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EXPLORING THE ROLE OF FAMILY CAREGIVERS DURING CARE TRANSITIONS OF RURAL OLDER ADULTS FOLLOWING A HIP FRACTURE

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EXPLORING THE ROLE OF FAMILY CAREGIVERS DURING CARE TRANSITIONS OF RURAL OLDER ADULTS FOLLOWING A HIP FRACTURE

(Exploring the Role of Family Caregivers)

(Thesis format: Integrated Article)

by

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Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Sciences

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Jacobi Brianne Elliott

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Exploring the Role of Family Caregivers during Care Transitions of Rural Older Adults Following a Hip Fracture

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Abstract

As the population ages, hip fractures become a major concern for older adults. Using an ethnographic approach, this research aimed to understand first, the role of family caregivers following a hip fracture, and secondly, to determine caregiver needs and what contributions they make to knowledge exchange. This was achieved by conducting in-depth interviews with eleven patients, eight family caregivers and twenty-two healthcare providers. The study took place in a small rural setting in south-western Ontario. Thematic analysis of the data indicated that family caregivers play a vital role in the rehabilitation journey of patients with a hip fracture. As well, family caregivers make an important contribution to knowledge exchange during transitions between care settings by providing valuable information about the patient. Future research needs to examine more closely how these contributions to knowledge exchange create smoother transitions. Going forward, healthcare providers and family caregivers should focus on co-creating knowledge and working together to benefit the patient.

Keywords: hip fracture; older adults; rural health; family caregivers; knowledge exchange; ethnography

Co-Authorship Statement

The written material in this thesis is the original work of the author. Jacobi Elliott participated in all aspects of the thesis project, including the review of pertinent literature, data collection and analysis, and preparation of the thesis document and manuscript. The work was done within a larger study, InfoRehab, funded by the Canadian Institutes of Health Research (Principal Investigator: Dr. Paul Stolee, University of Waterloo).

Dr. Christine Ceci, Dr. Bert Chesworth and Dr. Dorothy Forbes provided guidance for all aspects of the study and editorial input for the written work, including the manuscript.

Dedication

To my Dad, Jonathan and Laura – Thank you for all your love and support.
To my Mom - Miss you dearly.

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I would like to take this opportunity to acknowledge the individuals who helped with all aspects of this research project and thesis.

First, thank you to my joint supervisors, Dr. Bert Chesworth and Dr. Dorothy Forbes. I could not have achieved this without your guidance, knowledge and support throughout the past two years. Thank you to Dr. Christine Ceci, the third member of my thesis committee, for helping me through the past few months. Your suggestions and comments were so helpful.

To Helen Johnson, my co-researcher, it was such a pleasure working with you. You taught me so much; I can't begin to thank you enough.

Thank you to all the patients, families and healthcare providers who took the time to share their stories by participating in this research.

Finally, thank you to my family and friends. Your support and love mean the world to me.

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1 INTRODUCTION

1.1 Background

The year 2015 will mark the first time in history that Canada's aging population will be greater than the number of people under the age of fifteen (Canada's Aging Population, 2002). The full consequence of this "upside down pyramid" demographic distribution, also known as the graying effect, remains unknown, but it will undoubtedly have a profound impact on both individuals and communities and in particular, the provision of services of all kinds. Indeed, it is thought that the most significant impact of this changing demographic will be felt in the Canadian health care system (Canada's Aging Population, 2002). Therefore, there is an urgent need for research in the area of health and aging to understand the impact of these changes, and to alleviate the potential for an even greater pressure on the health care system. Specifically, research focusing on creating elder-friendly healthcare systems and implementing best practices is most needed.

One potential risk that is of concern to persons as they age is the possibility of experiencing a hip fracture. Hip fractures are a major musculoskeletal (MSK) health concern for older adults because people tend to have a decrease in both mobility and functional independence following a fracture (Hall et al., 2000). Musculoskeletal injuries involve any injury to the muscle or skeletal systems. As well, following this injury, patients experience multiple transitions through different care settings during the post surgical recovery period. Research that examines care transitions following acute hospitalization may contribute to improved patient care and at the same time reduce health care costs. As stated by Coleman and Berenson (2004a), older adults are more susceptible to receiving fragmented care as they move between various health care settings during their rehabilitation journey. This is attributed to the fact that many older adults have diverse and complex conditions and may require care from many different health care providers across many different settings. In the case of a patient with a hip fracture, frailty and co-morbidites add complexity to an already difficult situation. Not only does the patient require nurses, a surgeon and physiotherapists, but also possibly a geriatrician, a cardiologist, an internist, home care nurses, home care physiotherapists, and a general practitioner to monitor their condition. In order to carry out an effective transition, it is vital that important information moves with the patient to the next destination. Often however, the only common factor at each destination for patients moving between health care settings is their family caregiver(s) (Coleman et al., 2004b).

Involving family caregivers throughout the transition period is important, since they have knowledge about the patients and their circumstances that can assist health care practitioners to provide appropriate and high quality care. Knowledge exchange between health care providers, patients and family caregivers is a vital component of this process. Two well-known frameworks are currently used to guide the examination of knowledge exchange--the Promoting Action on Research Implementation in Health Services (PARiHS) framework (Rycroft-Malone et al., 2004), and the Knowledge-to-Action (KTA) framework (Graham et al., 2006). These frameworks describe the components or factors that are needed to ensure successful transfer and/or exchange of knowledge that promotes the implementation of best practices. Strengthening the process of knowledge exchange can improve health outcomes for the patients and their caregivers as well as system outcomes. This is especially important when working with older adults, as they often have complex care needs and require increased care.

