilization by 30% and decreased the overall cost of care, with RED patients accounting for 33.9% less dollars than usual care patients (Jack & Bickmore, 2011). Project RED has been adopted for additional settings, such as Skilled Nursing Facilities, with similar success (Berkowitz et al., 2013).

These interventions have all demonstrated effective results in reducing readmissions, hospital utilization, and cost, although uncertainty remains as to which of these interventions is most impactful (Hesselink et al., 2012). There is, in fact, evidence to suggest that the effectiveness of these models may not be universal. An evaluation of the implementation of Project RED in one hospital, for example, found no significant difference in readmission or emergency department visits at 30, 80, or 180 day follow up between those who received the intervention and usual care patients (Goldman et al., 2014). Additionally, many of these models face a variety of limitations that may impact their effectiveness. The Care Transitions Intervention, for example, has faced barriers to implementation, claims of duplication of the

work of discharge planning and home health nurses, and criticisms of its applicability to frail older patients (Parry et al., 2003; Coleman et al., 2004).

Additionally, these interventions have largely been developed and tested with patients with particular chronic conditions, such as heart disease, stroke, COPD, diabetes, and mental health conditions, with some studies focusing on general surgery patients (Rochester-Eyeguokan et al., 2016). The Transitional Care Model, for example, was created for and tested with patients with heart conditions, which may limit its generalizability to other chronic conditions (Naylor, 2004). Patients with these chronic diseases may have a different transitional care journey than patients with hip fracture, as complex patients with hip fracture often do not follow typical care trajectories (McLeod, McMurray, Walker, Heckman, Stolee, 2011). This may limit the applicability of these interventions to the care of patients with hip fracture. Other existing programs that work to enhance the care for older patients with hip fracture, such as orthogeriatric units, focus on improving outcomes through collaborative or shared care approaches, and may offer some support for patients in transition (Grigoryan, Javedan, Rudolph, 2014). Orthogeriatric units allow orthopaedic surgeons and geriatricians to share the care of older patients with hip fracture, which is thought to allow for optimal management of complex chronic conditions throughout the recovery process after hip fracture (González-Montalvo et al., 2010). Evidence of the effectiveness of these units however, also varies. One study found that, while the orthogeriatric unit shortened the time from admission to geriatric assessment and surgery, it did not significantly impact the patients' ability to walk after surgery (González-Montalvo et al., 2010). Another study however, found that orthogeriatric units improved both time to assessment and surgery, and functional outcomes (González-Montalvo et al., 2011). Studies have reported that orthogeriatric units may enhance placement of patients upon discharge, however their focus

is on enhancing patient care within hospital settings rather than across transitions (Khan, Fernandez, Kashif, Shedder, Diggory, 2002).

The effectiveness of the four models discussed by Enderlin et al. (2013) and Rochester-Eyeguokan et al. (2016) may be further impacted by the fact that each of the models was designed for implementation in a specific transitional setting: from hospital to home or community setting. Designing interventions for one particular transition may limit the applicability of the intervention in other transitional care settings (Enderlin et al., 2013) as transitions have been observed to be different across different settings (Toscan et al., 2013). Enderlin and colleagues (2013) express that, because of the variations present between different settings, transitional care interventions should only be used in the context for which they were created. Additionally, existing transitional care models are focused on intervening at the level of the individual (Naylor et al., 2010; Coleman et al., 2006; Li et al., 2015; Jack et al., 2008) despite findings that suggest that poor transitional care relates to restrictions at the system level (Heckman et al., 2013).

2.3.2 INVESTIGATIONS OF PARTICULAR TRANSITIONAL SETTINGS AND THE INFOREHAB STUDY

The volume of interventions developed for the transition from hospital to home seems to correspond to the extent to which this particular transition has been investigated. A majority of transitional care studies have investigated the transition from hospital to home, specifically from hospital acute or inpatient rehabilitative care to community care settings (Rochester-Eyeguokan et al., 2016). A relatively small number of studies have examined the transition from acute care to inpatient rehabilitation, acute care to ambulatory care clinics, or within-hospital transitions (Rochester-Eyeguokan et al., 2016). Transitions to community care involve moving the patient from a formal care setting to an informal care setting. As such, this transition is often assumed to

be very strenuous on both the patient and the caregiver (Coleman, 2003; Naylor, 2000; Naylor, 2002; Coleman & Boult, 2003). In fact, transitions to home are thought to be the most difficult transition for the caregiver, who is expected to assume the role of main care provider after a return to home (Giosa, Stolee, Dupuis, Mock, Santi, 2014).

Some studies, such as the InfoRehab Transitions project, examined the transitional journey as a whole, allowing for the understanding of transitional care across a variety of settings. The InfoRehab project investigated the transitional care experiences of health care providers, patients, and their family caregivers. Analyses of the InfoRehab data concluded that health care providers experience a lack of clarity regarding their roles across transitions, especially in relation to responsibilities in information sharing (Sims-Gould, Byrne, Hicks, Khan Stolee, 2012; Toscan, Mairs, Hinton, Stolee, 2012). The transfer of information across transitions is complicated by the unexpected and sudden nature in which transitions occur, resulting in delays, duplication, miscommunication, and sharing of incomplete or unnecessary information (Toscan, Mairs, Hinton, Stolee, 2012; McMurray, Stolee, Hicks, Elliott, Johnson, Byrne, 2013). Within the InfoRehab Transitions project, patients and their caregivers commonly expressed frustration in not being involved in care conversations and decisions (Toscan, Mairs, Hinton, Stolee, 2012; Toscan, Manderson, Santi, Stolee, 2013; Elliott, Forbes, Chesworth, Ceci, Stolee, 2014; Lafortune, Elliott, Egan, Stolee, 2017). This frustration was exacerbated when patients and caregivers could not distinguish between different health care providers, and therefore did not know whom they should approach with their questions (Toscan et al., 2012; Toscan et al., 2013). Some patients and caregivers attributed their comfort and confidence in the transition process to having positive interactions with the health care system in the past, while patients with no past experience or negative past experiences seemed to feel more hopeless and irrelevant in the

transition process (Elliott, Forbes, Chesworth, Ceci, Stolee, 2014; Lafortune, Elliott, Egan, Stolee, 2017). The InfoRehab Transitions study provided insight into the experiences and perspectives of health care providers, patients, and caregivers across their entire transitional care journey, allowing for the incorporation of many transitional settings into the findings and results. While the results from this study provide insight into experiences across a variety of transitions, analyses completed to date do not differentiate how experiences may be different in each different transition.

CHAPTER 3: STUDY RATIONALE

3.1 Research Gap

As the population continues to age, and complex multi-morbidity becomes more prevalent, the need to understand and optimize care for complex patients is likely to remain a major area of interest in health system research. As the population of persons with multi-morbid conditions increases, the need for transitions between health settings, and the threat of costly adverse events posed by poor transitional care, also continues to increase, and interventions for the improvement of transitional care will likely continue to be a focus in improving care and reducing health system costs. Existing transitional care efforts tend to focus on improving transitional care and outcomes at the level of the individual (Naylor et al., 2010; Coleman et al., 2006; Li et al., 2015; Jack et al., 2008), as opposed to the system level. Research has suggested however, that the difficulties faced by older adults related to poor coordination, navigation, and transitional care may be better addressed through system level intervention (Heckman et al., 2013). In order to develop effective interventions, it is important to understand the perspectives of patients, caregivers, and health care providers who have experienced transitions of care and can provide valuable insight into their needs and desires across various transitions across the health care system.

Current research on care transitions has focused on either a single transition, or the overall journey across the entire care continuum (Toscan et al., 2013; Richardson, Casey, Hinder, 2007). Focusing on one transition provides an understanding of a fragment of the patient's overall experience (Toscan et al., 2013; Richardson et al., 2007), while examining the entire care journey as one event may not allow for an in-depth understanding of specific transitions. Similarly, existing interventions target either a specific transition (Quinn et al., 2008) or the

entire care trajectory (McLeod et al., 2011; Toscan et al., 2012; Toscan et al., 2013; Johnson et al., 2013). Through an examination of the transitional care journey as a whole, Toscan et al. (2013) found evidence that experiences are not entirely consistent across different settings of care. Specifically, Toscan and Colleagues (2013) explained that patients in inpatient rehabilitation are expected to play a more active role in their care than patients in acute settings, suggesting that their experiences in these two settings differ. Separating the transitions within each patient's entire care trajectory may provide a more detailed view of each transition while still considering the broader care journey. This may allow for an understanding of how the same patient's, family caregiver's and health care provider's needs, experiences and perspectives differ across settings in their care journey. Understanding how patient, caregiver, and provider needs, experiences, and perspectives differ at various transition points may provide valuable information for future efforts aimed at tailoring care to the patient's, caregiver's, or provider's particular context.

3.2 Study Objectives

The main goal of this work was to understand the experiences of older patients with hip fracture, caregivers, and health care providers at each different point of transition, and how those experiences may differ in relation to the specific point of transition. The specific objectives of this study were:

1. *To identify experiences and characteristics specific to particular transition points across four specific transitions:1) from acute care to inpatient rehabilitation, 2) from acute care to home, 3) from acute care to long term care, 4) from inpatient rehabilitation to home, through a secondary analysis of patient, family caregiver, and health care provider transcripts.*

2. *To understand how the emerging themes from the secondary analysis relate to current practice and experiences of health care professionals, and to identify potential gaps in the secondary analysis findings, through a focus group interview.*

CHAPTER 4: METHODS

4.1 The InfoRehab Transitions Study

The CIHR funded InfoRehab study was developed in an effort to understand the informational challenges faced by vulnerable older adults transitioning through the health care system. The complex journey faced by older patients with hip fracture presented an ideal case in which complicated transitional care journeys could be examined. The goals of the InfoRehab Transitions project were to:

> 1. *Understand the culture and context, from the point of view of the patient, family, and health care provider, of the perceived need, use, and exchange of information regarding hip-fracture patients after surgery as they transition across settings.*
>
> 2. *Identify facilitators and barriers to efficient and effective information use and transfer across the care continuum.*
>
> 3. *Understand how transfer of important information can be enhanced to improve access and delivery of care for patients with hip fracture.*

4.1.1 METHODOLOGICAL APPROACH

Ethnographic approaches are commonly used to understand human experiences through a range of data types (Hammersley & Atkinson, 2007). Specifically, ethnographic research emphasizes the investigation of phenomena through participation in a person's daily life, observing, interviewing, and collecting documents (Atkinson & Hammersley, 2007). The collection of interview, observation, and documented data allows researchers to investigate multiple layers, sites, and perspectives to understand 'how things are done' (Lecompte, 2002).

The InfoRehab Transitions study followed an ethnographic approach, collecting interview data, field notes, and document reviews in an effort to describe the transitional care and information flow. Ethnographic approaches matched the goals of the InfoRehab project to

explore transitional care through the culture of information use and exchange across multiple locations, from the perspectives of multiple stakeholders.

4.1.2 STUDY SITES

The InfoRehab Transitions study was conducted across three Canadian locations: one large urban location, one small urban location, and one rural location. Within both urban locations, researchers partnered with acute care hospitals and rehabilitation hospitals, as well as home care services. In the rural location, researchers partnered with the hospital, which provided rehabilitation services on site, and home care services. As a result, researchers were able to follow patients as they transitioned between acute care, home, long term care, and inpatient rehabilitation settings.

4.1.3 SAMPLE AND RECRUITMENT

The InfoRehab study used a purposeful sampling strategy, as described by Patton (2002) to recruit patients, along with their family caregivers, post-hip surgery within the acute care setting. Considering that patients with hip fracture, even those with similar situations, frequently experience vastly different care trajectories, the patients were purposefully selected to illuminate information transfer issues across a variety of representative transitions. A minimum of two health care providers involved in admission or discharge of the patient at each setting were invited to participate.

Patients aged 65 and older with a diagnosis of a hip fracture who spoke English were invited to participate (Toscan, Mairs, Hinton, Stolee, 2012; Johnson, Forbes, Egan, Elliott, Stolee, Chesworth, 2013). Family members were included in the study if they spoke English and identified as a caregiver for the patient (Johnson et al., 2013). Health care providers were

included if they spoke English, were involved in the patient's circle of care, and could comment on the health care setting in which they worked (Johnson et al., 2013).

4.1.4 DATA COLLECTION

The InfoRehab Transition project collected multiple in depth interviews with patients, family caregivers, and health care providers at admission and discharge from each setting. Semi-structured interview guides (Appendix A) were developed through contexting interviews with investigators and collaborators with consideration of previous knowledge and research findings. Each interview was audio-recorded and transcribed verbatim.

4.2 Secondary Analysis

This thesis project analyzed a total of 103 interviews (n=40 patient interviews, n=17 family caregiver interviews, n=46 health care provider interviews) using line-by-line emergent coding in the software program NVivo 11. All interviews analyzed for this project were previously conducted in the InfoRehab Transitions study. The interviews that were analyzed for this project occurred across all three study sites and involved transitions from acute care to home, acute care to long term care, acute care to inpatient rehabilitation and inpatient rehabilitation to home. InfoRehab Transitions interviews that occurred with patients that were deceased by the end of the study, or their family caregivers and health care providers, were not analyzed (n=4). These four transcripts corresponded to two patients, who were either deceased before transitioning out of acute care, or because an interview did not take place after the transition from acute care. The transcripts pertaining to these two patients were therefore excluded, because the data did not represent a complete transition.

4.2.1 REFLEXIVE STANDPOINT

In qualitative research, reflexivity allows the researcher to identify how their 'biases, values, and personal background' influence their interpretation of the data (Creswell & Creswell, 2018, p.183). In this secondary analysis of previously collected InfoRehab interview data, reflexivity is important in fully understanding the context through which the emerging themes and results came to be. Creswell & Creswell (2018) suggest that qualitative researchers include a statement of their past experiences as they relate to the research problem, participants, or setting, and how those experiences may influence the interpretations made during the analysis. As such, I provide the following statement as a summary of my past experience with transitional care research:

> During my undergraduate degree, I completed an eight month cooperative work term with the Geriatric Health Systems research group, who were previously involved in the InfoRehab Transitions study. During this time, I was exposed to the transitions literature, including the published InfoRehab Transitions study. This exposure sparked my interest in experiences in transitional care.
>
> Throughout the course of this thesis work, I was aware of my previous research experience and understanding of transitional care that stemmed, in part, from previous InfoRehab publications. In keeping aware of this context, I was able to understand the biases that may have influenced the analysis and interpretation of the interview data. In my analysis of the data, I reviewed the transcripts and resulting nodes a number of times, ensuring that the emerging themes were a result of the data, rather than my bias. Regular discussions with my committee members through the course of analysis helped me to better understand where my biases may have influenced the emerging themes, allowing me to re-evaluate the findings to ensure that they truly emerged from the data.

4.2.2 EPISTEMOLOGY

For the purpose of this thesis, a social constructionist lens was adopted. Constructivist philosophies place 'emphasis on the world of experience as it is lived, felt, undergone by social

actors' (p.125), recognizing that objective truths are the result of perspective (Schwandt, 1994).

The constructivist view regards the interaction between researcher and participant as essential to

understanding the lived experience of the participant (Ponterotto, 2005). Social constructionism

assumes that people create a unique reality through the process of social exchange (Schwandt,

1994). In other words, knowledge is created through social processes and systems, rather than by

individual minds (Allen, 2005). Considering the goals of this thesis, an epistemological focus on

lived experience was most appropriate. In analyzing the qualitative transcripts, it was recognized

that the experiences were co-constructed between researcher and participant during each

interactive interview.

4.2.3 CODING, THEMING, AND INTERPRETING THE DATA

Prior to analysis, each interview transcript was actively read in its entirety to ensure the

researcher was familiar with the data (Braun & Clarke, 2006). After reading, the researcher

sorted the transcripts into one of four categories based on the transition in which the interview

took place. The four categories were: (1) acute care to home, (2) acute care to inpatient

rehabilitation, (3) acute care to long term care, and (4) inpatient rehabilitation to home. Each

category received a separate NVivo file. The patient and family caregiver transcripts were

additionally coded in separate files from the health care provider transcripts.

The data was analyzed using emergent coding techniques according to Lofland, Snow,

Anderson & Lofland (2006) and Braun & Clarke (2006). The experiences and perspectives of

patients, family caregivers and health care providers were considered throughout the emergent

coding process. The initial coding process allowed the researcher to develop a series of nodes

relevant to the transitional experiences of the participants. During this process, the researcher

inspected each transcript, line-by-line, and coded the data into emerging nodes based the on

open-ended questions outlined in Lofland et al. (2006):

- What is this? What does it represent? (Strauss & Corbin, 1990 in Lofland et al., 2006)
- What is going on? What is the person saying? How do the structure and context serve to support, maintain, impede or change these statements? (Charmaz, 2001 in Lofland et al., 2006)

The initial coding process was followed by a more structured theming process (Braun &

Clarke, 2006). This process built upon the initial coding to organize the existing initial nodes into

larger conceptual topics appropriate for further elaboration (Lofland et al., 2006; Braun &

Clarke, 2006). Prior to the theming process, the final nodes for each patient and family caregiver

transcript were labeled by the transition category. In other words, the nodes from each distinct

NVivo file were themed separately. The health care provider nodes were similarly sorted into

themes for each care setting. The final themes were then matched across transitions to develop an

understanding of the overlap and contrasts of themes across various transitions and settings.

Each of the developed themes were recorded, and refined. During this process, themes

lacking supporting data were discarded (Braun & Clarke, 2008). Additionally, similar themes

were combined while overwhelming themes were divided into additional categories (Braun &

Clarke, 2006). This process lead to the development of a final thematic map. The thematic map

contained each of the decided upon themes, while still reflecting the meanings in the dataset as a

whole (Braun & Clarke, 2006). The themes were then named and defined to explain the key

aspects of each theme (Braun & Clarke, 2006). After defining each theme, an analysis of the

overlap was completed by comparing and contrasting the themes and their definitions for each

transition category. During this stage, the themes were compiled, where possible, to demonstrate

the similarities and differences between transitional settings.