1.2 Study Aim

This study aims to identify the role of family caregivers in knowledge exchange with health care providers and to describe processes that facilitate and hinder successful communication during transitions in care following a hip fracture. Specifically, this thesis looks to answer two key questions. Firstly, *what role do family caregivers play during the care transitions of older adults following hip surgery?* And secondly, *what are family caregivers' information needs and what contributions do family caregivers make to information exchange between and within health care settings regarding older adults following hip surgery?*

1.3 Thesis conducted within a larger study

The larger study, titled *InfoRehab: Better Information for Better MSK Health and Quality of Life for Older Persons,* is a CIHR-funded research initiative that is examining the information needs of older adults with hip fractures. This study is ongoing and currently is being conducted at three diverse sites: a rural area near London, Ontario; a medium size urban location in Waterloo, Ontario; and a large urban location in Vancouver, British Columbia. The multidisciplinary research team brings together multiple areas of expertise such as geriatrics, rehabilitation sciences, nursing, health informatics, qualitative ethnographic approach and knowledge translation. The study has four main objectives:

1. To identify the information needs and preferred information presentation styles of stakeholders involved in MSK rehabilitation of older persons with hip fracture.
2. To test novel statistical techniques for answering pressing questions relevant to MSK health and quality of life of older persons, through analysis of existing databases used in rehabilitation.
3. To develop innovative strategies to support ongoing, effective use of this information to enhance MSK health, rehabilitation and quality of life of older persons.
4. To support ongoing exchange and translation of knowledge among key rehabilitation stakeholders.

To date, the study has supported five graduate students to take part in all aspects of the research process including participant recruitment, data collection, and data analysis, interpretation of the findings and dissemination of the results. As a member of the London site, myself and another graduate student recruited eleven patients, their family caregivers and the health care providers affiliated with these patients. We conducted observations at the care settings, interviews, gathered relevant patient documents, transcribed the data and analysed the data. With a keen interest in the caregiver roles, a portion of the data collected for the larger research project was examined for the purpose of this thesis.

1.4 Thesis Outline

This thesis document is presented in an integrated-article thesis format. Chapter Two is a review of literature related to the thesis topic. Reviews of literature related to hip fractures, care transitions, caregiving and knowledge exchange networks are included in this chapter.

Chapter Three is the article chapter. It provides specific details regarding the study background, methods, findings and limitations. Qualitative research, using an ethnographic approach was used. Data were collected through interviews with patients, family caregivers and healthcare providers and by observations of the process of transitions and the rehabilitation journey that supported creating understandings of the experiences of patients and their families throughout the recovery process.

Chapter Four focuses on a general discussion of the results and contributions to the field. As well, because a qualitative methodology was used, a description of the researcher reflexivity is described. Note that the integrated-article thesis format results in some repetition in the thesis document.

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2 REVIEW OF LITERATURE

This chapter starts by defining three key terms that are central to the thesis. Then it presents an overview of the hip fracture literature followed by a review of published research regarding family caregivers' experiences during transitional care as well as literature on knowledge translation and knowledge exchange. Both qualitative and quantitative studies were included in this review. The following databases were used to conduct the search: CINAHL©, PubMed© and Scopus©. Multiple articles were found using a combination of the following search terms: hip fracture, caregiving, care transition, transitions, family caregiver, knowledge transfer, knowledge translation, knowledge exchange, knowledge to action, and knowledge frameworks. The search was limited to articles that were published in English from 1990 to present.

2.1 Important Terminology

There are three important terms to define prior to reading this literature review. In this thesis, the term *care transition* is used to refer to "a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care in the same location" (Coleman & Berenson, 2004a, p.533).

A *family caregiver* is defined as anyone who provides care and assistance for a spouse, child, parent and other extended family member who is in need of support because of age, disabling medical conditions, chronic injury, long term illness or disability (Canadian Caregiver Coalition, 2001). For the purpose of this thesis, informal caregiver, spousal caregiver, and primary caregiver, will all be referred to as a family caregiver or caregiver.

The third and most important term that needs to be defined is *knowledge exchange*. Knowledge exchange can be defined as collaborative problem-solving that happens between two groups of people through linkage and exchange of information. For effective knowledge exchange, interaction is important and this results in mutual learning (Canadian Health Services Research Foundation, 2006). For the purpose of this study, knowledge exchange focuses on the exchange of information between healthcare providers and patients, as well as their caregivers. By definition, the mutual learning between these groups should result in the co-creation of new knowledge that is relevant to the needs and beliefs of the caregiver and should benefit the patients and healthcare providers as well.

2.2 Hip Fracture

As the number of older adults in Canada continues to increase, it is important to understand common health experiences of older adults. Osteoporosis is a common condition that influences the risk of an older adult experiencing a skeletal fracture. In 2009, it was estimated over 9 million new fractures occurred worldwide (Leslie, 2009). According to the Canadian Institute of Health Research (2010), musculoskeletal disease created an economic burden of $22.3 billion, making it the highest out of all other diseases.

Hip fractures are of particular concern as they are associated with morbidity, loss of independence and increased frailty. The death rate associated with a hip fracture is approximately 20% during the first year after surgery. Hip fractures affect 75% more women than men. This can be attributed to bone density decreases in women after menopause, but also to the fact that women are currently outliving men (Jaglal, 1996). As Canada's older population increases by 25% in 2036, comparative increases in the number of hip fractures are expected. In addition to the increased health care cost of fracturing a hip there is also the longer hospital stays that older adults tend to experience. This is likely due to the increased co-morbidities that are experienced with increasing age. This impact on hospital costs is estimated to more than double over the next few years (CIHR, 2010).