4.3 Focus Group Interview

In addition to the secondary analysis, a focus group interview with health care providers was conducted. Focus group interviews generate qualitative data through interaction and communication between a number of participants (Kitzinger, 1995). This allows for participants to expand upon one another's opinions and experiences, allowing for an in-depth exploration of the topic (Kitzinger, 1995).

Recruitment for this focus group interview occurred through existing relationships with a committee focused on system solutions for older adult issues within health care. As such, the focus group can be said to be 'naturally occurring' allowing for the members to more easily relate to each other's perspectives and experiences (Kitzinger, 1995). It is thought that naturally occurring groups provide more encouraging environments in which people can engage with one another and formulate unique ideas (Kitzinger, 1995).

During the focus group interview, the researcher presented the results of the secondary analysis and asked for feedback about how the results may relate to current practice, and about themes that may be missing from the data. While the members of the focus group were not the original interviewees from the InfoRehab Transitions study, this focus group interview may work as a member checking process in which the participants commented on the extent to which the themes represent their own experiences. Additionally, the results of this focus group provide valuable insight into which experiences are still relevant to the current health system.

The focus group interview was audio recorded, transcribed verbatim, and analyzed according to process outlined in section **4.2.2**. The emerging themes from the focus group interview were compared with the secondary analysis themes, and reported on accordingly.

4.4 Ensuring Methodological Rigour

In order to ensure trustworthiness of the findings, the criteria of credibility, dependability, confirmability, and transferability was applied (Lincoln & Guba, 1985).

Credibility refers to the accuracy in which the data has been represented and can be established through triangulation and member checking. This thesis examined the experiences of a wide range of participants by including patient, caregiver, and health care provider transcripts in the analysis. As Shenton (2004) explains, a range of viewpoints can be a source of triangulation when the perspectives and experiences can be verified against one another, providing a 'rich picture of the attitudes, needs or behaviour of those under scrutiny' (p.66). In addition, this thesis implemented a member checking process through a focus group interview, outlined in section **4.3**. Member checking allows participants to comment on the extent to which the results match their real experiences and perspectives (Creswell & Miller, 2000), and provides a strong method for ensuring credibility (Lincoln & Guba, 1985).

Dependability refers to the reproducibility of the study and can be established through thorough description of the research design and methods (Shenton, 2004). In this thesis, dependability was ensured through the detailed description of the research design and methods, including the coding and theming process.

Confirmability, or ensuring the results objectively match the data, can be established through the use of an audit trail (Shenton, 2004; Carcary, 2009). Through the process of secondary analysis, an audit trail was created to ensure thorough reflection and to clearly document decisions made throughout the analysis.

Transferability relates to the generalizability of the results to alternative contexts and how well the results can be applied to wider populations (Shenton, 2004). In this thesis, transferability was supported through the description of the settings in which the original data collection took place, the inclusion and exclusion criteria for the participants, the data collection methods, and the time period over which data collection took place (Shenton, 2004).

4.5 Ethical Considerations

Ethics clearance for the InfoRehab Transitions data collection and secondary analysis for this project was obtained through the University of Waterloo Office Research Ethics (ORE#15727). Ethics clearance for the potential focus group was also obtained through the University of Waterloo Office of Research Ethics (ORE#22936).

CHAPTER 5: RESULTS

5.1 Secondary Analysis Results

InfoRehab interviews conducted with nineteen patients, fourteen family caregivers, and fifty-nine health care providers were analyzed for the purposes of this project. Table 2 provides an overview of the number of patients, caregivers, and health care providers included in this analysis from each location and transition type. In many cases, the participants were interviewed on more than one occasion for each transition (i.e., in acute care prior to the transition and in inpatient rehabilitation after the transition); the number of transcripts analyzed per transition, setting, and participant group are outlined in Appendix G.

TABLE 2 PARTICIPANTS IN EACH TRANSITION, LOCATION, AND STAKEHOLDER GROUP

		Acute Care to Home	Acute to Long Term Care	Acute Care to Inpatient Rehabilitation	Inpatient Rehabilitation to Home
Patients	*Large Urban*	1	0	3	3
	Mid Size Urban	2	0	3	2
	Rural	5	1	2	2
	Total	**8**	**1**	**8**	**7**
Family Caregivers	*Large Urban*	1	0	1	1
	Mid Size Urban	2	1	3	2
	Rural	2	2	0	0
	Total	**5**	**3**	**4**	**3**
Health Care Providers	*Large Urban*	2	2	3	0
	Mid Size Urban	3	2	6	2
	Rural	1	2	1	2
	Total	**6**	**6**	**10**	**4**
Total		**19**	**10**	**22**	**14**

Family caregivers were children (n=7), the patient's spouse (n=5), or children-in-law (n=2). In some cases, interviews were completed with more than one caregiver per patient. Health care providers consisted of case managers (n=10), registered nurses (n=8), medical doctors (n=3), physiotherapists (n=13), occupational therapists (n=9), practical nurses (n=6),

clinical nurse leaders (n=3), surgeons (n=2), administrative staff (n=3) and physiotherapist

assistants (n=2). Most health care providers worked in acute care (n=22) and inpatient

rehabilitation (n=22), followed by home care (n=10) and long term care (n=5). Most often,

multiple providers were interviewed for each patient.

As outlined in Table 3, each patient transcript included in the analysis described a

transition between one and three times during the patient's care journey.

TABLE 3 PATIENT TRANSITIONS

Patient	Site	Location Prior to Fracture	Transition
Patient 1	Mid Urban	Home	Acute Care → Inpatient Rehabilitation → Retirement Home → Home Care
Patient 2	Mid Urban	Home	Acute Care → Inpatient Rehabilitation → Home Care
Patient 3	Mid Urban	Home	Acute Care → Home Care
Patient 4	Mid Urban	Home	Acute Care → Home Care
Patient 5	Mid Urban	Home	Acute Care → Inpatient Rehabilitation
Patient 6	Mid Urban	Long Term Care	Acute Care → Long Term Care
Patient 7	Rural	Home	Acute Care (Rural) → Retirement Home → Home (no home care)
Patient 8	Rural	Home	Acute Care (Rural)→ Long Term Care → Home (no home care)
Patient 9	Rural	Home	Acute Care (Urban) → Acute Care (Rural)→ Home Care → Out Patient Rehabilitation
Patient 10	Rural	Home	Acute Care (Rural) → Home Care
Patient 11	Rural	Home	Acute Care → Acute Care (Rural) →Long Term Care
Patient 12	Rural	Retirement Home	Acute Care (Rural) → Acute Care (Urban) → Acute Care (Rural) → Retirement Home (with home care)
Patient 13	Rural	Home	Acute Care (Rural) → Long Term Care
Patient 14	Rural	Home	Acute Care (Rural) → Home Care → Out Patient Rehabilitation
Patient 15	Rural	Home	Acute Care (Rural) → Home Care → Out Patient Rehabilitation
Patient 16	Large Urban	Home	Acute Care → Home Care
Patient 17	Large Urban	Home	Acute Care → Inpatient Rehabilitation → Assisted Living → Home Care

Patient 18	Large Urban	Home	Sub-Acute Care → Readmission → Inpatient Rehabilitation → Home Care
Patient 19	Large Urban	Home	Acute Care → Inpatient Rehabilitation → Home (no home care)

Patients, family caregivers and health care providers each had distinct perspectives on transitional care based on their personal experiences. Generally however, all three groups believed that transitional care could be improved. Seven key themes related to transitional care experiences were identified:

1. Multiple different providers contributed to patient and family caregiver confusion

2. Family caregivers were not considered important in the patient's care

3. System-related issues impacted care experience

4. Patients and family caregivers felt uninformed

5. Transitions increased stress in patients and family caregivers

6. Care was not tailored to patient needs

7. Providers faced barriers in getting adequate information

Certain themes appeared to be more relevant at select transition points in a patient's care. Table 4 outlines the prominent themes in each transition setting.

TABLE 4 THEMES BY TRANSITION SETTING

	Acute Care	Inpatient Rehabilitation	Long Term Care	Home
Multiple different providers contributed to patient and family caregiver confusion	X	X		
Family caregivers were not considered important in the patient's care	X	X	X	
System-related issues impacted care experience	X	X		

Patients and family caregivers felt uninformed	X	X	X	X
Transitions increased stress in patients and family caregivers	X			X
Care was not tailored to patient needs	X	X		X
Providers faced barriers in getting adequate information	X	X	X	X

Similarities seemed to exist in transitional experiences to home settings, and in transitional experiences to other formal care settings.

5.1.1 TRANSITIONS TO FORMAL CARE SETTINGS

In transitions to formal care settings, such as long term care and inpatient rehabilitation, similarities in experience emerged through the secondary data analysis. These similarities were largely related to three of the emerging themes: Multiple different providers contributed to patient and family caregiver confusion; Family caregivers were not considered important in the patient's care; System-related issues impacted care experience. In transitions to other formal care settings, patients, caregivers and health care providers seemed most concerned with their general confusion about the patients care and transition process.

5.1.1.1 MULTIPLE DIFFERENT PROVIDERS CONTRIBUTED TO PATIENT AND FAMILY CAREGIVER CONFUSION

In transitions to and from formal care settings, patients and caregivers frequently commented on the number of health care providers involved in their care. Patients and caregivers in the acute care to inpatient rehabilitation transition were especially troubled by confusion regarding the multiple providers involved in their care, and commonly described the difficulty they experienced in differentiating between various types of employees or providers in acute care and inpatient rehabilitation settings:

"It's not that I don't remember, I wouldn't know anyway because you don't know whether they're nurse, health provider or whether they're just one of the people that serve the meals. You don't know, because there's no indication on their uniform. And as it was, again I said, I'm not comparing this to the past, but there was a registered nurse. It always appeared where you could see it, your pin. And you would know what you were dealing with. But here it's just all the same; they have a little name dangling down here. Well you can't even catch the names." (Mid Urban, Patient 0, Acute to Inpatient Rehabilitation)

Patients and caregivers explained that with everyone dressed identically, and no one displaying a name tag, they often felt that they were directing questions towards the wrong individuals. One health care provider also identified this issue, explaining that adding more providers may not be the best solution for older people:

"There's so many people already involved with them and because there's seniors you go in and say 'did your physiotherapist…?', 'well which one's she?' So they see an OT, they see a PT, they see their staff nurse, they see the unit resource nurse, they see the doctor, and they see me, you know, and they're totally confused. So how do you get one more person, say I'm going to take your hand and we're going to walk through…. So I just question because it's a senior population, you know, the comorbidities, all these people they are in a four bed ward and there's people coming and going all day, they don't know whether they're house keeping or whether they're dinner tray or if they're actually going to say 'ok now we're going to get up and walk', you know. And to have someone else involved, I mean quite often we have geriatrics see them while they're here… They have geriatrics involved if they become confused you know post-op and so they see the geriatric nurse and she might say I think you need to see the psychologist you know, like they see a lot, a lot of people. So its not so much maybe the patient that needs the guidance as the family which is what we try to do…" (Mid Urban, Case Manager 4, Acute Care)

Patients and caregivers felt that too many providers where involved in their care in acute care and inpatient rehabilitation settings. This was even the case in the rural setting, where may patients transitioned within hospital from acute care to inpatient rehabilitation. Patients and caregivers explained that it was difficult to keep track of which provider was in charge of which aspect of care:

"I think it goes back to consistency. If I had somebody who knows what the history is and everything because every time I would ask the nurse she would have to go and look it up to come and give it to me but if I'm talking to somebody I can ask them medication, his blood pressure, how well is he doing in his physiotherapy and they would be able to

give me the full information but nobody has time to do that." (Mid Urban, Caregiver 1, Acute to Inpatient Rehabilitation)

Many patients and caregivers felt that there was a lack of communication between all of their providers. Patients and caregivers expressed their frustration with this fragmentation of care, citing the inconvenience in having to repeat their story to each provider. They explained that this lack of provider communication meant that no one had a view of the whole picture, resulting in greater confusion about their care and transition process.

5.1.1.2 FAMILY CAREGIVERS WERE NOT CONSIDERED IMPORTANT IN THE PATIENT'S CARE

Throughout all transitions of care, caregivers commented on how little they were considered in the patient's care. This was especially prominent in transitions to formal care settings. The new responsibilities associated with caring for the patient were often overwhelming for the caregivers. Caregivers frequently felt as though they were not included as a part of the patient's care, and their needs were not addressed by the system:

"you know, what seems to get lost in it, is somebody caring for an elderly person with a bad hip, you know, it just seems to be at the bottom of the totem pole." (Rural, Caregiver I202, Acute to Long Term Care)

One health care provider explained that the health care system, especially in acute and inpatient rehabilitation settings, asks caregivers to fit themselves into the system's rules and schedules, rather than working with the caregiver to find a mutually agreeable solution:

"…we're also dealing with families who are middle aged, generally, because our patients are elderly… Most of our family members are at a distance and we're asking them as family to leave behind all of their day to day routines and jump into our culture, our community, and follow our rules. 'The patient has to be out of here by eleven o'clock.' 'But I work?' 'Well you have to take a day off.' Um so, you know… we add stresses to these people just by the rules and policies that we have within the hospital environment, as well. (Mid Urban, Case Manager 7, Inpatient Rehabilitation)

Many caregivers had difficulty getting information from providers, and found it difficult to ask questions. This resulted in greater stress for the caregivers, who frequently felt unsure

about how to help the patient recover. Additionally, caregivers faced barriers in contacting patients in acute care and inpatient rehabilitation settings. Caregivers explained that their stresses and health were not considered in the health system, which is overwhelmingly focused on the patient. Caregivers felt that their needs were not addressed within the system, because they were not considered to be important:

> *"Well, yeah, but then by the same token, when this happened to Mom, it happened to us as well and so, we had to give up a lot of facets of our life, right? 'Cause unfortunately, we have our life to live as well, which is separate from Mom's, right? Even though we live in the same apartment building, we don't live together and even if we did live together we'd still have our own separate life, right?" (Large Urban, Caregiver 4, Inpatient Rehabilitation to Home)*

These feelings were more relevant in acute care, inpatient rehabilitation and long term care settings, where providers were solely focused on the patient. In fact, in the inpatient rehabilitation and acute care settings, providers rarely interacted with caregivers. Providers explained that since most caregivers visit after regular working hours, they never get the chance to talk in person. Additionally, many providers are tentative to have conversations with caregivers under the assumption that they will be difficult to manage, and have unrealistic expectations for the patient's care.

> *"Some of the challenges are family members who refuse to accept the changes that their family members-- you know, their-- that the patient has gone through. And they want them to return to exactly the same situation that they were in before they had their hip fracture, and that's not possible. And so we have to-- you know, it's time consuming to spend time with these people, to explain all the nuances of what's happened to their family member and that, you know-- and sometimes that just needs continued care of the family." (Large Urban, Clinical Nurse Leader 5, Inpatient Rehabilitation)*

In contrast, caregivers in transitions to home appreciated the respite and support of home care providers, that often worked to address their needs, as well as the patient's:

> *"... you know, it's just to have somebody here. But actually, I think I could even just leave him alone for an hour and a half to two hours on his own. 'Cause he's doing pretty good. But it's just peace of mind." (Large Urban, Caregiver 2, Acute to Home)*

Caregivers explained that it was even a relief to have a chance to run errands, which in many cases, they could not have done without the support of home care. However, caregivers in the home setting made it clear that they still felt the stress and pressure associated with their responsibility to ensure that the patient received adequate care.

5.1.1.3 SYSTEM-RELATED ISSUES IMPACTED CARE EXPERIENCE

Across all transitions, patients and caregivers felt that system issues negatively impacted their quality of care. Many patients and caregivers in transitions to formal settings, such as acute care and inpatient rehabilitation, felt that nurses were too busy to provide adequate and personalized care, or answer their questions in detail:

> *"I can see how people fall through the cracks for their condition. If it isn't highlighted there's some part of it slips by and it's not covered and then it doesn't get covered the next day, and eventually it might become an issue but by then they are two days late."*
> *(Mid Urban, Patient 3, Acute to Home)*

Patients explained that many providers in these settings were unfamiliar with their unique needs, conditions, and personality, making it difficult to get the care they need, and ask questions about their care. Many patients, especially those in the inpatient rehabilitation setting recalled asking questions about when they were going home, and having providers avoid answering the question or explain that they did not know the answer, leaving them feeling confused about the next step in their care.

The impersonal and rushed care that patients reported experiencing in the acute care and inpatient rehabilitation settings left the patient feeling doubtful about their care and recovery status:

> *"Just the last few years I've noticed it becoming worse. It's not getting better; it's getting worse. They're getting too far away from the people that they're supposed to be taking care of without them even being aware of it themselves. They don't come and take the*

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time to listen to you. They're telling you things. They don't-- and then they say, 'any questions?' But by that time your head's so full of information from them, how can you sort it out to ask a question? And then if you do ask a question then they're short of time. "I'll be back next-- I'll be back tomorrow. I'll see you on Friday." They don't mean harm but it's doing harm." (Large Urban, Patient 4, Inpatient Rehabilitation to Home)

After as little as a single negative experience, many patients reflected negatively upon the care that they received across their journey, and expressed doubt about the ability of the Canadian health system to address the needs of older people.