In 2001, Wiktorowicz et al. estimated the cost to the Canadian health care system if someone experienced a hip fracture (Table 1).

Table 1. *Health Care Costs following a Hip Fracture**

Resource	Unit Cost(CDN$)	Data Source
Internal medicine consultation	105.40/consult	OHIP[a]
Orthopedic surgeon fee	376.00/surgery	OHIP
Orthopedic daily visit in hospital	17.00/visit	OHIP
GP[c] visit	24.80/visit	OHIP
Specialist visits	69.30/visit	OHIP
Community Care		
Homemaking	16.96/hour	CCAC[b]
Nursing	43.17/visit	CCAC
Physical Therapy	71.07/visit	CCAC
Occupational Therapy	88.39/visit	CCAC
Alternate Level of Care	332.00/day	
Inpatient Rehabilitation	268.00/day	
Day program rehabilitation	186.00/day	
Long-term care	90.46/day	
Fracture clinic	31.00/visit	
Informal care	6.85/hour	
Sensitivity analysis	16.96/hour	

*Adopted from "Economic Implications of Hip Fracture: Health Service Use, Institutional Care and Cost in Canada" (Wiktorowicz et al., 2001, p.272)

[a] OHIP, Ontario Health Insurance Plan
[b] CCAC, Community Care Access Centre
[c] GP, General Practioner

Based on these numbers, Wiktorowicz et al. (2001) calculated the total cost of a hip fracture for a community-dwelling older adult who was discharged to his/her pre-fracture dwelling as $21,385. However, costs more than doubled ($44,156) when the same individual was transferred to a long-term care facility after surgery. Note that these amounts will have only increased since the time of publication. For instance the cost of informal care ($6.85/hour) was based on the Ontario minimum wage at the time, which has increased to $10.50/hour in 2010.

2.3 Care Transitions

Following a hip fracture, patients experience multiple transitions throughout their recovery. Research conducted in the United States has examined the importance of good transitional care (Coleman, 2003; Coleman et al., 2002; Coleman et al., 2004a, Coleman et al., 2004b; Simpson, 2002). For older adults who have multiple chronic conditions, it is important to have a high-quality transition as these patients move through various health care settings. This helps to ensure the patient is getting the care that is needed (Naylor, 2008). Evidence shows that patients making transitions are more vulnerable to breakdowns in care (Coleman et al., 2004a). This is especially noticeable when patients are moving between rather than within health care settings. Healthcare providers operate in their own settings, sometimes described as silos, and are independent from each other with no consistent form of communication or care plan (Coleman, Smith, & Frank, 2004b). Naylor (2003) suggests that poor communication, missing information, inadequate education for patients and their caregivers, limited access to services, and poor continuity of care all contribute to the gap in care experienced by patients and their families during transitions. Coleman (2003) agrees, suggesting that the system of care does not allow clinicians to ensure that essential information is communicated to the next care setting. There are multiple points during the transition process where a breakdown in communication and care can occur, starting at the point of admission with a failure to prepare both the patient and the family for the transition. As well, communication of vital information, medication reconciliation, and follow-up with patients, diagnostic imaging results and availability of care are also associated with areas where breakdowns can occur (Coleman, 2003).

Many hip fracture patients have complex health care needs as they are frail and elderly (Coleman, 2003). Patients with complex needs are at an even greater risk for experiencing fragmented care, because of the multifaceted nature of their health problems (Coleman, 2003).

2.4 Caregiving

2.4.1 Family Caregiver

Based on information collected by the Canadian Institute for Health Information (CIHI, 2010) over 2 million people in Canada are providing some form of care to a family member. This statistic alone indicates the importance of understanding family care giving. People over the age of 45 make up the majority of caregivers (70%), and one-quarter are at least 65 years of age. Seventy-seven percent of all caregivers are female. Family caregivers provide more than 80% of the care needed by their family members, which translates to more than $25 billion of unpaid labour annually (CIHI, 2010).

2.4.2 Caregiving following a hip fracture

This section provides a review of research undertaken to improve the understanding of caregiver experiences during the rehabilitation journey. This includes examination of both the needs and issues that were faced by families. Following a hip fracture, assistance from a family caregiver is essential during the recovery process as this time is particularly difficult for older adults. Unfortunately, for the most part these caregivers assume their role without much preparation or education on what the future will hold for the patient. For example, Nahm (2010) investigated the experiences of family caregivers within the first six months of hip fracture recovery with two open-ended interviews. Caregivers reported concerns related to the transfer of information, lack of communication and unmet knowledge needs during the recovery and transitional care of their loved ones. With this lack of information, it is not surprising that family caregivers tend to feel lost and frustrated throughout the process. As Coleman and Smith (2004) point out, caregivers are extremely important during the transition process as they are often the only common link between the healthcare settings as patients make their transitions.

To better meet caregivers' needs, healthcare providers require better preparation to educate the family prior to discharge, and to insure that the families and patients are involved in all the decision-making. A qualitative pilot study by Macleod et al. (2005) examined how caregivers are involved in care and rehabilitation. Twenty-five caregivers participated in 30 minute semi-structured interviews. One of the greatest difficulties family caregivers reported facing when trying to help care for their family members following a fracture was the lack of communication provided by hospital staff. The participants commented that they either received information when they asked for it, received information over the phone, or only received information through the patient (Macleod et al., 2005).

Caregivers can be heavily involved in helping with physical rehabilitation, but it was also found that through interaction with the patient, they offer emotional support throughout the rehabilitation process (Macleod et al, 2005). Not only is it beneficial to have caregivers for their physical, emotional, and social support, but caregivers are also considered an important source of information about their family members. Macleod et al. (2005) acknowledged that family caregivers can help provide knowledge regarding the patients' previous capabilities and past medical history. Naylor (2008) has also noted that when family caregiver involvement in decision-making is absent, there is an even greater burden felt by these caregivers.

2.4.3 Caregiving following other acute illnesses

Given that there are only limited studies relating specifically to caregiving and hip fractures, it is important to review other literature for a better understanding of the role that caregivers play and the needs they have. Research by Fleury et al. (1999) examined the importance of involving the families, rather than focusing on just the patients following an acute illness, in this case, a myocardial infarction. Following an acute illness, shock and emotional distress are experienced by both the patient and family, but family caregivers most often must respond to the patient's need for support during rehabilitation (Fleury et al., 1999). A family-centered intervention was conducted and research findings showed that involving families in patient care provided them with information needed for preparing for discharge and future rehabilitation.

In another cardiac study by Moser et al. (1993), research findings showed that family caregivers reported a need for information from care providers regarding the condition of the patient, available resources, and care and treatment options that are available. As well, they also expressed a need for reassurance and acceptance from healthcare providers. After being discharged from the hospital, family caregivers reported that they were unclear as to how to handle the patient at home resulting from a lack of information provided to them by healthcare providers.

2.5 Knowledge Exchange Frameworks

The following two sections outline two valuable knowledge exchange frameworks that are commonly used, the PARiHS framework and the Knowledge to Action framework. They are important because a considerable amount of research evidence concerning best practices in healthcare systems shows that the uptake of this evidence is limited. Patients are denied treatment that is proven to be of benefit because of the time it takes for the research to be implemented into daily practice (Graham et al., 2006). This is supported by research conducted in the United States that indicates an estimated 30-45% of patients are not receiving care that has been proven to work (Schuster, McGlynn, & Brook, 1998). Throughout this section, the term knowledge exchange will be used to describe any process of transferring knowledge. No matter the term used, knowledge exchange is the sharing of research evidence and experiential knowledge between health care providers, patients and caregivers. Rather than being a uni-directional effort of moving research evidence to practice, knowledge exchange is very much a back and forth process of sharing research knowledge and experiential knowledge (Sudsawad, 2007). The main characteristics of knowledge exchange include: multidirectional communication, interactive processes and multiple activities. All the steps involved between the creation of new knowledge and its application are important.

2.5.1 PARiHS Framework

The PARiHS framework is a well-known framework used to guide the transfer and uptake of knowledge (Kitson, Harvey, & McCormack, 1998; Rycroft-Malone et al., 2004; Rycroft-Malone et al., 2002). The framework is made up of three sections or dimensions that come together to facilitate successful implementation of research into practice (Figure 1). According to the model, successful implementation is a function of the relationship between the three dimensions. These are the type/level of evidence to be used, the methods used to facilitate the implementation stage, and lastly, the context or environment in which the research is going to be implemented.

Evidence is the source of knowledge including research evidence, professional evidence and patient and family caregivers' experiences. Rycroft-Malone et al., (2002) explains that each type of evidence is rated on a scale from low-evidence to high-evidence. For example, high evidence would include knowledge that is valued in all areas - research, clinical and patient experiences. Furthermore, the high-evidence research is understood as arising from a well-conducted study with results that are well accepted by the intended audience. Opposite to this would be low-evidence, research that has no relevant value to clinical or patient experiences and/or was not conducted well.

The next section, *facilitation*, helps to enhance the implementation process by providing education and resources. Facilitation is defined as "a technique by which one person makes things easier for others" (Rycroft-Malone et al., 2002, p.177). This indicates that the facilitator of knowledge plays an important role in helping other individuals understand the changes that need to be made to practice. There are three themes that affect facilitation: (1) purpose, (2) roles, and (3) skills and attributes (Sudsawad, 2007). According to the framework, these themes are evaluated on a low-to-high continuum, meaning a low facilitation theme would predict unsuccessful implementation, whereas high facilitation implies that the appropriate facilitation was done depending on the needs of the specific situation.

Lastly, the *context* refers to the environment in which the knowledge translation is taking place (Kitson, et al., 2008). The context can include not only the physical environment where the change might be occurring, but also the characteristics that are favourable to the use of the research such as the operational boundaries or the culture of the organization. Again, there are three themes involved in this dimension of the framework: (1) culture, (2) leadership, and (3) evaluation. Rycroft-Malone et al. (2004) also identified resources (e.g., time, equipment, and clinical skills) as important domains of the work setting that facilitate the use of research evidence in practice. These themes are also rated on the low-to-high continuum. An example of a high context would be one that has a culture that values staff and clients and has effective leadership within the team.

The PARiHS framework puts heavy emphasis on the implementation stage of knowledge translation. When all three dimensions are operating on the high end of the continuum, successful implementation is more likely to occur. Although this stage is important when trying to get evidence-based research to practice, this framework does not discuss the factors related to the creation of the knowledge even though this is a vital component of knowledge translation.