Patients and caregivers that had previous experience in the health care system explained that this experience made it slightly easier to navigate the system, especially in acute and inpatient rehabilitation settings, where acquiring information was easier with knowledge of where to look and who to ask. One health care provider commented on why the health system complicates transitional care for patients, caregivers, and providers:

"...it's a system that you don't know anything about until you need to be involved in it or you've had another family member be involved in it. And the second thing is its not a system. As system is made up of parts that interact and the health care environment they don't interact. You know when you're in hospital there's no communication with the people outside." (Mid Urban, Case Manager 1, Acute Care)

5.1.2 TRANSITIONS TO HOME

Similarities also existed between transitions to home, whether from acute care or inpatient rehabilitation settings. Specific similarities existed in relations to the following four emerging themes: Patients and family caregivers felt uninformed; Transitions increased stress in patients and family caregivers; Care was not tailored to patient needs; Providers faced barriers in getting adequate information. In transitions to home, patients, caregivers, and healthcare providers generally discussed their feelings of being unprepared.

5.1.2.1 PATIENTS AND FAMILY CAREGIVERS FELT UNINFORMED

In all transitions, information about the patient's condition, care, and transition trajectory was not readily available or provided to patients or caregivers. This lack of information was especially relevant for patients and caregivers transitioning from acute care to home, or inpatient rehabilitation to home.

Caregivers that experienced transitions from acute care explained that they were often not given any information. The patient however, was often overloaded with information while sedated, tired, or otherwise preoccupied:

> *"… the people that come along and they tell Mom this stuff, but telling someone who's on meds, who's in pain, what they need when all they want to do is curl up and want--go to sleep and just ignore what's going on, because I mean, that's anyone's basic, you know, go fetal. I hate this. I don't want to deal with this" (Large Urban, Caregiver 4, Acute to Inpatient Rehabilitation)*

Patients felt that getting all of the information at once, either upon arrival or after surgery, was not an effective way of providing patients with an understanding of their care trajectory. On occasion, patients were provided with pamphlets or fact sheets containing general information about hip fracture and surgery, but were left to interpret this information independently. In some cases, these pamphlets and fact sheets were passed along to them by patients who had received similar procedures, such as hip replacements. Many of the questions patients had however, pertained to their *unique* care needs and recovery process. Therefore, the standard written information provided by pamphlets was not helpful in answering patients' questions or preparing them for returning to home. Interestingly, health care providers in rural settings commented on how their familiarity with the community may have provided opportunity to better tailor information for the patient's and caregiver's unique circumstance.

"So a lot of questions, they can answer themselves…so when it comes to where the patient lives, or how they were moving before, things like that, a lot of the nurses are good for knowing that stuff." (Rural, Physiotherapist 3, Inpatient Rehabilitation)

In transitions to home settings, caregivers explained that they felt uncertain about their ability to continue caring for the patient and promoting the patient's recovery at home, largely because they were uncertain about what the patient needed moving forward:

"You know I wasn't sure what we needed, whether we needed the physiotherapy or anything extra or what we needed at the time." (Mid Urban, Caregiver 1, Inpatient Rehabilitation to Home)

Caregivers experiencing a transition from acute care to home or inpatient rehabilitation to home expressed their concerns about having little to no information about how to care for the patient in their home setting. This lack of information contributed to increased stress for the caregiver, and feelings of uncertainty in the patient.

The difficulty that patients and caregivers faced in getting information from providers contributed to a sense of being instructed through their care, rather than being actively involved in their care decisions. Patients and caregivers did not feel involved in the decisions made about their care. These feelings of uninvolvement were more evident in transitions from acute care and inpatient rehabilitation settings.

"I guess I could have been more involved but I just kind of got the impression the decisions were already made… I mean I asked a lot of questions and whatever but I suppose if I was really dead set against them I could have made a fuss but I didn't really feel that it was really up to me." (Mid Urban, Caregiver 0, Inpatient Rehabilitation to Home)

Patients and caregivers often attributed this lack of involvement to the speed at which transition decisions needed to be made. Discharge decisions were frequently made last minute, and patients reported feeling that they were being discharged so that a new patient could have their bed. Due to the speed and lack of involvement with which decisions were made, patients

and caregivers had to repeatedly ask the same questions to multiple providers in order to receive the information that they needed. Patients and caregivers explained that the lack of involvement in their care and the speed at which their transition occurred left them feeling unprepared for their return to home.

5.1.2.2 TRANSITIONS INCREASED STRESS LEVELS IN PATIENTS AND FAMILY CAREGIVERS

During transitions, caregivers felt overwhelmed with their increased responsibilities. While this was a common theme across all transitions, it was especially relevant for transitions to home. Caregivers of patients that were moving home were often left to prepare the environment for the patient's return, ensure that the patient was properly cared for, and arrange all follow-up appointments. Caregivers explained that this was a difficult task, given that they had little information on what the patient might need. Caregivers did their best to adjust their home for the returning patient, but were often left guessing what was required:

> *"I made sure a bed was down here and he had a raised toilet seat and he had his walker and he had a cup thing that if he had to go at night he could pee in that, and all the equipment. I was thinking of all the equipment that he would need to make him comfortable." (Mid Urban, Caregiver 2, Acute to Home)*

Many caregivers found that the equipment they had installed in their home was not useful or comfortable for the patient. This left the caregiver scrambling to retrieve more appropriate equipment, while the patient struggled to use what was currently installed.

Patients and caregivers transitioning from acute care settings seemed most concerned with the lack of involvement in their care transitions. In this transition, patients and caregivers wished they had more tailored information about the process and future care:

> *"I would like to know how… he's progressing approximately. Will he be out with, say, a week if he really works hard? Is there any other place that he could go to for*

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rehabilitation besides here? Do they have other hospitals that have rehab?" (Large
Urban, Caregiver 2, Acute to Inpatient Rehabilitation)

In transitions from the acute setting, it was especially important for patients and

caregivers to understand their specific and unique care trajectory. In contrast, patients

transitioning from inpatient rehabilitation seemed more concerned about the lack of constant

professional support they might experience at home, which resulted in uncertainty regarding

their ability to succeed at home:

> *"But there's a big "but" in there that, you know, will I able to manage all right." (Large*
> *Urban, Patient 3, Inpatient Rehabilitation to Home)*

Patients and caregivers transitioning from inpatient rehabilitation were often

apprehensive about transitioning from an environment with high support, to one of low support.

Patients worried that they may not be ready to return home, or may not be successful in

recovering at home.

5.1.2.3 CARE WAS NOT TAILORED TO PATIENT NEEDS

Many patients transitioning from acute to home, or inpatient rehabilitation to home,

commented on the fact that the care they received in acute care and inpatient rehabilitation

settings was not helpful within their next setting, especially when their next setting was home.

Patients explained that these uncertainties left them feeling anxious and unprepared for the

transition:

> *"Always in the back of your mind you're wondering, like, what are my limits? And*
> *nobody really has an answer for that because I guess it depends on your particular hip*
> *problem. So you have to judge that for yourself. And hopefully you'll do the right thing."*
> *(Large Urban, Patient 5, Inpatient Rehabilitation to Home)*

However, after returning home, many patients explained that these feelings of uncertainty

were reduced by the efforts of the home care providers. Patients appreciated the providers'

efforts to personalize their therapy to their particular lifestyle and home environment. However, patients expressed disappointment about the limited number of appointments for some provided home care services, such as physiotherapy.

Many patients, especially those in inpatient rehabilitation facilities, felt neglected and lonely. They explained that the lack of time spent with people, including providers, contributed to these feelings:

> *"And I guess that's what the frustrating part of it all is. It's that you're here on your own and you can't do anything. You're just here and you can't talk to anybody. You can talk but you don't have anybody to talk to. And they just sort of, well you do this, you know, and then that's it, goodbye type of thing." (Mid Urban, Patient 0, Acute to Inpatient Rehabilitation)*

Patients explained that this isolation also contributed to a lack of social and cognitive stimulation in acute care, inpatient rehabilitation, and long term care settings. Patients in these settings explained that they experienced a decline in their cognitive capabilities during their stay. These feelings of loneliness and isolation often left the patient feeling hopeless in their recovery.

5.1.2.4 PROVIDERS FACED BARRIERS IN GETTING ADEQUATE INFORMATION

Providers in all settings explained that electronic medical records were very useful for retrieving information about the patient. However, without compatible systems across different settings, providers had limited access to a patient's previous records.

> *"I truly believe electronic medical records to be shared between institutions is the way to go. I cannot believe that in this day and age we're still relying on pencil and paper and that is definitely where the cracks are. Because I think if information was readily available, electronically, you wouldn't be tracking people down. You wouldn't be chasing them down. So, to me, that's the number one issue is information flow is poor between institutions because we're not on-- all on the same EMR. So then we then rely on humans, and, of course, the human chain and link is prone and folly to human error which is why sometimes despite our best intentions, people fall through the cracks." (Large Urban, Physiotherapist 4, Acute to Home)*

To address these gaps, each provider in a new setting resorted to completing their own assessment of the patient. In addition to these assessments, providers often relied on patients and caregivers for information that they could not retrieve from a previous setting. This added to the workload of the providers, who already felt constrained in the amount of time that they could afford to spend with patients. The lack of communication also added stress to the patient, who continually had to reiterate information to each new provider, while still feeling that no one had a strong grasp of their condition or recovery needs.

This gap in information sharing was particularly problematic for home care providers. Providers in the home explained that they often saw a patient for an initial assessment without any previous knowledge of their condition.

> *"So I know that discharge planning can change quite quickly, you know, the discharge date. Ideally, yes, we like to know all those-- that bit of information, that everything was in place prior to the client coming home. But I know it's not done and I know it's because you've got the O.T. doing her thing, the physio doing her thing in the community... I mean, there's just so many pieces happening, that supposedly somebody's looking at the big picture." (Large Urban, Case Manager 4, Acute to Home)*

It often took so long for the patient's records to be shared with the home care provider that, by the time they were received, the provider already knew the patient in more detail than the records could provide them. Home care providers explained that not having access to a patient's charts resulted in a longer intake assessment, which ultimately limits the time that they can spend with the patient working on recovery treatments and strategies. Providers working in the home setting went on to explain that without a common chart, the patient is assessed and treated in pieces, which prevents providers from understanding the patient as a whole.

5.2 Focus Group Interview Results

After completion of the secondary analysis, a focus group interview was conducted with a group of 15 participants involved in health system-level initiatives related to the care of older adults. The participants spoke to the care of older adults in the same mid-sized urban location originally investigated in the InfoRehab study. The participants worked in Home and Community Care (n=2), Regional Community Services (n=1), Community Support Services (n=1), Primary Care (n=1), Specialized Geriatric Services (n=4), the Alzheimer's Society (n=1), Regional Outreach Programs (n=1), Long Term Care (n=1), Hospital Clinical Services (n=1), and the Local Health Integration Network (n=1). Four of the participants identified as health care providers, including a nurse practitioner (n=1), social workers (n=2), and an occupational therapist (n=1). The focus group interview participants were provided with an overview of the secondary analysis findings, accompanied by a verbal description of the results. Participants were asked to comment on how the results matched their experiences in the current health care systems, and about gaps within the findings.

Analysis of the focus group interview transcript led to the development of 5 key themes:

1. Enhancing knowledge and understanding in patients and family caregivers is important for safe and effective transitions

2. Appropriate collaboration and communication between health care professionals improves transitions

3. Consistency in health care providers can support system navigation and transitional care

4. Development of system solutions should involve input from patients, caregivers, and front-line providers

5. Transitional care may be improved through interventions aimed at enhancing communication and information sharing

Overall, the participants were not surprised to learn that experiences of those transitioning to home settings were similar, as were experiences of those transitioning to other formal care settings, commenting on how it reflects the significance of system-level influence on transitional care:

"I don't think it's surprising at all. And I think it just goes to show the system level impact, regardless of where you are going" (*Focus Group Participant 2*)

5.2.1 ENHANCING KNOWLEDGE AND UNDERSTANDING IN PATIENTS AND FAMILY CAREGIVERS IS IMPORTANT FOR SAFE AND EFFECTIVE TRANSITIONS

The focus group interview participants commented on the extent to which the secondary analysis results demonstrated the lack of information sharing between health care providers, and patients and caregivers. One participant explained that, in acute care settings, there seems to be a great amount of variability in information sharing from one health care provider to the next:

"...the variability in acute care with providers who do provide information and include them as part of the team, and people who walk in as though their invisible. So I think there's a disconnect there." (Focus Group Participant 1)

The participants also spoke about the importance of engaging patients and caregivers at the centre of their care, rather than retroactively fitting them into the care plan:

"I think the idea of using care conferences with people that are involved. Both from the perspective of everyone can meet everybody at the same time, they don't have to... because that's onerous. And the second thing is that they can understand the, the team can understand, so what's that goal of that person, and that family, and then we can organize ourselves around that versus how does the family and the care partner fit in. So I think that a care conference is a great opportunity." (Focus Group Participant 5)

That participants also explained that patients and caregivers need to have their care plans explained to them, in order to ease their nerves about the uncertainty to come, especially when returning to home.

"The other thing…was 'we want to be part of the decision making'. They're often receivers of information but have not been part of the process and that leaves them in a really, and as you've said with you're data, in a really compromised position when they're going home, and they don't really know how to put this all together." (Focus Group Participant 5)

They also explained that building confidence in the patient and their caregiver, especially in transitions to home, is key in ensuring a better patient experience and effective transition:

"What is also interesting to me, when I think about all of the tools that we have access to as health care professionals to coordinate care, and we often don't even… like if I'm reading ClinicalConnect and I call the doctor's office or the nurse and say this is going on, and say 'oh, I didn't know, oh I didn't know'. So if I don't feel confident, imagine the caregiver's going home and feeling… Because it is about bolstering confidence and making them feel supported right? So if we have all this information available to us and people still aren't feeling supported and confident…" (Focus Group Participant 6)

One key comment however, surrounded the need to provide patients and caregivers with the *right* amount of information, and ensuring that they are not overwhelmed with too much information. Interestingly, one participant explained how sharing a lot of information is beneficial to the health care provider:

"And I think for service providers and the care team there is a certain comfort in giving lots, right? It helps calm the nerves of that hospital team as the person is transitioning to the community. And so, how do you build that comfort in listening to the patient and family about, 'what do you really need?' for a successful transition home, or to rehab." (Focus Group Participant 2)

The focus group interview participants generally agreed that better information sharing and education of the patient and caregiver would work to improve transitional care.

5.2.2 APPROPRIATE COLLABORATION AND COMMUNICATION BETWEEN HEALTH CARE PROFESSIONALS IMPROVES TRANSITIONS

The focus group interview participants explained that, in their experience, communication across the system is a major issue. One participant explained that there are often too many providers involved, which leads to poor coordination between providers.

"I think there's so many people involved in the care and they're not linked, which causes a lot of issues." (Focus Group Participant 7)

Despite general agreement that including more people made it more difficult to coordinate, participants still felt that it was important to include as many of the patient's providers in care conferences as possible.

"We try to have all the care providers there and available to speak to the family and the caregiver at the same time. Nothing's perfect, but there's definitely opportunities." (Focus Group Participant 3)

The participants went on to explain the difficulties of preparing to receive a patient when information has not been communicated to them, using long term care as an example.

"There's still some challenges with acute care seeing that long term care is in the circle of care when you send somebody to the hospital... because we have a responsibility to ensure that our staff are able to talk to the hospital staff, to be able to talk and plan about 'what's the progress of Mr. Smith? When can we expect him back? What do we need to have in place?'.... And really it's just good care, it's in the best interest of the client, of the resident, of the patient. That's really why we want to have that conversation, it's not we're trying to be nosey about somebody, it's just that we really need to know. Information is power, and we need to have that information in order to do the best planning, and have the best possible chance at success for a transition, both ways." (Focus Group Participant 3)

The participants stressed the importance of engaging providers on both sides of the transition in care conversations, to ensure that transitions are streamlined.

5.2.3 CONSISTENCY IN HEALTH CARE PROVIDERS CAN SUPPORT SYSTEM NAVIGATION AND TRANSITIONAL CARE

The participants in the focus group interview commented on how the secondary analysis results indicated that a lack of consistency across settings tended to increase stress in patients and caregivers, especially in transitions to home. The participants commented on how, in some settings such as inpatient rehabilitation to home, patients and caregivers may have a more streamlined experience:

> *"So that might be one aspect of rehab that might be more effective, around working with home and community care, and around knowing what your first appointment is, and who you're going to see when you get home, for that transition from rehab to home. But we do know that there are definitely a lot of opportunities to improve." (Focus Group Participant 3)*

The participants explained that transitional experiences can be improved by maintaining a consistent provider across settings. One participant explained that the current model in which nurses in acute care settings work long shifts over a short period of time may be a barrier to consistency:

> *"...12 hour shifts. Because if you think about it, four days in, and nobodies there for a solid week anymore, like its four days. And I've heard nurses say, those last few hours, like they're just trying to get everything done. And so that continuity of care, if you think about it, so every four days somebody is changing." (Focus Group Participant 8)*

Conversely, the participants commented on the effectiveness of some rural models of care that involve the same, familiar provider in each setting of care, thereby enhancing continuity:

> *"I think it would be interesting to look at the [Rural Hospitals] Model, where the doctor is the doctor. Like he's in and out of the hospital, and versus the hospitalist. I just think there's a disconnect. Like you just see it, it's like coming into a whole brand new setting, nobody knows you, and when you observe – and I'm just observing here—[Rural locations] where the is no hospitalist, the family doctor goes in, knows you, knows what that plan is, knows when the next appointment is, knows when you're going to be*

discharged, knows what you're going to do. And I have to say, I do wonder what hospitalists have done to the whole impact of transition of care..." (Focus Group Participant 8)

"And having the same care coordinator follow those patients into the hospital and back to the community. Whereas, the other hospitals in [Region] is where there are care coordinators on-site, and then community care coordinators. So that—that similar disconnect, or transition of care between providers." (Focus Group Participant 1)

Participants also suggested that transitional care could be improved through better system navigation, commenting on the need to "*walk with someone*" *(Focus Group Participant 3)* across their care journey. One participant suggested having a single, consistent contact person to answer questions and coordinate patient care:

"And the family can have, maybe, one person that they connect with, and then they're responsible for letting the team know. That's been helpful. Same thing with family physicians. Family physicians say, 'I don't want 7 providers calling me with the same information, can you pick one person and have that person send off a note on behalf of everybody or calling my nurse or myself- one time'." (Focus Group Participant 5)

The idea of a consistent contact for patients, caregivers, and health care providers was popular among the focus group interview participants, who commented on how this might save time and result in better coordination.