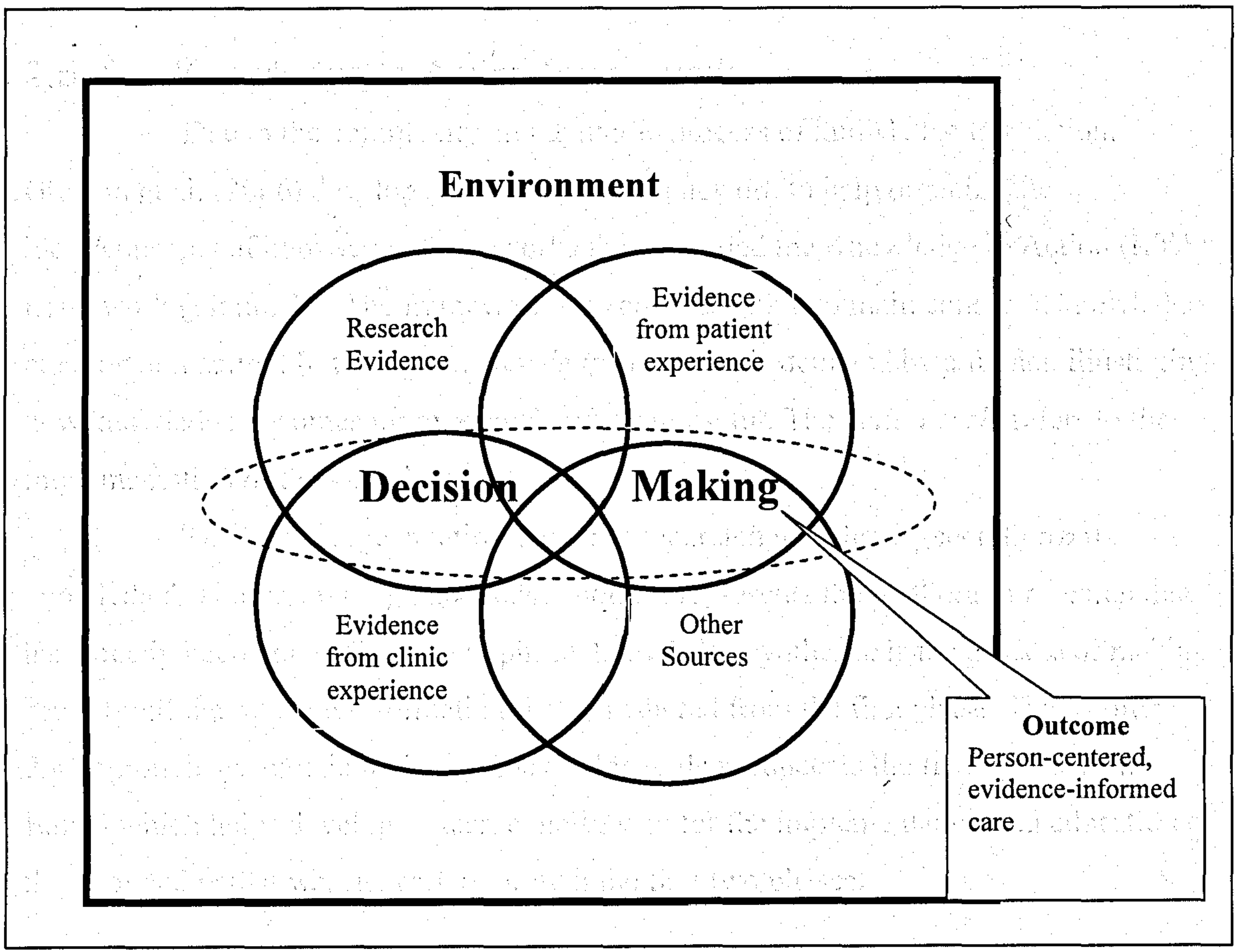

Figure 1. Adapted from the PARiHS Framework (Kitson et al., 2008)

2.5.2 Knowledge to Action Framework

Due to the complexity and dynamic process of knowledge translation, Graham et al. (2006) developed a conceptual framework to help organize the ideas/concepts of knowledge frameworks that preceded the Knowledge to Action (KTA) framework (Figure 2)[1]. The framework was created with two main concepts, knowledge creation and action. In the figure, *knowledge creation* is depicted by a funnel, illustrating how knowledge becomes more refined and more useful. The *action cycle* refers to the implementation of the knowledge.

The knowledge creation funnel is separated into three 'generations of knowledge'. The first phase, knowledge inquiry, represents the plethora of research that has already been done. The second phase, knowledge synthesis, is the process of making sense of all the relevant information that is gathered from the first phase. This is often done through systematic reviews. Knowledge tools/products is the final phase of the funnel which helps develop a clear, concise way for the implementation and education of the knowledge that was generated through the first two phases.

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[1] See Appendix H for copyright permission.