5.2.4 DEVELOPMENT OF SYSTEM SOLUTIONS SHOULD INVOLVE INPUT FROM PATIENTS, CAREGIVERS, AND FRONT-LINE PROVIDERS

The focus group interview participants explained that the secondary analysis findings indicated that system level solutions may be required, and stressed the importance of including patients and families in health system planning.

"the inclusion of patients and caregivers in, not only planning individualized care, but planning programs and planning services is really paramount as we work towards changing the culture as to how we think about the people that we serve, and really working together with them to ensure that we're planning together, that there's a shared understanding..." (Focus Group Participant 1)

One participant cautioned that, while it is important to include patients and caregivers, it

is equally important to include front-line health care providers. The participant went on to

explain that educating front-line staff on the current system and services should be a priority:

> "And so often, you know, questions come to the front line therapists, nurses, and it just
> quickly gets passed to the care coordinator, but the care coordinator is one for a couple
> of units perhaps, right? So, it's spread very thin. So there's need for the whole team to be
> able to answer questions. Yes, there may be things that are very specific that need one
> particular expertise of one particular person, but there should be enough knowledge…
> We want to get to a point where there's enough knowledge that we're operating as one
> team…" (Focus Group Participant 1)

The participants generally agreed that all parties should be engaged in the development of

transitional care interventions.

5.2.5 TRANSITIONAL CARE MAY BE IMPROVED THROUGH INTERVENTIONS AIMED AT ENHANCING COMMUNICATION AND INFORMATION SHARING

The participants of the focus group interview came up with a number of potential

solutions and strategies for improving transitional care. On participant discussed the need to

improve patient-provider communication, and how that might be accomplished by incorporating

more time for communication in routine care:

> "We need to carve out some time for old fashioned care and old fashioned talking to
> people, where I think we've really minimized that in becoming so…'effective' [laughs].
> But we need to go back to actually talking to each other, asking people about what they
> need, what they want, what do they understand, what do they not understand? And
> that takes time." (Focus Group Participant 7)

Another participant discussed the need for better communication regarding the discharge

plan, explaining that patients and caregivers should know the plan as soon as it is created:

> "So really we should be doing discharge planning all along, knowing where they are,
> and any time they fall off of that trajectory, then you re-evaluate. But the discharge
> planning should be ongoing, and should really begin on that very first day… So, if right
> off the bat, you have somebody planning, proactively, I think we can facilitate easier,

better transitions, better communication, and better quality of care all around." (Focus Group Participant 8)

That participant also discussed the potential for harnessing technology to facilitate better transitions through information sharing and education:

"I think we could almost do like an orientation too, like have video. I think if we use technology... I think of when kids go off to university they get to click on a link that says this is what you can expect, here are some frequently asked questions... I think, if you had that orientation, you could do it in different methods, where they just watch it on their own, or with frequently asked questions we could say these are the questions to make sure you have answered prior to—throughout each stage of your family member's stay, or your stay in hospital. Or you could have it set up where they watch it, there is a certain time in the day in the hospital where they could watch it and then a social worker comes in and answers any questions afterwards. Like I think there are different methods of how you could do that piece." (Focus Group Participant 8)

Participants cautioned however, that many of these solutions are challenged by the short length of stay within many of these settings:

"We have to think about too the length of stay, so that's the other part of it. Is how quick turn over occurs, in many areas, not all, but you know certainly in many areas." (Focus Group Participant 3)

The participants suggested that a problem as complex as care transitions may not easily be addressed through single-faceted solutions.

CHAPTER 6: DISCUSSION

Secondary analysis of the InfoRehab Transitions data resulted in seven key themes related to the transitional care experiences of older patients with hip fracture, their family caregivers, and their health care providers. This analysis demonstrated that transitional care experiences differed by transition type, but that similarities existed between transitions to formal care settings (i.e., long term care, inpatient rehabilitation) and between transitions to home. The results of the focus group interview provided five emerging themes that commented on the role of the system in transitional care, suggesting that many of the themes from the secondary analysis may best be addressed through multi-faceted, system level solutions.

6.1 Transitions to Formal Care Settings

In transitions to long term care and inpatient rehabilitation, patients, caregivers, and health care providers had generally reported feeling uninformed, having difficulty with information sharing, and challenges with involving multiple providers in the patient's care. Generally, patients, caregivers, and health care providers involved in transitions to other care settings felt confused about the patient's care and the transition process. Additionally, aspects of other themes, such as increased stress in patients and caregivers, and system-related issues, also shared similarities in transitions to formal care settings.

While being uninformed and uninvolved was common across all participant and transition types, transitions to other formal care settings seemed to leave patients and caregivers especially confused about their transition, their care, and their progression. The focus group participants explained that this was understandable, considering the number of providers involved in these transitions, and the tendency for providers in the current setting to not

communicate with providers in the next setting. Previous InfoRehab studies have reported on the difficulty that patients, family caregivers, and health care providers have in obtaining the information they need (Toscan et al., 2012; McLeod et al., 2011; Johnson et al., 2012; Glenny, Stolee, Shebian, Jaglal, 2013; Toscan et al., 2013; McMurray et al., 2013; Elliott et al., 2014). In fact, Toscan and colleagues (2012) reported that patients were commonly completely uninvolved in conversations about their care. Patients and caregivers seemed to attribute the lack of information to the sudden nature of transitions, explaining that because they were unaware of when they would transition, many of their questions went unasked and unanswered. Interestingly, the focus group interview participants commented on the need to inform patients and caregivers on their discharge plan, as soon as one has been created, and suggested that more patient-centred approaches should be embraced.

This analysis revealed that in transitions to formal care settings, patients and caregivers reported feeling 'out of the loop' and unimportant to their health care providers. Toscan and colleagues (2012) reported that InfoRehab patients 'disengaged from management of their own care' due to the perception of their role as a passive participant with 'no control and personal autonomy over their care' (p.6-7).

This secondary analysis also revealed that family caregivers were rarely involved in care decisions in acute care, inpatient rehabilitation, and long term care settings. Caregivers explained that transitions between these settings seemed to occur suddenly based on decisions of which they were not aware, again connecting with the focus group's comments about better communication of the discharge plan. Glenny and colleagues (2013) explain that, while providers involved in the InfoRehab study valued the information that family caregivers could provide, they did not feel obligated to contact the caregivers unless they had difficulty getting

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information from the patient themselves. Patients and caregivers may have felt 'out of the loop' because health care providers were focused on receiving information, rather than providing information (Glenny et al., 2013). This secondary analysis suggested that, despite not having important information about the transition, family caregivers still felt responsible for certain aspects of the patient's care across transitions to formal care settings. Toscan and colleagues (2012) suggest that caregivers experience these continual responsibilities, regardless of how prepared they may feel, because they serve as a common link on which health care providers can rely, as they move across care settings with the patient.

Patients and caregivers were often concerned about the number of different health care professionals involved in their care, which left them unsure of who was responsible for what portion of their care. The focus group participants suggested that patients and caregivers be connected with one lead health care provider, to whom their questions could be directed. McLeod and colleagues (2011) reported that the use of multidisciplinary teams is a common strategy intended to enhance the care of complex patients, but noted that as the patient's complexity grows the size of their 'circle of care' also grows. McLeod and colleagues (2011) go on to report that, for InfoRehab health care provider participants, larger circles of care were challenging to effectively coordinate in fast-paced acute settings, but seemed to be more effective in relatively steady settings, such as inpatient rehabilitation. The findings of this analysis indicated that while health care providers in inpatient rehabilitation settings found the multidisciplinary approach beneficial, patients and caregivers still seemed to find the variety of providers confusing. One suggested solution that emerged in both the secondary analysis and focus group interview related to the idea of having a single provider to coordinate the care of the patient. This suggestion mirrors the Transitional Care Model, which works to coordinate care

through a Transitional Care Nurse who follows the patient and enhances continuity of care (Naylor et al., 2010). Similar models of coordinating care, in which a health care professional works as a 'navigator', have been successful in improving quality of life and satisfaction with care, reducing length of stay, and enhancing integration and coordination in various patient populations and health settings (Lee et al., 2011; Kelly et al., 2014; Ferrante, Cohen, Crosson, 2010)

Patients and family caregivers in both acute care and inpatient rehabilitation settings worried that, in segmenting the patient's care to various different specialized professionals, no one was seeing the whole picture. As Toscan and colleagues (2012) explained, InfoRehab health care provider participants seemed to feel less responsible for the patient's care as the size of their circle of care grew. Similarly, caregivers and patients seemed to take a passive role in the transition process, perhaps due to the number of individuals already involved in their care (Toscan et al., 2012).

The feelings of being uninformed and uninvolved were consistent throughout the experiences of patients, caregivers, and health care providers transitioning to other formal care settings. This lack of involvement and information sharing seemed to cause a great deal of confusion among all parties involved. Patients, caregivers, and health care providers generally felt that if they had been engaged in the entire care process, they would have felt more confident and knowledgeable about the upcoming transition. Various studies have concluded that patient and family engagement can result in improved health outcomes, better quality of care, and increased patient safety (Carman et al., 2013; Epstein & Street, 2008; Coulter & Ellins, 2007; Coulter, 2012; Simmons, Wolever; Bechard, Snyderman, 2014). As explained by Wagner, Austin, & Von Korff (1996), optimal health outcomes for patients with chronic diseases require

the patient and family to be engaged and active in the management of their own condition, as opposed to passive receivers of care. Wagner's Chronic Care Model suggests that patients and caregivers should be enabled to self-manage their conditions in order to enhance care and promote long-term wellness (Bodenheimer et al., 2002). Including the patient and caregiver in decision-making and care conversations can enhance their confidence, which ultimately works to support self-management and therefore better health outcomes (Wagner et al., 1996; Bodenheimer et al., 2002)

6.2 Transitions to Home Settings

In transitions to home, from either acute care or inpatient rehabilitation settings, patients, caregivers, and health care providers discussed concerns about feeling unprepared and unconfident in their transition, providers having difficulty obtaining the information they needed, and family caregivers feeling stressed about the care of the patient. Overall, patients, caregivers, and health care providers felt unprepared for transitions to home settings.

This secondary analysis demonstrated that in transitions to home, patients and family caregivers felt that they did not have enough information to support their recovery and future care at home. Focus group interview participants responded to these concerns by suggesting various solutions for better education and information sharing that would work to bolster confidence in transitions to home. Patients and caregivers commented on their uncertainty that the 'cookie cutter' care they received in acute care or inpatient rehabilitation would not help them to adjust in their unique home setting. Toscan and colleagues (2014) explained that in transitions to home, the biggest challenge is isolation and doubt in one's own abilities, suggesting that this uncertainty can be a significant hurdle for patients and caregivers transitioning to home settings. The secondary analysis revealed that in some cases, this doubt and

uncertainty was mitigated by home care professionals that worked with the patient to tailor their recovery routine to their specific goals and environment. Toscan and colleagues (2013) reported that, for InfoRehab patients, a tailored approach that met their individual needs was an important component for high quality care. The rigidity of the health care system however, was reported as a barrier to providing personalized and individualized care for unique patients (Toscan et al., 2013).

This secondary analysis revealed that providers, especially those working in home settings, also had significant difficulty obtaining the information they needed from the previous care setting. The focus group participants commented on the tendency for formal care setting providers to not include home setting providers in the circle of care, which may further complicate transitions of care. Multiple previous InfoRehab publications have reported barriers for health care providers retrieving information (McLeod et al., 2011; Johnson et al., 2012; Toscan et al., 2012; Glenny et al., 2013; McMurray et al., 2013; Elliott et al., 2014). Due to these barriers, health care providers often rely on family caregivers, who transition with patients across all settings of care (Toscan et al., 2012). Toscan and colleagues (2014) however, reported that information sharing errors were common in transitions to home, where health care providers relied on verbal means of communicating important information with caregivers.

This analysis demonstrated that transitions to home were particularly stressful for family caregivers, who were suddenly responsible for a majority of the patient's care. Caregivers were expected to manage the transition to home, which involved a variety of care tasks, including transporting the patient. These expectations often came without any flexibility or consideration of the caregiver's availability and without direct instruction about how best to provide the patient with the care they need at home. Toscan and colleagues (2012) explain that this reliance on

family caregivers results in unease and stress, especially since caregivers lack the skills and knowledge to adequately care for the patient at home.

Caregivers explained that the health care system did not address their needs, especially in transitions to home settings. While a focus on the patient was important, caregivers ultimately felt that there was little consideration of their health, wellness, and needs throughout the patient's care journey. Toscan and colleagues (2014) found that home care case managers recognized a need for improved family caregiver supports, explaining that support for caregivers would be 'essential to maintaining their capacity to provide care' (p. 145).

In transitions to home settings, patients, caregivers, and health care providers seemed to feel very unprepared and uncertain about the care of the patient in the future. This feeling of being unprepared was especially difficult on the caregivers, who felt very unsure about how to care for the patient at home. Interestingly, providers in the rural setting felt that they had better knowledge of the patient and their circumstance because they were familiar with the community, and those that lived there, which may have provided an opportunity to better prepare patients and caregivers for their transition to home. Weaver, Perloff & Walters (1998) concluded that, in transitions to home, caregiver stress is associated with a lack of information. Providing caregivers with adequate information and engaging them in self-management practices may help to decrease caregiver burden while also decreasing the risk of suboptimal health outcomes in complex or chronically ill patients (Wagner et al., 1996). Effective information sharing and communication between patients, caregivers and health care providers is considered crucial to patient safety and health outcomes (Sutcliffe, Lewton, Rosenthal, 2004). The Chronic Care Model suggests that information sharing between providers can be enhanced through the use of clinical information systems to enhance communication of patient status (Bodenheimer et al.,

2002). Communicating information with patients and caregivers however, may be more complex. Wagner and colleagues (1996) explain that within the acute-focused health system it can be incredibly challenging to enable self-management due to the time-consuming nature of preventative interventions, training and education, psychosocial support, follow-up, and continual assessment. The Chronic Care Model therefore, suggests a redesign of health care delivery to redistribute the work of health professionals to better suit the needs of complex patients (Bodenheimer et al., 2002).

6.3 Alignment of Themes with Existing Interventions

Rochester-Eyeguokan and colleagues' (2016) list of 14 factors for safe and effective care transitions corresponds with many of the themes emerging from this secondary analysis. In comparing this list to components of four existing transition interventions: the Transitional Care Model (Naylor & Van Cleave, 2010); the Care Transitions Intervention (Coleman et al., 2006); Project BOOST (Li et al., 2015); and Project RED (Jack et al., 2008) (**Table 1**), none of the interventions addressed all 14 factors. In addition, none of these interventions provide a solution that addresses all the themes emerging from this analysis.

One of the suggested components relates to the idea that transitional care information flow would improve with the use of a transition record (Rochester-Eyeguokan et al., 2016). This record would ideally include information about the patient, their condition, their various care providers, their family caregivers, their transition plan, and other important medical information (Rochester-Eyeguokan et al., 2016). It is thought that this transition record would work to enhance the flow of information across multiple settings of care, making it easier for the patients, caregiver, and various providers to access important transition related information. This suggestion mirrors the thoughts of several InfoRehab health care providers, who felt that a single

record would greatly enhance information flow and reduce duplication, especially in transitions to formal care settings. Interestingly, none of the four interventions outlined in **Table 1** included this tool in their approach (Rochester-Eyeguokan et al., 2016).

Rochester-Eyeguokan and colleagues (2016) also suggest that inpatient rounds should be completed in interdisciplinary teams, in the hopes that the patient would receive more holistic care, and the providers would better collaborate and streamline their efforts. The findings of this, and previous, InfoRehab analyses suggest that, while a team-based approach may have benefits, careful organization and management is necessary to avoid overwhelming or confusing patients and caregivers (McLeod et al., 2011). The focus group commented on the need for better coordination between health care providers involved in a patient's care. This need for better coordination and collaboration was most prominent in transitions between formal care settings. Again, none of the four transitional care interventions mentioned in **Table 1** included interdisciplinary rounds in their approach.

Rochester-Eyeguokan and colleagues (2016) additionally suggest that all transitional care interventions contain a strategy for educating patients or promoting self-management. The focus group suggested that self-management may be an effective strategy to improve confidence through better information sharing and education, thereby decreasing doubt. In transitions to home, patients and family caregivers in the InfoRehab study indicated that more education, information, and the ability to self-manage would be extremely valuable, often explaining that their lack of understanding of the care process and care needs greatly impacted their confidence and increased their stress. Each of the four interventions outlined in **Table 1** include an education and self-management component (Rochester-Eyeguokan et al., 2016).

It is also suggested that coordinating care among team members is crucial for high quality transitional care Rochester-Eyeguokan et al., 2016). Providers involved in the InfoRehab study also stressed the importance of sharing complete and up-to-date information as the patient transitions, especially when the electronic medical records systems are not compatible. The focus group participants commented on the need to involve teams in both settings in the patient's care circle. This theme was particularly relevant in transitions to home. Interestingly, three of the four interventions included in **Table 1** (the Transitional Care Model, Project BOOST, and Project RED) had specific strategies for enhancing coordination and communication among team members (Rochester-Eyeguokan et al., 2016).

Lastly, Rochester-Eyeguokan and colleagues (2016) suggest that interventions aimed at enhancing transitional care work to enlist social and community supports. Social and community support may help to reduce the caregiver burden discussed by InfoRehab participants. Participants of the focus group commented on the amount of social and emotional support provided by community services in transitions to home settings. All four interventions includes a strategy for enlisting social and community support (Rochester-Eyeguokan et al., 2016).

Each of the interventions outlined in **Table 1** was developed for transitions to home or community settings (Rochester-Eyeguokan et al., 2016). Interestingly, the components of the interventions do not align well with themes related to transitions to formal care settings. Instead, the components of these interventions correspond with themes related to transitions to home. The results of this secondary analysis revealed that patients, caregivers, and providers have different experiences in different transitions, specifically transitions to home versus transitions to formal care settings. The focus group interview participants explained that it is not illogical that these

experiences would differ, especially considering the impact that the structure of the health system has on care experiences.

6.4 Strengths and Limitations

One potential limitation of this work pertains to the fact that a single researcher completed the analysis. This limitation was mitigated through two main strategies. First, the researcher examined the emerging themes in relation to existing published research resulting from the InfoRehab Transitions project. In completing a secondary analysis of the InfoRehab Transitions transcripts, it was expected that the emerging themes would overlap with existing findings in InfoRehab publications. As a secondary analysis of the data, entirely unique themes did not emerge, nor were they expected to; instead, the results of this analysis revealed which emerging themes related to each particular transition. This overlap allowed the researcher to confirm the findings of the analysis. Secondly, all emerging themes were discussed with a member of the original InfoRehab Transitions team. These discussions helped to verify that emerging themes objectively match the data.

The focus group completed for this thesis was limited to a single interview with a group of participants representative of only one of the provinces in which the original InfoRehab study was conducted. This may affect the transferability of the findings. Despite this potential limitation, the group of participants involved in the focus group interview provided a valuable perspective. Inclusion of a range of individuals involved in system solutions, and with backgrounds in a variety of health care settings and professions, allowed for the incorporation of a system lens in interpreting the findings of the secondary analysis. This unique perspective may work to extend the findings and provide context for system level interventions.

One strength of this thesis is the amount of data analyzed. The researcher analyzed transcripts from interviews with three different types of stakeholders (patients, family caregivers, and health care providers), within three different locations of sites (rural, small urban, and large urban), and across up to four different transitions (acute care to home, acute care to long term care, acute care to inpatient rehabilitation, and inpatient rehabilitation to home). In total, over 100 transcripts from diverse participants, with a minimum of twelve per transition type, were analyzed. During the analysis, saturation was reached for each transition type, providing meaningful and truly representative themes that reflect the lived experiences of the participants (Charmaz, 2006; Guest, Bunce, Johnson, 2006). The researcher however, considered the point of saturation for each transition type, but not for participant type. While saturation was reached for transition type, the researcher cannot say with confidence that saturation was achieved for participant type or for each participant group within each transition type, which may be a limitation of the study.

6.5 Conclusions

The findings of this thesis suggest that patients, caregivers, and health care providers experience transitions between various settings of care differently, and that the health system may play a role in these differences. As such, these findings may have implications for the implementation of existing transitional care interventions, or creation or novel transition interventions. Future research should further explore the ways in which other transition settings may impact patient, caregiver, and health care provider experience, and quality of care, for a variety of complex health conditions. Additional research may aim to alter existing interventions, or develop new ones, that better address the needs of those transitioning between formal care settings.

REFERENCES

Allen, B. J. (2005). Social constructionism. *Engaging organizational communication theory and research: Multiple perspectives*, 35-53.

Anderson, M. A., & Helms, L. B. (1995). Communication between continuing care organizations. *Research in nursing & health*, *18*(1), 49-57.

Barlow, J., Wright, C., Sheasby, J., Turner, A., Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. *Patient education and counseling*, 48, 177-187. DOI: https://doi.org/10.1016/S0738-3991(02)00032-0

Berkowitz, R.E., Fang, Z., Helfand, B.K.I., Jones, R.N., Schreiber, R., Paasche-Orlow, M.K. (2013). Project ReEngineered Discharge (RED) Lowers Hospital Readmission of Patients Discharged from a Skilled Nursing Facility. *J Am Med Dir Assoc*, 14(10), 736-740. DOI: 10.1016/j.jamda.2013.03.004

Bodenheimer, T., Wagner, E.H., Grumbach, K. (2002). Improving primary care for patients with chronic illness. *JAMA,* 288(14), 1755-1789.

Boockvar, K. S., Litke, A., Penrod, J. D., Halm, E. A., Morrison, R. S., Silberzweig, S. B., et al. (2004). Patient relocation in the 6 months after hip fracture: Risk factors for fragmented care. *Journal of the American Geriatrics Society*, 52(11), 1826-1831.

Burke, R. E., Kripalani, S., Vasilevskis, E. E., & Schnipper, J. L. (2013). Moving beyond readmission penalties: creating an ideal process to improve transitional care. *Journal of hospital medicine*, *8*(2), 102-109.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101. ISSN1478-0887 Available from: http://eprints.uwe.ac.uk/11735

Canadian Institute for Health Information (CIHI). (2017) Seniors in Transition: Exploring Pathways Across the Care Continuum. Ottawa, ON: CIHI; https://www.cihi.ca/sites/default/files/document/seniors-in-transition-report-2017-en.pdf

Canadian Medical Association. (2013). Health and Health Care for an Aging Population. Retrieved from: https://www.cma.ca/Assets/assets-library/document/en/advocacy/policy-research/CMA_Policy_Health_and_Health_Care_for_an_Aging-Population_PD14-03-e.pdf

Canadian Nurses Association (CNA). (n.d.) RN Solutions in the Care of Older Adults: Transitions across the continuum of care. Retrieved from: https://www.cna-aiic.ca/-/media/cna/files/en/transition_older_adult_e.pdf

Carcary, M. (2009). The Research Audit Trial--Enhancing Trustworthiness in Qualitative Inquiry. *Electronic Journal of Business Research Methods*, *7*(1).

Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 2: 223-231. doi: 10.1377/hlthaff.2012.1133

Charmaz, K. (2006). *Constructing grounded theory*. Sage.

Charmaz, K., & Mitchell, R. G. (2001). Grounded theory in ethnography. *Handbook of ethnography*, *160*, 174.

Coffey, C., Greenwald, J., Budnitz, T., Williams, M.V. (2013). Project BOOST Implementation Guide. Society of Hospital Medicine. Retrieved from: https://shm.hospitalmedicine.org/acton/attachment/25526/f-04f0/1/-/-/-/-/BOOST%20Guide%20Second%20Edition.pdf

Coleman EA. (2003) Falling through the cracks: challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatrics Society* [serial online] 51(4):549–55. Available from: doi: 10.1046/j.1532-5415.2003.51185.x

Coleman EA, Berenson RA. (2004) Lost in transition: challenges and opportunities for improving the quality of transitional care. *Annals of Internal Medicine* 140:533–6.

Coleman, E.A., Smith, J.D., Frank, J.C. Min, S.J., Parry, C., Kramer, A. (2004) Preparing patients and caregivers to participate in care delivered across settings: the care transitions intervention. *Journal of the American Geriatrics Society,* 52, 1817-1825. DOI: https://doi.org/10.1111/j.1532-5415.2004.52504.x

Coleman, E. A., & Boult, C. (2003). Improving the quality of transitional care for persons with complex care needs. *Journal of the American Geriatrics Society*, *51*(4), 556-557.

Coleman EA, Mahoney E, Parry C. (2005).Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Medical Care* 43(3):246–55

Coleman, E. A., Parry, C., Chalmers, S., & Min, S. J. (2006). The care transitions intervention: results of a randomized controlled trial. *Archives of internal medicine*, *166*(17), 1822-1828.

Coulter, A. (2012). Patient engagement—what works? *J Ambul Care Manage*. 35(2), 80-89. DOI:10.1097/JAC.0b013e318249e0fd.

Creswell, J.W., Creswell, J.D. (2018) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, *Fifth Edition*. Sage Publications

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into practice*, *39*(3), 124-130.

Davis, M. M., Devoe, M., Kansagara, D., Nicolaidis, C., & Englander, H. (2012). "Did I do as best as the system would let me?" Healthcare professional views on hospital to home care transitions. *Journal of general internal medicine*, *27*(12), 1649-1656.

Elliott, J., Forbes, D., Chesworth, B., Ceci, C., & Stolee, P. (2014). Information sharing with rural family caregivers during care transitions of hip fracture patients. *International journal of integrated care*, *14*(2).

Enderlin, C. A., McLeskey, N., Rooker, J. L., Steinhauser, C., D'avolio, D., Gusewelle, R., & Ennen, K. A. (2013). Review of current conceptual models and frameworks to guide transitions of care in older adults. *Geriatric Nursing*, *34*(1), 47-52.

Ferrante, J.M., Cohen, D.J., Crosson, J.C. (2010). Translating the patient navigator approach to meet the needs of primary care. *J Am Board Fam Med.* 23(6), 736-744. doi:10.3122/jabfm.2010.06.100085

Freeborn, D. K., Pope, C. R., Mullooly, J. P., & McFarland, B. H. (1990). Consistently high users of medical care among the elderly. *Medical Care*, 527-540.

Giosa, J. L., Stolee, P., Dupuis, S. L., Mock, S. E., & Santi, S. M. (2014). An examination of family caregiver experiences during care transitions of older adults. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, *33*(2), 137-153.

Glenny, C., Stolee, P., Shebian, L., Jaglal, S. (2013). Communicating during care transitions for older hip fracture patients: family caregiver and health care provider's perspectives. *International Journal of Integrated Care,* 13(4). DOI:http://doi.org/10.5334/ijic.1076

Goldman, L.E., Sarkar, U., Kessell, E., Guzman, D., Schneidermann, M., Pierluissi, E., Walter, B., Vittinghoff, E., Critchfield, J., Kushel, M. (2014). Support from hospital to home for elders: a randomized trial. *Ann Intern Med,* 161(7), 472-481. DOI: 10.7326/M14-0094

González-Montalvo, J.I., Alarcón T., Mauleón, J.L., Gil-Garay E., Gotor, P., Martín-Vega, A. (2010). The orthogeriatric unit for acute patients: a new model of care that improves efficiency in the management of patients with hip fracture. *Hip Int,* 20(2), 229-235.

González-Montalvo, J.I., Gotor Pérez P., Martín-Vega, A., Alarcón T., Álvarez de Linera, J.L., Gil-Garay E., García Cimbrelo, E., Alonso Biarge, J. (2011). The acute orthogeriatric unit. Evaluation of its effect in the clinical course of patients with hip fracture and estimation of its economic impact. *Spanish Journal of Geriatrics and Gerontology*, 46(4), 193-199. DOI: https://doi.org/10.1016/j.regg.2011.02.004

Grigoryan, K.V., Javedan, H., Rudolph, J.L. (2014). Ortho-Geriatric Care Models and Outcomes in Hip Fracture Patients: A Systematic Review and Meta-Analysis. *J Orthop Trauma,* 28(3), e49-e55. DOI: 10.1097/BOT.0b013e3182a5a045

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, *18*(1), 59-82.

Hammersley M, Atkinson P. *Ethnography: Principles in practice. 3rd ed.* London: Routledge; 2007

Hansen, L.O., Greenwald, J.L., Budnitz, T., Howell, E., Halasyamani, L., Maynard, G., Vidyarthi, A., Coleman, E., Williams, M. (2013). Project BOOST: Effectiveness of a multihospital effort to reduce rehospitalization. *Journal of Hospital Medicine*, 8(8), 421-427. https://doi.org/10.1002/jhm.2054

Health Quality Ontario (HQO). (2013). bestPATH Evidence Informed Improvement Package. Retrieved from: http://www.hqontario.ca/Portals/0/documents/qi/health-links/bp-improve-package-transitions-en.pdf

Heckman, G. A., Hillier, L., Manderson, B., McKinnon-Wilson, J., Santi, S. M., & Stolee, P. (2013). Developing an integrated system of care for frail seniors. *Healthcare management forum* (Vol. 26, No. 4, pp. 200-208).

Hesselink, G., Schoonhoven, L., Barach, P., Spijker, A., Gademan, P., Kalkman, C., Liefers, J., Vernooij-Dassen, M., Wollersheim, H. (2012). Improving patient handovers from hospital to primary care: a systematic review. *Ann Intern Med,* 157(6), 417-428. DOI: 10.7326/0003-4819-157-6-201209180-00006.

Hicks E, Sims-Gould J, Byrne K, Khan KM, Stolee P. (2012) "She was a little bit unrealistic": choice in healthcare decision making for older people. *Journal of Aging Studies*. 26(2):140–8.[cited 2013 Mar 1]. Available from:http://linkinghub.elsevier.com/retrieve/pii/S0890406511000879. doi: 10.1016/j.jaging.2011.10.004.

Hirschman, K., Shaid, E., McCauley, K., Pauly, M., Naylor, M. (2015). Continuity of Care: The Transitional Care Model. *The Online Journal of Issues in Nursing*. 20:3, Manuscript 1.

Hung WW, Morrison RS. (2011). Hip fracture: a complex illness among complex patients. *Annals of Internal Medicine* 155:267–8.

Institute of Medicine. (2001). Crossing the Quality Chasm: A New Health System for the 21st Century. Retrieved from: https://www.ncbi.nlm.nih.gov/books/NBK222274/

Jack, B., Bickmore, T. (2011). The Re-Engineered Hospital Discharge Program to Decrease Rehospitalization. *Care Management.* 12-15. Retrieved from: https://www.bu.edu/fammed/projectred/publications/CMdec2010jan2011.pdf

Jack, B., Greenwald, J., Forsythe, S., O'Donnell, J., Johnson, A., Schipelliti, L., ... & Manasseh, C. (2008). *Developing the tools to administer a comprehensive hospital discharge program: the ReEngineered Discharge (RED) program*. In Advances in Patient Safety: New Directions and Alternative Approaches (Vol 3.: Performance and Tools.) Rockwille, MD: Agency for Healthcare Research and Quality.

Jaglal, S. B., Sherry, P. G., & Schatzker, J. (1996). The impact and consequences of hip fracture in Ontario. *Canadian journal of surgery*, *39*(2), 105.

Johnson H, Forbes D, Egan M, Elliott J, Stolee P, Chesworth BM, the InfoRehab Team. (2013). Hip fracture care in rural Southwestern Ontario: an ethnographic study of patient transitions and physiotherapy handoffs. *Physiotherapy Canada* 65:266-75.

Kelly, E., Fulginiti, A., Pahwa, R., Tallen, L., Duan, L., Brekke, J.S. (2014). A pilot test of a peer navigator intervention for improving the health of individuals with serious mental illness. *Community Mental Health Journal, 50(4):* 435-446.

Khan, R., Fernandez, C., Kashif, F., Shedden, R., Diggory, P. (2002). Combined orthogeriatric care in the management of hip fractures: a prosepective study. *Ann R Coll Surg Engl*, 84, 122-124.

Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *BMJ: British medical journal*, *311*(7000), 299.

Koval, K.J., Skovron, M.L., Aharonoff, G.B., Meadows, S.E., Zuckerman, J.D. (1995) Ambulatory ability after hip fracture. *Clinical Orthopedic* 310, 150–159.

Kripalani, S., LeFevre, F., Phillips, C. O., Williams, M. V., Basaviah, P., & Baker, D. W. (2007). Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. *JAMA*, *297*(8), 831-841.

Lafortune, C., Elliott, J., Egan, M. Y., & Stolee, P. (2017). The rest of the story: a qualitative study of complementing standardized assessment data with informal interviews with older patients and families. *The Patient-Patient-Centered Outcomes Research*, *10*(2), 215-224.

Lecompte, M. (2002). The transformation of ethnographic practice: past and current challenges. *Qualitative Research*, *2*(3), 283-299

Leslie, W.D., O'Donnell, S., Jean, S., Lagace, C., Walsh, P., Bancej, C., Morin, S., 101 Hanley, D.A., Papaioannou A. (2009) Trends in Hip Fracture Rates in Canada. *JAMA,* 302(8): 884-889.

Li, J., Williams, M. V., & Young, R. S. (2015). Project BOOST®: A Comprehensive Program to Improve Discharge Coordination for Geriatric Patients. In *Geriatrics Models of Care* (pp. 115-122). Springer, Cham.

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic inquiry*, *289*, 331.

Lofland, J., Snow, L., Anderson, L., Lofland, L.H. (2006). *Developing Analysis. Analyzing Social Settings: A Guide to Qualitative Observation and Analysis (4th Ed.).* Belmont, CA: Wadsworth Thomson.

Marengoni A, Rizzuto D, Wang H-X, Winblad B, Fratiglioni L. (2009) Patterns of chronic multimorbidity in the elderly population. *Journal of the American Geriatrics Society* [serial online] Feb;57(2):225–30.[cited 2013 Mar 25]. doi: 10.1111/j.1532-5415.2008.02109.x.

McLeod J, McMurray J, Walker JD, Heckman GA, Stolee P. (2011) Care transitions for older patients with musculoskeletal disorders: continuity from the providers' perspective. *International Journal of Integrated Care* 11:e014.

McLeod J, Stolee P, Walker J, Heckman G. (2014) Measuring care transition quality for older patients with musculoskeletal disorders. *Musculoskeletal care* 12(1):13-21. Available from http://www.ncbi.nlm.nih.gov/pubmed/23300145. doi: 10.1002/msc.1043.

McMurray, J., Stolee, P., Hicks, E., Elliott, J., Johnson, H., & Byrne, K. (2013). The role of documentation and inter-provider information exchange in care continuity for older hip fracture patients. *Studies in health technology and informatics*, *192*, 1197-1197.

McPhail, S. M. (2016). Multimorbidity in chronic disease: impact on health care resources and costs. *Risk management and healthcare policy*, *9*, 143.

McWilliam, C. L., & Sangster, J. F. (1994). Managing patient discharge to home: the challenges of achieving quality of care. *International Journal for Quality in Health Care*, *6*(2), 147-161.