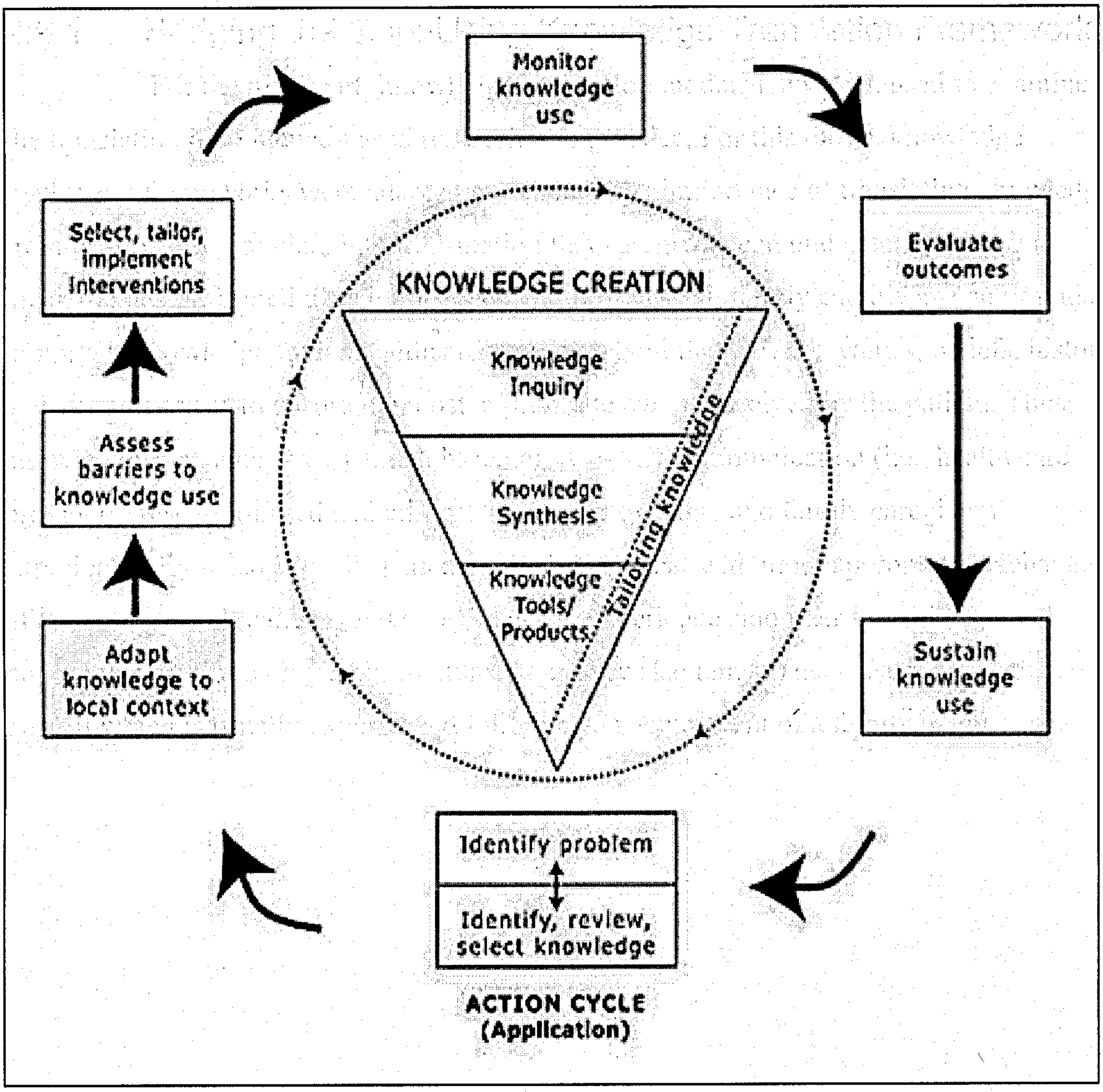

Figure 2. Knowledge to Action Process (Graham et al., 2006)

2.6 Gaps in the Literature and Rationale for Study

After performing multiple data searches, it was evident that there is a large knowledge gap pertaining to the role of family caregivers during patient transitions between care settings following surgery for a hip fracture. In total, approximately 25 articles were found, relating slightly to the topic of interest. Given the lack of understanding and existing research in the area of knowledge exchange and the contributions of family caregivers, this thesis aimed to fill these knowledge gaps.

2.6.1 Bridging the Gap: Using Knowledge Translation Frameworks

For the most part, knowledge translation models have been used to examine the translation of evidence-based research into practice. For this thesis, knowledge translation frameworks were adapted to examine the importance of translating knowledge from health care providers into information that caregivers can understand and use to make the best informed decision for their family. As well, family caregivers can provide important knowledge to the healthcare provider about the patient's values, beliefs, history and circumstances to ensure the most appropriate care is received by the patient. Thus, knowledge exchange is very much based on two-way communication (i.e., health care providers' research-based and clinical 'how to' knowledge and family caregivers' experiential knowledge of the patient). The hope is that with more appropriate exchange of knowledge both patients and caregivers can experience smoother transitions, and a better recovery following a hip fracture. The study also aims to decrease the caregiver burden which is usually experienced following an acute event of a family member.

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3 EXPLORING THE ROLE OF FAMILY CAREGIVERS DURING CARE TRANSTIONS

This is the article chapter. A version of this manuscript will be submitted for publication in the Canadian Journal on Aging.

3.1 Background

The number of older adults in Canada is on the rise and more than 2 million Canadians are involved in informal caregiving for these adults (CIHI, 2010). Although previous studies have explored the importance of caregivers, little attention has been paid to the roles and contributions of family caregivers during care transitions. Following an acute event such as a hip fracture, caregivers become extremely important for patients as they begin a long rehabilitation journey after surgery. In particular, satisfactory knowledge exchange between healthcare providers, patients and family caregivers becomes vital to ensure appropriate and needed information is being exchanged.

This study aimed to contribute knowledge regarding the role caregivers play during transitions and the importance of their involvement during the rehabilitation process. The objective of this analysis was to focus specifically on the caregiver data that was obtained from a larger study, *InfoRehab: Better Information for Better MSK Health and Quality of life for Older Persons.* More specifically, this study looked to 1) examine the role caregivers play during patient transitions following a hip fracture and 2) determine the caregiver information needs and 3) identify the contributions that they can make to knowledge exchange.

3.2 Methods

3.2.1 Theoretical Positioning

This research followed a qualitative methodology which is "designed to describe and interpret the experiences of research participants in a context-specific setting" (Ponterotto, 2005, p.128). Initially, it is important to examine the theoretical positioning in which the research is being conducted. A *constructivist-interpretivist* stance was taken throughout the research. The main component of this theoretical position is the emphasis on understanding the participants experiences. Findings are constructed jointly between the researcher and the participants through the interview questions, as well as more information arising from conversational dialogue and interpretation. An interview guide was used to guide the conversations between the interviewer and the participant. As stated by Schwandt (1994), this allows the researcher to begin to understand an experience from listening to the words of people who live it day to day. Also central to constructivist thinking is the idea that reality is constructed by the participant (Ponterotto, 2005). This means that the participants in the study constructed their reality of the transition journey.

Ontology raises questions concerning the nature of reality and being, asking "what is the form and nature of reality and what can be known about reality?" (Ponterotto, 2005, p.130). In regards to a contructivist-interpretivist approach, it is believed that multiple constructed realities exist, rather than one single reality, and these are influenced by the situation, experience, perceptions and interaction between the participant and the researcher (Ponterotto, 2005). That being said, rather than one real world, being a constructivist-interpretivist influences the perceptions of reality. Researcher-participant interaction and being immersed in the setting were important to coming to understand the day-to-day life experiences of these individuals. As well, when analyzing the data, specific themes are identified in relation to the experiences people shared of their reality (Ponterotto, 2005).

Ethnography

This study used a qualitative focused ethnographic approach. Although ethnography can be defined in various ways, at minimum, it usually refers to research that has emphasis on understanding the experiences of a certain group of people (Hammersley & Atkinson, 1995). In its most simple terms, ethnography refers to the researcher gaining direct contact with others, drawing close to people and events, and then writing about what was learned during the experience (Van Maanen, 2004). Ethnography usually occurs with a small-scale group over a longer period of time, looking to understand, describe and explain the particular case that is being studied

(Hammersley, 1992). Hammersley and Atkinson (1995) also state that it is characteristic in ethnography for researchers to participate "overtly or covertly, in people's daily lives for extended periods of time, watching what happens, listening to what is said and/or asking questions through informal and formal interviews, collecting documents" (p.3). The social world is constructed through interpretations and actions based on these interpretations. This approach allowed researchers to use in-depth interviews, participant observation of interactions, and an examination of documents to study real life patient transitions across health care settings and the involvement (or lack of involvement) of family caregivers. The research and observations were done within a constructivist-interpretivist paradigm, as previously described. Ponterotto (2005) states that the "researcher's values are central to the task, purpose and methods of research" (p. 127). It is widely noted that the fieldwork and observation phase of ethnography is the most important, however, the "write-up" is also important. Ethnography research allows the research to present the work in a descriptive or interpretive way, which is heavily based on the researcher "being there" (Van Maanen, 2004).

3.2.2 Developing the Interview Guide

An interview guide was created for the purpose of the larger InfoRehab study. InfoRehab, is a study funded by the CIHR Team Emerging Grant. The interview guide includes a wide range of questions regarding the transfer and exchange of knowledge, as well as the experiences that people have gone through. Three interview guides were created, one directed toward the patient, one for the family caregiver and one for the health care provider. Each guide had multiple sections. The patient interview guide had sections such as, Admission to Hospital, Discharge from Hospital, or Living at home (Appendix A). Secondly, the health care provider interview guide asked questions regarding what information they generally send or receive when transferring a patient, as well as asking whether or not they include family caregivers as a source of information (Appendix B). The family caregiver guide focused on exploring how they help the patient (roles). As well, many questions focused on whether family caregivers received necessary information about the patients' situation (knowledge exchange) (Appendix C).

Each of these sections were completed at the various locations along the rehabilitation journey.

3.2.3 Participants

Purposive sampling was conducted between December 2009 and January 2011 in order to ensure a variety of participants and post-surgical care settings were included in the study. Patients who were undergoing surgery after a hip fracture, and were over the age of 65, were eligible to be included in the study. Patients with cognitive impairments were also eligible to be included, provided that their next of kin gave informed consent. If there was any indication that there was cognitive impairment, informed 'assent' was requested prior to each interview with a patient with cognitive impairment. Family caregivers were eligible to be included in the study if they were identified as being involved in the care of the patient. Also, patients' health care providers were eligible to be included from the various health care settings that the patients were admitted to. While the focus of this thesis was on patients and their family caregivers, healthcare provider data were included because they were a part of the communication dynamic during care transitions.

Participants were recruited through a collaborator, a physiotherapist, at a rural hospital in south-western Ontario. After the potential participants were approached by this collaborator, they signed a "Consent to be Contact" form (Appendix D) if they were interested in finding out more about the study. The information was passed on to the researchers who then contacted the patients to arrange to meet them in person. At this time the letter of information (Appendix E) was given along with an in-depth explanation of the study. Patients who signed the consent form (Appendix E) were enrolled in the study. In total, 11 patients, 8 family caregivers, and 22 health care providers consented to participate. The mean age of the patients was 80.4 years. **{SD RANGE}** There were eight females and three males enrolled in the study. The majority of patients (n=9) lived at home with a family member (spouse or adult children) prior to fracturing their hip. Of the eight family caregivers enrolled in the study, six were adult children. The mean age was 57.5 years. Table 2 gives a description of the patients, their relationships and the transitions they experienced.

Table 2. Participant Characteristics

Patient	***Caregiver***	***Relationship***	***Transitions****	***# HCP Interviewed***
Heidi	Joy	Daughter	H- R – R - Deceased	3
Todd	None		H – R – RH – H(NHC)	2
Lily	Walter	Son	H – R – LTC – H (NHC)	1
Abbey	Holly	Daughter	RH – R – R – LTC – R - LTC	6
Ernest	Lana	Wife	H – U – R – H (HC) - OP	2
Leslie	Julie	Daughter	H – R – H (HC)	2
Terri June	June	Daughter	H – R – LTC	0
Paula	None		RH – R – U – R – RH (HC)	1
Ingrid	Peter	Son	H – R – LTC	2
Beatrice	None		H – R – H (HC) – OP	2
William	Joanne	Husband	H – R – H (HC) - OP	1

*H – Home, R – Rural Hospital, U – Urban Hospital, RH – Retirement Home, LTC – Long-term Care, NHC – No Homecare, HC – Homecare, OP - Outpatient

3.2.4 Data Collection

Data were collected through in-depth semi-structured interviews and observations. The interviews were held in quiet places, such as offices or patient homes, and were roughly 30-45 minutes in length. The majority of the interviews were conducted face-to-face, but three were done over the telephone. The interview guides were used as a foundation for the discussion but questions were open-ended in nature and allowed the participant an opportunity to expand on a thought or idea wherever necessary. In total 58 interviews were completed. They were recorded using a digital recorder and transcribed verbatim off-site at a later date.