Ministry of Health and Long-Term Care (MOHLTC). (2007). Preventing and Managing Chronic Disease: Ontario's Framework. Retrieved From: http://www.health.gov.on.ca/en/pro/programs/cdpm/pdf/framework_full.pdf

Naylor, M. D. (2000). A decade of transitional care research with vulnerable elders. *Journal of Cardiovascular Nursing*, *14*(3), 1-14.

Naylor, M. D. (2002). Transitional care of older adults. *Annual review of nursing research*, *20*(1), 127-47.

Naylor, M. D. (2004) Transitional Care for Older Adults: A cost effective model. *Leonard Davis Institute of Health Economics-Issue Briefs.* 9(6). Retrieved from: https://pdfs.semanticscholar.org/3976/7621a98e8a4d45c99d43b8f17259374ee030.pdf

Naylor, M. D., Brooten, D., Campbell, R., Jacobsen, B. S., Mezey, M. D., Pauly, M. V., & Schwartz, J. S. (1999). Comprehensive discharge planning and home follow-up of hospitalized elders: A randomized clinical trial. *JAMA*, 281(7), 613-620. doi: joc80991

Naylor, M. D., Brooten, D. A., Campbell, R. L., Maislin, G., McCauley, K. M., & Schwartz, J. S. (2004). Transitional care of older adults hospitalized with heart failure: A randomized, controlled trial. *Journal of the American Geriatrics Society*, 52(5), 675-684. doi: 10.1111/j.1532-5415.2004.52202.xJGS52202

Naylor, M., Brooten, D., Jones, R., Lavizzo-Mourey, R., Mezey, M., & Pauly, M. (1994). Comprehensive discharge planning for the hospitalized elderly. A randomized clinical trial. *Annals of Internal Medici*ne, 120(12), 999-1006.

Naylor, M. D., & Van Cleave, J. A. N. E. T. (2010). Transitional care model. Transitions Theory: Middle-range and Situation-specific Theories in Nursing Research and Practice. New York: Springer Publishing, 459-65.

Naylor, M. D., Kurtzman, E. T., & Pauly, M. V. (2009). Transitions of elders between long-term care and hospitals. *Policy, Politics, & Nursing Practice*, *10*(3), 187-194.

Parry, C., Kramer, H.M., Coleman E.A. (2003). The Care Transitions Intervention: A patient-centered approach to ensuring effective transfers between sites of geriatric care. *Home Health Care Services Quarterly.* 22(3): 1-17. DOI: 10.1300/J027v22n03_01

Parry, C., Kramer, H.M., Coleman, E.A. (2006). A qualitative exploration of a patient-centered coaching intervention to improve care transtions in chronically ill older adults. *Home Health Care Services Quarterly,* 25(3-4), 39-53. DOI: 10.1300/J027v25n03_03.

Patton MQ. (2002). *Qualitative Research and Evaluation Methods. Third Edition*. Thousand Oaks, CA: Sage Publications, Inc.

Ponterotto, J. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science, *Journal of Counselling Psychology*, 52(2), 126- 136.

Primary Health Care Advisory Group. (2016). Better Outcomes For People with Chronic and Complex Health Conditions. Retrieved from: https://www.health.gov.au/internet/main/publishing.nsf/Content/76B2BDC12AE54540CA 257F72001102B9/$File/Primary-Health-Care-Advisory-Group_Final-Report.pdf

Quinn, C. C., Port, C. L., Zimmerman, S., Gruber-Baldini, A. L., Kasper, J. D., Fleshner, I., ... & Magaziner, J. (2008). Short-Stay Nursing Home Rehabilitation Patients: Transitional Care Problems Pose Research Challenges. *Journal of the American Geriatrics Society*, 56(10), 1940-1945.

Randell, A.G., Nguyen, T.V., Bhalerao, N., Silverman, S.L., Sambrook, P.N., Eisman, J.A. (2000) Deterioration in quality of life following hip fracture: a prospective study. *Osteoporosis International* 11, 460–466.

Reid, R. J., Roos, N. P., MacWilliam, L., Frohlich, N., & Black, C. (2002). Assessing population health care need using a claims-based ACG morbidity measure: a validation analysis in the Province of Manitoba. *Health services research*, 37(5), 1345-1364.

Registered Nurses Association of Ontario (RNAO) (2014). Care Transitions: Clinical Best Practice Guidelines. Retrieved from: http://rnao.ca/sites/rnao-ca/files/Care_Transitions_BPG.pdf

Richardson S, Casey M, Hinder P. (2007) Following the patient journey: older persons' experiences of emergency departments and discharge. *Accident and Emergency Nursing* 5(3):134–40.

Roberts, K. C., Rao, D. P., Bennett, T. L., Loukine, L., & Jayaraman, G. C. (2015). Prevalence and patterns of chronic disease multimorbidity and associated determinants in Canada. *Health promotion and chronic disease prevention in Canada: research, policy and practice*, *35*(6), 87.

Roche, J. J. W., Wenn, R. T., Sahota, O., & Moran, C. G. (2005). Effect of comorbidities and postoperative complications on mortality after hip fracture in elderly people: prospective observational cohort study. *BMJ*, *331*(7529), 1374.

Rochester-Eyeguokan, C. D., Pincus, K. J., Patel, R. S., & Reitz, S. J. (2016). The current landscape of transitions of care practice models: a scoping review. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy*, *36*(1), 117-133.

Ryan, P., Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nurs Outlook,* 57, 217-225. DOI: 10.1016/j.outlook.2008.10.004

Schultz, K., Carayon, P., Hundt, A. S., & Springman, S. R. (2007). Care transitions in the outpatient surgery preoperative process: facilitators and obstacles to information flow and their consequences. *Cognition, Technology & Work*, *9*(4), 219-231.

Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. *Handbook of qualitative research*, *1*, 118-137.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*(2), 63-75.

Simmons, L.A., Wolever, R.Q., Bechard, E.M., Snyderman, R. (2014). Patient engagement as a risk factor in personalized health care: a systematic review of the literature on chronic disease. *Genome Medicine* 6(16). https://doi.org/10.1186/gm533

Sims-Gould, J., Byrne, K., Hicks, E., Khan, K., & Stolee, P. (2012). Examining "success" in post-hip fracture care transitions: a strengths-based approach. *Journal of Interprofessional Care*, *26*(3), 205-211.

Snow, V., Beck, D., Budnitz, T., Miller, D. C., Potter, J., Wears, R. L., ... & Williams, M. V. (2009). Transitions of care consensus policy statement: American college of physicians, society of general internal medicine, society of hospital medicine, american geriatrics society, american college of emergency physicians, and society for academic emergency medicine. *Journal of Hospital Medicine*, *4*(6), 364-370.

Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Sage Publications, Inc.

Sutcliffe, K.M., Lewton, E., Rosenthal, M.M. (2004). Communication failures: An insidious contributor to medical mishaps. *Academic Medicine,* 79(2): 186-194.

Toscan J, Mairs K, Hinton S, Stolee P. (2012) Integrated transitional care: patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture. *International Journal of Integrated Care* 12:e13.

Toscan, J., Manderson, B., Santi, S. M., & Stolee, P. (2013). "Just another fish in the pond": the transitional care experience of a hip fracture patient. *International Journal of Integrated Care* 13e023.

Wagner, E.H., Austin, B.T., Von Korff, M. (1996). Organizing care for patients with chronic illness. *The Milbank Quarterly,* 74(4):511-544. http://www.jstor.org/stable/3350391

Weaver, F.M., Perloff, L., Waters, T. (1998) Patients' and caregivers' transitions from hospital to home: Needs and recommendations. *Home Health Services Quartlery,* 17(3): 27-48. DOI: 10.1300/J027v17n03_03

Wells, J. L., Seabrook, J. A., Stolee, P., Borrie, M. J., & Knoefel, F. (2003). State of the art in geriatric rehabilitation. Part II: Clinical challenges1. *Archives of physical medicine and rehabilitation*, *84*(6), 898-903.

Young, Y., German, P., Brant, L., Kenzora, J. & Magaziner, J. (1996) The predictors of surgical procedure and the effects on functional recovery in elderly with subcapital fractures. *Journals of Gerontology.* Series A, Biological Sciences & Medical Sciences 51, 0M158–164.

Zinden, L., Kreuter, M. & Frandin, K. (2010) Long-term effects of home rehabilitation after hip fracture- 1-year follow-up on functioning, balance confidence, and health-related quality of life in elderly people. *Disability and Rehabilitation* 32(1): 18-32.

APPENDIX A

INFOREHAB SEMI-STRUCTURED INTERVIEW GUIDE - PATIENT

(**Ensure the study ID is recorded with the interview.)

Study ID: _____

Name: _____

Remove this top page and shred after recording the study participant(s) on the Master List and entering the study ID number(s) on page 2 below.

Interview Guide for Patients

*(**Ensure the study ID is recorded with the interview.)*

<u>Background Information about Caregiver</u>

Study ID: _____

Year of Birth: _____

Sex: _____

Country of Origin: _____

City: _____

Relationship to person family caregiver (interviewed for study): _____

Living Arrangements (with family caregiver, or without): _____

Dwelling Type (house, apartment, condo): _____

<u>Background Information about Care recipient</u>

When did you fracture your hip?

How did you fracture your hip?

Was this your first hip fracture?

Was this your first fracture?

How long have you been cared for by your friend/relative?

What has your friend/relative done to assist you?

Determining the Trajectory of Care

I want to know more about the various places that you received care since you fractured your hip. To begin with, can you name/tell me the various hospitals that you have been at since fracturing your hip? So starting with...... (get participant to name each care setting if possible – draw it if it helps)

(Probe for length of time at each place)

(** at SMGH this will 'not' be applicable in acute care because the patient had surgery here. At FCHS this will be applicable on initial admission because the patient was transferred from a surgical setting)

Exploring each Care Setting in the Trajectory

The following questions will be asked about admission and discharge (where applicable) at each of the following care settings: emergency; acute; sub acute/rehab; and long term care.

Admission

......can you walk me through what happened when you were admitted to _____?

When you arrived on the unit, did you speak to anyone about your care?

Did you receive any information about your care?/ What did they talk to you about when you arrived?

What kinds/types of information did you receive?

Who provided this information?

How was this information provided? (probe: paper forms, face to face meeting with a health care provider, telephone conversation with a health care provider)

Did anyone talk to you about your needs when you arrived?

Did you receive information about your own needs while at _____?

Were there times while you were on the unit when you needed to know something about your care? OR can you think of an example during the time you were on the unit/in this setting when you needed to know something about your care?

How did you go about finding this out? Who did you talk to?

(Were there things that made it easier to find out the information you needed?)

(Were there things that made it difficult to find out the information you needed?)

In thinking about the time you spent at _____ hospital, did you feel involved in decisions about the care you received?

Discharge

Can you walk me through what happened when you were discharged from_____?

Before you left_____, did you speak to anyone about your care?

Did you receive any information about your care prior to leaving?

What did they talk to you about before leaving?

Who provided this information?

How was this information provided? (Probe: paper forms, face to face meeting with a health care provider, telephone conversation with a health care provider)

Did anyone talk to you about your own needs before you left?

Before you left the unit, did someone explain the types of care you would need at home?

Did someone talk to you about any services you might receive once home?

In the days leading up to discharge, when you had a question about your care, how did you go about finding an answer? OR Can you think of an example during the days leading up to discharge when you needed to know something about your care? (Probe for more than one example)

How did you go about finding the answer?

In general, did you feel like you had a say in what happened to you while you were at_____?

Yes/No

Tell me more about that?

Were you involved in the decision to go to rehab/home/long term care? If so, how? Tell me more about that....

<u>Home with and without Home Care (for those receiving home support – these may not apply)</u>

How did you find out you would have home care once discharged from.....?

Did anyone from the home care agency come and speak with you and/or your family caregiver once you were discharged?

Did you receive any information about your care once you arrived home?

What kinds/types of information did you receive?

Who provided this information?

How was this information provided? (probe: paper forms, face to face meeting with a health care provider, telephone conversation with a health care provider)

When you had/have a question about your care, how do you go about finding an answer?

Did anyone talk to you about your own needs when you got home?

Were any services offered to you to help you care for yourself or a spouse/friend/relative who needed help? If yes, what are they?

Were any services offered to you to help you care for yourself? If yes, what are they?

How would you cope without home support?

When you first got home from _____, did you need help with your exercises? If yes, how did you do this?

What did you find difficult about doing your exercises?

What help did you need to be able to do your exercise?

Did your family caregiver (friend/relative) accompany you to your appointment with the orthopedic surgeon?

Exploring Current Situation

Describe a typical day in your life now that you have been home for.......?

What are the top 3 information needs that you have 'right now' regarding your care? (probes: what is it that you really need to know about your care right now)

If you need/needed to know something about your care right now, how do you/would you go about finding this out? (probes: who would you contact?)

Do you have any concerns about continuing to care for your care at home? If yes, what are they?

Have you talked to anyone about these concerns? If so, who have you talked to?

Does anyone else assist you or your friend/relative? If yes, who, and what do they do?

Why do they provide the care to you? (explore relationship with care recipient)

Study specific questions (**these may have been covered by this point in the interview – please ensure these questions have been addressed):

What information about your hip fracture status, are you using 'right now' to help you care for your health and recovery as best as you can?

What information about your hip fracture status, do you see as 'critical for you to know right now' to help you care for your health and recovery as best as you can?

What information about your hip fracture status, <u>did you actually receive</u> from health care providers to help you care for your hip fracture before/after moving from the previous care setting?

What do you think are the most important facilitators to exchanging information between health care providers and patients like yourself?

What do you think are the most important barriers to exchanging information between health care providers and patients like yourself?

How do you think the use and exchange of patient information can be enhanced between health care providers and patients like yourself, when patients like you transfer from one health care setting to another?

<u>Concluding Questions</u>

Is there anything else that you feel is important for us to know to understand your experiences?

APPENDIX B

INFOREHAB SEMI-STRUCTURED INTERVIEW GUIDE – CAREGIVER

(**Ensure the study ID is recorded with the interview.)

Study ID: _____

Name: _____

Remove this top page and shred after recording the study participant(s) on the Master List and entering the study ID number(s) on page 2 below.

Interview Guide for Family Caregivers

(**Ensure the study ID is recorded with the interview.)

<u>Background Information about Caregiver</u>

Study ID: _____

Year of Birth: _____

Sex: _____

Country of Origin: _____

City: _____

Relationship to person receiving care (experiencing hip fracture): _____

Living Arrangements (with care recipient, without): _____

Dwelling Type (house, apartment, condo): _____

<u>Background Information about Care recipient</u>

When did he/she fracture his/her hip?

How did your relative fracture his/her hip?

Was this his/her first hip fracture?

Was this his/her first fracture?

If applicable, how long has your friend/relative been experiencing cognitive difficulties?

Diagnosis of dementia:

How long have you been involved in caring for your friend/relative?

How have you been involved? What have you been doing to assist them?

Determining the Trajectory of Care

I want to know more about the various places that your friend/relative has received care since he/she fractured his/her hip. To begin with, can you name/tell me the various hospitals that he/she has been since fracturing his/her hip? So starting with...... (get participant to name each care setting if possible – draw it if it helps)

(Probe for length of time at each place)

(** at SMGH this will 'not' be applicable in acute care because the patient had surgery here. At FCHS this will be applicable on initial admission because the patient was transferred from a surgical setting)

Exploring each Care Setting in the Trajectory

The following questions will be asked about admission and discharge (where applicable) at each of the following care settings: emergency; acute; sub acute/rehab; and long term care.

Admission

......can you walk me through what happened when your friend/relative was admitted to _____?

When you arrived on the unit, did you speak to anyone about your friend/relative's care?

Did you receive any information about your friend/relative's care?/ What did they talk to you about when you arrived?

What kinds/types of information did you receive?

Who provided this information?

How was this information provided? (probe: paper forms, face to face meeting with a health care provider, telephone conversation with a health care provider)

Did anyone talk to you about your needs when you arrived? (probe for respite, etc.)

Did you receive information about your own needs while at _____?

Were there times while you were on the unit when you needed to know something about your relative's care? OR can you think of an example during the time your relative was on the unit/in this setting when you needed to know something about your relative's care?

How did you go about finding this out? Who did you talk to?

(Were there things that made it easier to find out the information you needed?)

(Were there things that made it difficult to find out the information you needed?)

In thinking about the time your relative spent at _____ hospital, did you feel involved in decisions about the care he/she received?

Discharge

Can you walk me through what happened when your friend/relative was discharged from_____?

Before you left_____, did you speak to anyone about your friend/relative's care?

Did you receive any information about your relative's care prior to leaving?

What did they talk to you about before leaving?

Who provided this information?

How was this information provided? (Probe: paper forms, face to face meeting with a health care provider, telephone conversation with a health care provider)

Did anyone talk to you about your own needs before you left? (probe for respite, etc.)

Before you left the unit, did someone explain the types of care he/she would need at home?

Did someone talk to you about any services you might receive once home?

In the days leading up to discharge, when you had a question about your relative's care, how did you go about finding an answer? OR Can you think of an example during the days leading up to discharge when you needed to know something about your relative's care? (Probe for more than one example)

How did you go about finding the answer?

In general, did you feel like you had a say in what happened to your relative while they were at_____?

Yes/No

Tell me more about that?

Were you involved in the decision for your relative to go to rehab/home/long term care? If so, how? Tell me more about that....

Home with and without Home Care (for those receiving home support – these may not apply)

How did you find out your friend/relative would have home care once discharged from.....?

Did anyone from the home care agency come and speak with you and/or your friend/relative once he/she was discharged?

Did you receive any information about your friend/relative's care once you arrived home?

What kinds/types of information did you receive?

Who provided this information?

How was this information provided? (probe: paper forms, face to face meeting with a health care provider, telephone conversation with a health care provider)

When you had/have a question about your relative's care, how do you go about finding an answer?

Did anyone talk to you about your own needs when you got home? (probe: for respite, etc.)

Were any services offered to you to help you care for your friend/relative? If yes, what are they?

Were any services offered to you to help you care for yourself? If yes, what are they?

If your friend/relative is receiving home support, do you assist the home support workers? IF yes, what do you do? Do they help you? If yes, what do they do?

How would you cope without home support?

When your relative first got home from _____, did you help him/her with his/her exercises? If yes, how did you do this?

What did you find difficult about helping him/her with his/her exercises?

What helps you to be able to help him/her with his/her exercise?

Do you feel like you play a role in helping your relative participate in activities outside of the home? How so?

Did you accompany your relative to his/her appointment with the orthopedic surgeon?

<center>Exploring Current Situation</center>

Describe a typical day in your life now that your friend/relative has been home for.......?

What are the top 3 information needs that you have 'right now' regarding the care of your friend/relative? (probes: what is it that you really need to know about the care of your friend/relative right now

If you need/needed to know something about your friend/relatives care right now, how do you/would you go about finding this out? (probes: who would they contact?)

Do you have any concerns about continuing to care for your friend/relative at home? If yes, what are they?

Have you talked to anyone about these concerns? If so, who have you talked to?

Does anyone else assist your friend/relative? If yes, who, and what do they do?

Do they assist you? If yes, who, and what do they do?

Why do you provide the care that you do? (explore relationship with care recipient)

Study specific questions (**these may have been covered by this point in the interview – please ensure these questions have been addressed):

What information about your friend/relative's hip fracture status, are you using 'right now' to help you care for his/her health and recovery as best as you can?

What information about your friend/relative's hip fracture status, do you see as 'critical for you to know right now' to help you care for his/her health and recovery as best as you can?

What information about your friend/relative's hip fracture status, did you actually receive from health care providers to help you care for your friend/relative's hip fracture before/after s/he moved from the previous care setting?

What do you think are the most important facilitators to exchanging information between health care providers and family caregivers like yourself?

What do you think are the most important barriers to exchanging information between health care providers and family caregivers like yourself?

How do you think the use and exchange of patient information can be enhanced between health care providers and family caregivers like yourself, when patients transfer from one health care setting to another?

Concluding Questions

Is there anything else that you feel is important for us to know to understand your experiences?

APPENDIX C

INFOREHAB SEMI-STRUCTURED INTERVIEW GUIDE – HEALTH CARE PROVIDER

(**Ensure the study ID is recorded with the interview.)

1. General Background Information

a) Please describe your position here at [INSERT LOCATION, e.g. SMGH or FCHS]?

b) How many years have you been employed in this position?

c) Have you ever worked in other areas at [INSERT LOCATION e.g. SMGH or FCHS]?

(**Probe around specific role during patient transition points, such as admission and discharge; responsibility.)

2. Patient Transitions

a) Thinking about [INSERT a specific post-hip fracture patient] with whom you are working with, please walk me through the steps related to the process of admitting this person to this unit. I would like to hear about all the people (health care providers) involved.

(**Probes: What is your role in this process? Who else is involved? How are they involved?)

(**identify what transition point this interview is addressing)

3. Information Exchange

a) When a patient comes to this setting (e.g. unit):

    i. What information is generally received from the previous setting (e.g. unit)?

    ii. Who is responsible for sending/ getting the information to this unit?

        (***Probe: who gives this information?*)

    iii. How is this information received?

        (***Probe: forms, informal communication with health care providers, formal communication or meetings, family caregivers, key person etc.*)

    iv. Are there any specific forms that are sent from the previous setting (e.g. unit)?

          i. (**IF YES*), can we have a blank or de-identified copy of this form(s)?

      v.   Is there information that you need from the previous setting that you do not receive?

          i. (**IF YES*) Can you give me an example of this?

         ii. Why do you think you didn't receive this information?

      vi.   How do you typically resolve a situation where you do not receive the information needed?

    (**Probe: did you seek the information you needed, if yes, how and from whom?*)

      vii.   What information is collected once the patient is on this unit?

         i. How is this information collected?

    (**Probe for forms, etc.*)

         ii. Who is this information collected from?

    (**Probe: patient, family*)

4. Patients/Caregivers Involvement

a) What is the normal process of admission? What information is given to clients/family caregivers when they arrive on this unit?

    i.   Who provides this information?

    ii.   How is this information provided?

    (**Probe: handouts, around meetings they may have with clinicians, etc*)

b) What information is provided by family caregivers?

c) What information is provided by clients?

d) Are there challenges associated with working families during times of transition?

e) Do family members make your work more difficult?

    i.   (**IF YES*) How?

f) Do family members help your work?

    i.   (**IF YES*) How?

g) Do your clients ever make your work more difficult?

    i. (***IF YES*) How?

h) Do your clients ever help you in your work?

    i. (***IF YES*) How?

5. Discharge

a) Now thinking about a hip fracture patient being discharged to (go through relevant settings):

- Rehabilitation unit/sub-acute care
- Long term care
- Home care
- Short stay bed in NH

.... walk me through the steps related to the process of discharging this person. I would like you to tell me about all the people involved (e.g. health care providers).

b) What steps are taken to prepare clients?

(***Probe: For example, what information is given to clients before they leave?*)

c) When is this information provided?

d) How is this information provided?

(***Probe: forms, meetings, etc*)

e) Who provides this information?

f) To what extent are clients and families involved in decision making about where they go next?

6. Concluding questions

a) What do you think are the strengths of how information from other health care settings is shared with you?

b) What do you think are the challenges of sharing information from other health care settings with you?

c) What do you think can be done to improve how information is sent and received to and from one health care setting to another?

d) Is there anything else that you feel is important for us to know about the flow of information for patients who have fractured a hip and for those professionals who work with them?

**Italics – Notes for interviewer, not to be said to interviewee.

APPENDIX D

FOCUS GROUP SEMI-STRUCTURED INTERVIEW GUIDE

Hello, my name is _____ and I am a _____ working under the supervision of Dr. Paul Stolee in the School of Public Health and Health Systems at the University of Waterloo.

You have all expressed interest in participating in a focus group as part of a research study that we are conducting. In contributing to this study, I am hoping that you can provide your perspectives and thoughts about the results of a secondary analysis I have previously conducted. I will first present the findings from that study to you, then we will discuss how these findings relate to your experience working with older adults as they transition across various health care settings. The presentation will be approximately 10 minutes, and the focus group interview will last approximately 60 minutes. Your decision to participate is completely voluntary.

I would like to assure you that this study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision to participate is yours.

PRESENT SECONDARY ANALYSIS FINDINGS

Semi-Structured Focus Group Interview Guide

1. Can you introduce yourself, describe your role, and the setting in which you work?

2. Are there any findings from this review that stood out to you?

    a. Were any of the themes not relevant within your role and setting? Which ones?

       Why?

    b. Were any of the themes particularly relevant to you, or within your practice? Which

       ones? Why?

3. Do you think that there are any additional themes that might have been missed in this

   review?

    a. In which setting is this most relevant?

    b. To which stakeholder (patient, caregiver, and provider) is this most relevant?

APPENDIX E

INFOREHAB ETHICS CLEARANCE

UNIVERSITY OF WATERLOO
OFFICE OF RESEARCH ETHICS

Feedback on Ethics Review of Application to Conduct Research with Humans

All research involving human participants at the University of Waterloo must be carried out in compliance with the Office of Research Ethics Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.

ORE File #: 15727

Project Title: InfoRehab: Enhancing MSK Rehabilitation through Better Use of Health Information

Principal/Co-Investigator: Paul Stolee	**Department/School:** Health Studies & Gerontology
Principal/Co-Investigator: Katherine Berg	**Department/School:** Physical Therapy - University of Toronto
Principal/Co-Investigator: Bert Chesworth	**Department/School:** Physical Therapy, University of Western Ontario
Principal/Co-Investigator: Richard Cook	**Department/School:** Statistics and Actuarial Science
Principal/Co-Investigator: Mary Egan	**Department/School:** Occupational Therapy, University of Ottawa
Principal/Co-Investigator: Kerry Byrne	**Department/School:** University of British Columbia
Principal/Co-Investigator: Ann Cranney	**Department/School:** Faculty of Medicine - University of Ottawa
Principal/Co-Investigator: Clair-Johanne Dubouloz	**Department/School:** Faculty of Health Sciences - University of Ottawa
Principal/Co-Investigator: John Hirdes	**Department/School:** Health Studies & Gerontology
Principal/Co-Investigator: Susan Jaglal	**Department/School:** Phyiscal Therapy - University of Toronto
Principal/Co-Investigator: Jeff Poss	**Department/School:** Health Studies & Gerontology
Principal/Co-Investigator: Jennie Wells	**Department/School:** Geriatric Medicine - University of Western Ontario
Principal/Co-Investigator: Mu Zhu	**Department/School:** Statistics and Actuarial Science
Principal/Co-Investigator: Christine Ceci	**Department/School:** Faculty of Nursing - University of Alberta
Principal/Co-Investigator: David Bryan Hogan	**Department/School:** Faculty of Medicine - University of Calgary
Principal/Co-Investigator: Dorothy Forbes	**Department/School:** Faculty of Health Sciences - University of Western Ontario
Principal/Co-Investigator: Joan Sims-Gould	**Department/School:** Faculty of Medicine - University of British Columbia
Principal/Co-Investigator: Brandie Steeves	**Department/School:** Health Studies & Gerontology
Student Investigator: Jordi McLeod	**Department/School:** Health Studies & Gerontology
Collaborator: Ian Joiner	**Department/School:** Canadian Institute for Health Information
Collaborator: Sharon Straus	**Department/School:** University of Calgary
Collaborator: Corinne Schalm	**Department/School:** Shepherd's Care Foundation
Collaborator: Claudia von Zweck	**Department/School:** Canadian Association of Occupational Therapists
Collaborator: Dawn Burnett	**Department/School:** Canadian Physiotherapy Association
Collaborator: Rob Mackenzie	**Department/School:** St. Joseph's Healthcare London
Collaborator: Flora Dell	**Department/School:** Seniors' Information Centre
Collaborator: Kim Voelker	**Department/School:** Senior Director, Client Services, Waterloo Wellington CCAC
Collaborator: Nancy Cox	**Department/School:** CSSS Cavendish

The above research application has undergone ethics review through the Office of Research Ethics and received the following ethics review category:

☐ **Ethics Clearance**. The application is considered acceptable on ethical grounds and complies with ORE Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. No revisions are required.
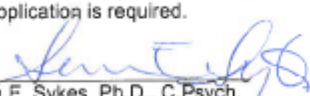
CONDITIONS ASSOCIATED WITH ETHICS CLEARANCE:
1. Ethics clearance is valid for four years from the date ethics clearance is granted.
2. Projects must be conducted in accordance with the description in the application for which full ethics clearance is granted. All subsequent modifications to the protocol must receive prior ethics clearance through the Office of Research Ethics.
3. An annual progress report (ORE Form 105) must be submitted for ethics review for each year of an ongoing project.
4. Any events, procedures, or unanticipated problems that adversely affect participants must be reported to the ORE using ORE Form 106.

☐ The application is considered acceptable on ethical grounds and complies with ORE Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. * **Minor/editorial revisions are required** as outlined in a transmitted email. Revised materials must be provided for the ORE file.

☑ Acceptance of the application on ethical grounds is **conditional on revisions and/or additional information**. The following revisions and/or additional information must be provided for ethics review and are requested within **10 days**. A study may not begin until it receives ethics clearance.
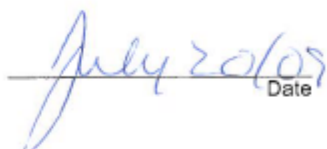
　　☐ Information Letter was not provided and is required for ethics review.

　　☐ Information Letter provided is incomplete and requires revisions outlined in the email message.

　　☐ Information Letter and Consent Form were not provided and are required for ethics review.

　　☑ Information Letter and Consent Form provided are incomplete and require revisions outlined in the email message.

　　☐ Copy of interview/survey questions was not provided and is required for ethics review.

　　☑ Other revisions/information are required as outlined in the email message.

☐ Due to the level and/or number of questions and concerns raised during the ethics review process the application is considered not acceptable on ethical grounds at this time . Comments are summarized in the attached ethics review feedback. A new application is required.

_____
Susan E. Sykes, Ph.D., C.Psych.
Director, Office of Research Ethics

OR
Susanne Santi, M. Math
Senior Manager, Research Ethics

OR
Julie Joza, B.Sc.
Manager, Research Ethics

July 20/09
Date

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APPENDIX F

FOCUS GROUP ETHICS CLEARANCE

Dear Researcher:

The recommended revisions/additional information requested in the ethics review of your application for the study:

Title: Improving Transitions of Care for Older Adults Living with Frailty ORE #: 22936

Principal/Co-Investigator: Paul Stolee (stolee@uwaterloo.ca)

Principal/Co-Investigator: Jacobi Elliott (j7elliot@uwaterloo.ca) Student Investigator: Laura Brooks (labrooks@uwaterloo.ca)

have been reviewed and are considered acceptable. A University of Waterloo Research Ethics Committee is pleased to inform you this study has been given ethics clearance.

A signed copy of the notification of ethics clearance will be sent to the Principal Investigator (or Faculty Supervisor in the case of student research). Ethics approval to start this research is effective as of the date of this email. The above named study is to be conducted in accordance with the submitted application (Form 101/101A) and the most recent approved versions of all supporting materials.

University of Waterloo Research Ethics Committees operate in compliance with the institution's guidelines for research with human participants, the Tri-Council Policy Statement for the Ethical Conduct for Research Involving Humans (TCPS, 2nd edition), Internalization Conference on Harmonization: Good Clinical Practice (ICH-GCP), the Ontario Personal Health Information Protection Act (PHIPA), and the applicable laws and regulations of the province of Ontario. Both Committees are registered with the U.S. Department of Health and Human Services under the Federal Wide Assurance, FWA00021410, and IRB registration number IRB00002419 (Human Research Ethics Committee) and IRB00007409 (Clinical Research Ethics Committee).

APPENDIX G

Number of Transcripts for Each Transition, Stakeholder Group, and Location

		Acute Care to Home	Acute to Long Term Care	Acute Care to Inpatient Rehabilitation	Inpatient Rehabilitation to Home
Patients	*Large Urban*	2	0	10	8
	Mid Size Urban	2	0	6	3
	Rural	10	3	3	2
Family Caregivers	*Large Urban*	3	0	1	1
	Mid Size Urban	2	1	4	3
	Rural	2	3	0	0
		Acute	Long Term Care	Inpatient Rehabilitation	Home
Health Care Providers	*Large Urban*	7	0	3	4
	Mid Size Urban	9	4	8	5
	Rural	6	1	11	1

APPENDIX F

OVERLAP OF THEMES

PATIENTS GETTING INFORMATION

Acute To Home	Acute to Rehab	Acute to LTC	Rehab to Home
Caregivers were not provided updates on the patient's status and were often not informed when the patient was discharged. Patients explained that they had to be insistent to get information from providers in acute care, and were often unsure of their condition, and the next steps in their care. Caregivers felt that the information that was provided to patients was not given to them at an appropriate time or in an appropriate manner. Patients and caregivers felt that they were not involved in making decisions about their care, which left them feeling even more uninformed.	Patients were frequently given different information from different providers, leaving them confused, and unsure of the next steps for their care. Patients and caregivers felt that they were not involved in making decisions about their care, which left them feeling even more uninformed.	Patients felt unaware of their own health status and were not told how they were progressing. Patients felt like their questions went unanswered.	Patients explained that they had to be insistent to get information from providers about updates in their care. Caregivers felt that they were not involved in the decisions made about the patient's care, and were instead just informed that a decision had been made. At home, caregivers had difficulty contacting providers, and noticed the lack of communication between providers. Caregivers were left feeling unsure about what services the patient needed moving forward, and how they could help the patient progress at home.
A majority of the information shared with the patient in acute settings is shared verbally. Providers expect the patient to independently read and understand any written information provided to them. Acute providers initiate conversation with the patient by retrieving the information they need, followed by ensuring the patient is aware of, and agrees to, their care plan. At home, providers deliver a majority of the information verbally, and have very limited resources for hip surgery patients	A majority of the information shared with the patient in acute settings is shared verbally. Providers expect the patient to independently read and understand any written information provided to them. Acute providers initiate conversation with the patient by retrieving the information they need, followed by ensuring the patient is aware of, and agrees to, their care plan. Providers in the rehab setting provide some written information to patients, but leave it to the patient to read the information. Rehab providers initiate	A majority of the information shared with the patient in acute settings is shared verbally. Providers expect the patient to independently read and understand any written information provided to them. Acute providers initiate conversation with the patient by retrieving the information they need, followed by ensuring the patient is aware of, and agrees to, their care plan. Patients entering long term care are given some written information about safety procedures, but long term care providers tend to focus on	Providers in the rehab setting provide some written information to patients, but leave it to the patient to read the information. Rehab providers initiate conversation with the patient by retrieving the information that they need, followed by setting achievable goals with the patient. At home, providers deliver a majority of the information verbally, and have very limited resources for hip surgery patients that did not have a planned surgery. Providers in the home care setting focus their communications

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that did not have a planned surgery. Providers in the home care setting focus their communications around the patient's goals and work to build a relationship with the patient.	conversation with the patient by retrieving the information that they need, followed by setting achievable goals with the patient.	retrieving the information they need from the patient.	around the patient's goals and work to build a relationship with the patient.

Patients and Caregivers: Patients going home needed more information. Patients had difficulty getting meaningful information from providers. Caregivers felt that provider communication was inadequate. Patients and caregivers were not involved in decisions.

Providers: Providers focused conversations on retrieving information from patients rather than sharing information. Providers shared information verbally. Written information provided to patients was not explained. Home care providers build relationships and focus on patient goals.

Acute To Home	**Acute to Rehab**	**Acute to LTC**	Rehab to Home
Caregivers and patients with experience in the system felt that they had an advantage in navigating the system, although they still faced many barriers. Caregivers felt that patients were not receiving good care because providers were overworked and too busy to get to know the patient.	Patients that had caregivers with experience working in health care felt more comfortable going home because their caregiver could provide proper care. Caregivers were surprised by the low quality of care patients received in hospitals, explaining that it is easy to see how people fall through the cracks.	Caregivers that had experienced institutionalization felt guilty placing the patient in long term care. Caregivers felt that the health care system needs to receive more money, because operating above its capacity has resulted in poor care quality for patients.	Caregivers and patients with experience in the system felt that they had an advantage in navigating the system, although they still faced many barriers. Patients feel that a more patient centred approach to care is needed. However, patients and caregivers recognize that providers are overworked and hospitals need more providers to provider better care.
Providers in acute care settings feel that patients with strong social supports have an advantage over patients without those supports. Acute care providers felt that the GP should be more involved to enhance care after discharge. Acute care providers felt that providers across all settings of care should be aware of and agree to the patient's care plan to enhance the patient's experience through discharge. Home care providers often feel that patients were discharged too soon because of the pressure for hospital providers to discharge, and the assumption that home care can pick up the pieces.	Providers in acute care settings feel that patients with strong social supports have an advantage over patients without those supports. Acute care providers felt that the GP should be more involved to enhance care after discharge. Acute care providers felt that providers across all settings of care should be aware of and agree to the patient's care plan to enhance the patient's experience through discharge. Rehab providers felt that there was a limited understanding of the roles of other providers in different settings.	Providers in acute care settings feel that patients with strong social supports have an advantage over patients without those supports. Acute care providers felt that the GP should be more involved to enhance care after discharge. Acute care providers felt that providers across all settings of care should be aware of and agree to the patient's care plan to enhance the patient's experience through discharge. Providers in long term care settings felt that admitted patients without strong social supports should be considered more urgent than patients with caregivers.	Providers feel that information sharing between health care providers in home care needs to improve. This is difficult because home care providers rarely come in contact with one another. Home care providers often feel that patients were discharged too soon because of the pressure for hospital providers to discharge, and the assumption that home care can pick up the pieces. Rehab and home care providers felt that there was a limited understanding of the roles of other providers in different settings.

Home care providers felt that there was a limited understanding of the roles of other providers in different settings.			

Patients and Caregivers: Patients and caregivers felt that the system issues negatively impact quality of care. Caregivers with experience in they system felt guilty placing patients in institutions. Caregivers and patients with experience in the system were more successful in navigating the system.

Providers: Providers recognized the importance of social supports and caregivers. Providers had poor understanding of other roles, or their own roles in alternative settings. Home care providers felt patients were discharged too soon. Providers felt that other, different providers should be more involved in discharge.

Acute To Home	Acute to Rehab	Acute to LTC	Rehab to Home
Patients felt that acute care providers didn't spend the time to get to know patients, and rarely knew the patients' health status. However, patients felt that one committed provider could make a considerable difference in the quality of their care. Patients that needed to see specialists for non-hip related care while in acute care had difficulties arranging those appointments. Patients at home greatly appreciated the care and information provided by home care physiotherapists.	Patients felt alone in acute care, explaining that they had no one to talk to, and that no one really cared about them. Patients and caregivers felt that acute care providers showed no compassion and didn't know them as a person. Patients felt that the provided care in rehab was very standardized and didn't suit their needs, lifestyle or goals. Patients moving from acute care received confusing information about convalescent care and often thought they were being moved to long term care permanently. Patients felt that being optimistic about their health outcomes aided in their recovery.	Caregivers felt that the physiotherapy provided to patients in long term care wasn't enough to help them progress through their condition.	Patients in rehab felt that the setting did not address their psychosocial needs. Patients felt that their mental health deteriorated in the rehab setting. Patients explained that they often had to resort to expressions of anger to be heard. At times, patients were forced to remain in uncomfortable positions for lengthy amounts of time. Patients felt that providers failed to communicate across settings, leaving them confused about their transition home. Patients appreciated having a home care physiotherapist, but at times, they felt that they physiotherapist didn't fully understand their ability, providing care plans that were too ambitious. Patients felt that their personal supports, combined with homecare, allowed them to succeed in their recovery at home.
Providers are conscious of financial considerations that may be barrier for some patients. Providers in acute care felt that patients that victimized themselves often had poorer experiences than those who felt determined to recover. Providers in acute settings understood that addressing a patient's specific goals was important to ensure positive experiences. Providers explained that if they had been given more notice of discharge, they would have had more time to prepare the patient. Providers also felt that time constraints	Providers are conscious of financial considerations that may be barrier for some patients. Providers in acute care felt that patients that victimized themselves often had poorer experiences than those who felt determined to recover. Providers in acute settings understood that addressing a patient's specific goals was important to ensure positive experiences. Providers explained that if they had been given more notice of discharge, they would have had more time to prepare the patient. Providers also felt that time constraints impacted	Providers are conscious of financial considerations that may be barrier for some patients. Providers in acute care felt that patients that victimized themselves often had poorer experiences than those who felt determined to recover. Providers in acute settings understood that addressing a patient's specific goals was important to ensure positive experiences. Providers explained that if they had been given more notice of discharge, they would have had more time to prepare the patient. Providers also felt that time constraints impacted	Rehab providers noted that showing commitment to the patient enhanced the quality of care experienced by the patient. Ensuring the patient's autonomy and allowing them to make their own decisions resulted in better care experiences. Rehab providers understood the importance of individualized goals. Providers in rehab recognized the need for more psychosocial care and stimulation in the rehab setting. Home care providers explained their notion of an ideal patient. Patients that did not fit those ideals were considered outliers. When

impacted patient care because they were never able to get to know the patient. Providers stated that it was their responsibility to give the patient information, but the patient's responsibility to read and understand the information. Home care providers explained their notion of an ideal patient. Patients that did not fit those ideals were considered outliers. When imperfect patients experienced difficulty in recovering at home, the troubles were attributed to their outlier status, rather than the care they had received.	patient care because they were never able to get to know the patient. Providers stated that it was their responsibility to give the patient information, but the patient's responsibility to read and understand the information. Rehab providers noted that showing commitment to the patient enhanced the quality of care experienced by the patient. Ensuring the patient's autonomy and allowing them to make their own decisions resulted in better care experiences. Rehab providers understood the importance of individualized goals. Providers in rehab recognized the need for more psychosocial care and stimulation in the rehab setting.	patient care because they were never able to get to know the patient. Providers stated that it was their responsibility to give the patient information, but the patient's responsibility to read and understand the information.	imperfect patients experienced difficulty in recovering at home, the troubles were attributed to their outlier status, rather than the care they had received.

Patients and Caregivers: Patients felt that their transitions were confusing due to poor communication by providers. Patients felt that their care was not customized to suit their needs or goals. Patients felt neglected and lonely. Patients transitioning to home appreciated home care and physiotherapy services. Patients in acute settings felt that one committed provider could make a world of difference. Patients in long term care felt the provided physiotherapy wasn't enough. Patients experienced poor quality of care in rehab settings. Patients felt that their outlook impacted their recovery.

Providers: Providers felt that sharing information was an obligation, but ensuring understanding was not their role. Providers blamed poor outcomes on abnormalities of the patient. Providers recognized the need for psychosocial care. Providers understood the importance of personalized, goal oriented care. Providers felt that patients' outlook impacted recovery. Providers sympathized with patients facing financial barriers. Providers felt that showing commitment enhanced quality of care. Providers felt that they needed more time to provide better care.

Acute To Home	Acute to Rehab	Acute to LTC	Rehab to Home
Patients and caregivers felt that there should be a provider dedicated to arranging discharge. Patients were thankful to have devices that would help them recover at home, but often found the devices uncomfortable to use. Caregivers felt that the transition from acute to home greatly increased their responsibilities and stresses. However, most caregivers felt relieved to have the patient home safe. Many patients were unsatisfied with the communication surrounding their discharge. Sometimes, the caregiver was not informed when the patient was discharged.	Patients felt that the move from acute to rehab settings went smoothly, especially when the acute and rehab facilities were a part of the same organization. However, patients found that having very short notice of the move was disruptive. Caregivers complained that they were often given no notice that the patient had been moved.	Some patients in long term care, who had been readmitted to acute care for complications, faced financial barriers when asked to pay for their room, food and services in long term care, as well as their hospital bed. Caregivers, especially those that worked full time, struggles to arrange transportation for the patient to get to and from long term care. These caregivers were expected to work on the hospital's schedule, which was often inconvenient for them.	Patients were thankful to have devices that would help them recover at home, but often found the devices uncomfortable to use. Some caregivers were unimpressed with the limited support that home care provided in this transition. Many patients felt worried or nervous returning home, and some even considered long term care. Patients felt that the rehab setting hadn't prepared them for the realities of returning to home. However, upon their return to home, many patients felt comfortable in their surroundings and happy with their progress.
Acute providers have no contact with providers in other settings after discharge, and therefore do not know the results of a discharge. In some acute settings, patients and family are involved in discussions about discharge through a family meeting. However, providers explained that when the time comes, the patient is told that they are being discharged, regardless of whether they have had a family meeting or not. The discharge decisions are made by providers based on where and whether there are beds available as well as the patient's condition. Providers find that sharing information across settings can be frustrating. Home care providers experience difficulty communicating to other home care providers, leaving	Acute providers have no contact with providers in other settings after discharge, and therefore do not know the results of a discharge. In some acute settings, patients and family are involved in discussions about discharge through a family meeting. However, providers explained that when the time comes, the patient is told that they are being discharged, regardless of whether they have had a family meeting or not. The discharge decisions are made by providers based on where and whether there are beds available as well as the patient's condition. Providers find that sharing information across settings can be frustrating. Rehab providers felt that they did not receive enough information from previous settings. Rehab providers felt that many patient preferences and goals got lost in the transition between	Acute providers have no contact with providers in other settings after discharge, and therefore do not know the results of a discharge. In some acute settings, patients and family are involved in discussions about discharge through a family meeting. However, providers explained that when the time comes, the patient is told that they are being discharged, regardless of whether they have had a family meeting or not. The discharge decisions are made by providers based on where and whether there are beds available as well as the patient's condition. Providers find that sharing information across settings can be frustrating. Long term care providers feel that the communication across settings should be more standardized to ensure that everyone gets the	Rehab providers felt that they did not receive enough information from previous settings. Rehab providers felt that many patient preferences and goals got lost in the transition between settings, especially with the pressure to discharge quickly. Rehab providers feel reassured discharging patients home because they can rely on home care to help the patient transition. Home care providers feel that they support the patient with these transitions, but often feel forced to work beyond their scope. Home care providers wish they had more support from other types of providers to handle the issues that are beyond their scope, or they don't feel comfortable with.

the patient and caregiver as their main information source. Acute providers feel reassured discharging patients home because they can rely on home care to help the patient transition. Home care providers feel that they support the patient with these transitions, but often feel forced to work beyond their scope. Home care providers wish they had more support from other types of providers to handle the issues that are beyond their scope, or they don't feel comfortable with.	settings, especially with the pressure to discharge quickly.	information they need, when they need it, and that all providers are clear on who should be completing each task within the care plan.	

Patients and Caregivers: Patients were thankful for home care devices, despite minor problems. Caregivers felt that the transition added to their daily stresses. Patients felt nervous and unprepared for the transition from rehab to home. Patients felt that more communication about the discharge from acute settings was needed. Patients and caregivers were happy to transition home. Patients felt that transitions went smoothly when moving within the same organization.

Providers: Providers occasionally involved patients and caregivers in decision making. Providers base discharge decisions on a variety of factors. Providers in acute and rehab care are reassured in their discharge decisions because of home care. Providers feel that the lack of information sharing across settings impacts care. Often patients are discharged without warning, due system factors. Home care providers need more assistance to provide adequate care.

Acute To Home	Acute to Rehab	Acute to LTC	Rehab to Home
	Patients and caregivers explained that they found it difficult to determine which people were providers, and which were house-keeping or custodial staff due to undistinguishable differences in uniform, and a lack of name tags. This made it difficult for patients and caregivers to seek answers to their questions, because they felt unsure of who they should ask. Patients and caregivers felt that there were too many people involved in their care. Their care felt very divided or segmented among providers, rather than focusing on the patient as a whole. Patients and caregivers felt that their questions were dismissed if the provider was not responsible for that piece of their care, even when the questions were broad or general.		

Patients and Caregivers: Patients and caregivers were confused with multiple providers. Patients and caregivers felt that too many providers where involved, resulting in fragmented care.

Acute To Home	Acute to Rehab	Acute to LTC	Rehab to Home
Caregivers felt responsible for ensuring the safety and comfort of the patient while at home. Caregivers appreciated the help from home care in securing the required devices, but often found that more guidance was needed in doing this. Caregivers felt reassured by home care services that gave them some piece of mind. However, many providers felt that home care services were not enough to save them from feeling burnt out by the extra responsibilities.	Caregivers quickly learned that in order to insure that the patient received adequate care, they had to speak with the primary providers regularly. Caregivers had to be persistent and frequently repeat questions to get information from providers.	Caregivers that can afford the time to do so, often attempt to ease the transition to long term care by visiting as frequently as possible. Caregivers often feel relieved when the patient enters long term care, assuming some of their responsibilities will be lifted. However, caregivers often discover that the care the patient receives in long term care is not as comprehensive as they had expected. Caregivers feel that they are not a priority for the system, leaving their needs and concerns unaddressed. For example, providers that could visit patients in retirement or long term care homes were told that they would receive fewer services from home care and the facility.	Caregivers at home often have to take initiative to get patients the care that they need. However, many caregivers feel confused and unsure of what the patient's needs are. Some caregivers felt guilty asking providers for help or information because they were "too busy" or had "more important" work to do. Caregivers were often tasked with dealing with the patient's devices and trying to secure them for longer periods if necessary.
Providers in acute settings find that they rarely interact with caregivers, since they tend to be present after regular work hours. Providers in acute settings find that caregivers have useful information, especially in the case of patients being discharged home. On occasion, providers complain about caregivers being over-bearing, difficult and unrealistic. Home care providers have to have the permission of the patient to speak with caregivers that do not live with the patient. For that reason, providers rarely speak to caregivers not living with the patient. Providers in home care recognize that patients	Providers in acute settings find that they rarely interact with caregivers, since they tend to be present after regular work hours. Providers in acute settings find that caregivers have useful information. On occasion, providers complain about caregivers being over-bearing, difficult and unrealistic. Providers in the rehab setting commented on the lack of caregiver involvement in their setting. Providers understand the value of caregiver engagement, but are often discouraged by the potential frustrations involved in engaging caregivers. Providers in rehab settings understand that	Providers in acute settings find that they rarely interact with caregivers, since they tend to be present after regular work hours. Providers in acute settings find that caregivers have useful information. On occasion, providers complain about caregivers being over-bearing, difficult and unrealistic. Long term care providers feel that caregivers are often too optimistic, thinking that the patient will make a full recovery when that is not a possibility.	Providers in the rehab setting commented on the lack of caregiver involvement in their setting. Providers understand the value of caregiver engagement, but are often discouraged by the potential frustrations involved in engaging caregivers. Providers in rehab settings understand that caregivers are often busy and may face obstacles to providing care for the patient, especially those living in a different city. Providers realize that the system is not set up to address caregiver needs. Home care providers have to have the permission of the patient to speak with caregivers that do not live with the patient. For that reason, providers rarely speak to caregivers not living with the patient.

who have caregivers that live in other cities often need more assistance at home. Providers are sensitive to the increased stress and responsibility placed on caregivers after a sudden injury like a hip fracture.	caregivers are often busy and may face obstacles to providing care for the patient, especially those living in a different city. Providers realize that the system is not set up to address caregiver needs.		Providers in home care recognize that patients who have caregivers that live in other cities often need more assistance at home. Providers are sensitive to the increased stress and responsibility placed on caregivers after a sudden injury like a hip fracture.

Patients and Caregivers: Caregivers felt that is was their responsibility to ensure the patient received adequate care at home. Caregivers relied on providers for information, but often had difficulty getting it. Caregivers with time constraints struggled to help the patient transition to long term care. Caregivers were thankful for the relief provided by home care services and long term care. Many caregivers felt overwhelmed with new responsibilities. Some caregivers found it difficult to approach providers with questions.

Providers: Providers rarely interact with caregivers. Providers recognize that caregivers are an important source of information. Providers often avoid conversations with caregivers because of their tendency to be difficult to deal with. Some providers in long term care felt that caregivers had unrealistic expectations. Providers understand the barriers that caregivers face.

PROVIDERS GETTING INFORMATION

Acute To Home	Acute to Rehab	Acute to LTC	Rehab to Home
Upon admission, each different provider completes their own assessment to retrieve information from the patient. Often providers do not receive the information that they need from the previous setting, and rely on the patient and caregiver for this information. In some cases, the EMR system can help with information sharing, but this is very limited across settings. Home care agencies do not use the same charting tools, and often struggle to obtain information from hospitals.	Upon admission, each different provider completes their own assessment to retrieve information from the patient. Often providers do not receive the information that they need from the previous setting, and rely on the patient and caregiver for this information. In some cases, the EMR system can help with information sharing, but this is most often the only the case within similar settings.	Upon admission, each different provider completes their own assessment to retrieve information from the patient. Often providers do not receive the information that they need from the previous setting, and rely on the patient and caregiver for this information. In some cases, the EMR system can help with information sharing, but this is most often the only the case within similar settings.	Home care agencies do not use the same charting tools, and often struggle to obtain information from hospitals.

Providers: The EMR system was very useful for retrieving information about the patient, but it couldn't provide information from different settings. Each provider completed their own assessment of the patient upon admission to gain information. Providers often relied on patients and caregivers for information that they could not retrieve from a previous setting.