Field notes of observations were completed prior to and following the interviews and participant visits to compliment interview transcriptions. The use of field notes provided additional information about the non-verbal exchange of information between patients, caregivers and healthcare providers as participants transitioned between various health care settings. The notes captured behaviours of the patients, family caregivers and health care providers, as well as the interaction between all three parties. As well, events such as rehabilitation exercises and the discharge process were also observed and recorded on observation forms (Appendix F). During these periods of observation, the researchers gained a sense of the culture amongst the healthcare staff, families and patients in the various facilities. Researchers were able to better understand the environment where the information exchanges took place and who was initiating the conversations. Over the course of the data collection period, 65 hours of observation time was recorded.

Medical documents relevant to patient care and transfers between and within each health care setting were also collected, providing important additional information about the participants. These documents were scanned, and the content was analyzed through a document review phase. The three sources of evidence, face-to-face interviews, observations, and document review provided the opportunity for triangulation of the data.

Data collection stopped because saturation was achieved for the larger study. The final interviews that were conducted did not provide any new information that hadn't been provided in previous interviews.

3.2.5 Data Analysis

Analysis of the interviews, observation field notes and relevant documents were entered into a qualitative data management program, NVivo 8. For the purpose of analyzing the data, thematic analysis was completed. Thematic analysis is the process of identifying groups of words that relate to meanings or concepts that have been identified. These concepts are identified as being important to the research, either positive or negative. The analysis process begins with an identification process (Graneheim & Lundman, 2004). The primary data source for analyzing caregiver roles and contributions to knowledge exchange were a data subset of eight caregiver interviews and observation notes specific to observing caregiver roles and knowledge exchange. Specific to this research, the unit of analysis was the caregivers and the aim was to determine the role caregivers have and the knowledge they contribute and need to help patients through the transition process. Pertinent references to caregivers made by healthcare providers and patients, or found in healthcare documents, were also incorporated into the data analysis.

An inductive, data-based analytic approach was informed by the guidelines of Lofland et al. (2006) and Graneheim and Lundman (2004). "To obtain a sense of the whole", interview transcripts, field notes and healthcare documents were all read through three times (Graneheim & Lundman, 2004, p.108). Following this, line by line coding was completed, then general categories, a collection of codes with shared content/aims, were developed (Graneheim & Lundman, 2004). A few examples of categories that were coded for this research are 'distant families', 'family as information source', 'exhaustion', 'transition nightmare', or 'prior experience'. These initial categories were reviewed by the team of four researchers to ensure a consistency of understanding. Codes were then used to link ideas and statements to further develop interpretations. The experience that was captured in the field notes, interview transcripts and healthcare documents evolved into the themes presented in the findings.

Criteria described by Lincoln and Guba (1994) regarding the trustworthiness of the findings (credibility, dependability, confirmability and transferability) were applied. Peer debriefing which consisted of describing the collection of data and analysis processes to the larger InfoRehab group ensured credibility of the data. Transferability refers to whether or not the findings can be transferred to other settings or groups (Graneheim &Lundman, 2004). It is important to note that this study was conducted in a rural setting, which included a hospital that lacked many services. Therefore the results of this research could be relevant to other rural settings. Confirmability was achieved through the use of an audit trail that would allow another researcher or reader to follow the progression of events in the study and understand the logic. The audit trail was on-going and was completed after each event. Multiple strategies were used to assure dependability. First, the supervisory committee was involved in reviewing and editing of this thesis. Secondly, triangulation was used to facilitate validation of the data. Triangulation was accomplished by using multiple methods of data collection such as field notes, interviews, memos, and document review. These various sources of data collection all contributed to the interpretations during data analysis. Thirdly, other researchers involved with the larger study and peers who were not involved reviewed select excerpts and shared their interpretation of the meaning of the excerpts. This process ensured that the researcher had examined the excerpts from different perspectives and was open to different ways of thinking, resulting in richer interpretations of the data.

Reflexivity was also used to facilitate validation of the data. Outlined by Finlay (2007), the process of reflexivity has three stages: pre-research stage, data collection stage and the data analysis stage. Reflexivity starts at the beginning by examining the literature and clarifying the research questions. It ends by examining the analysis and reflecting on the experiences. A description of my personal reflexive can be found in chapter 4 that describes how my experiences perhaps influence the conduct of the research process and interpretation of the findings.

3.2.6 Ethical Considerations

Prior to starting the study, ethical approval for this project was granted by The University of Western Ontario Health Sciences Research Ethics Board (HSREB; Appendix G). To ensure confidentiality throughout the study, participants were given pseudonyms and all the identifying information was removed from the collected data. All participant information related to the study was kept in a secure location, or on a password encrypted hard drive.

3.3 Findings

The findings from this study are summarized below (Figure 3) in three categories which correspond to the three research questions identified earlier. The figure below outlines each of the findings that will be described in this section (Figure 3).

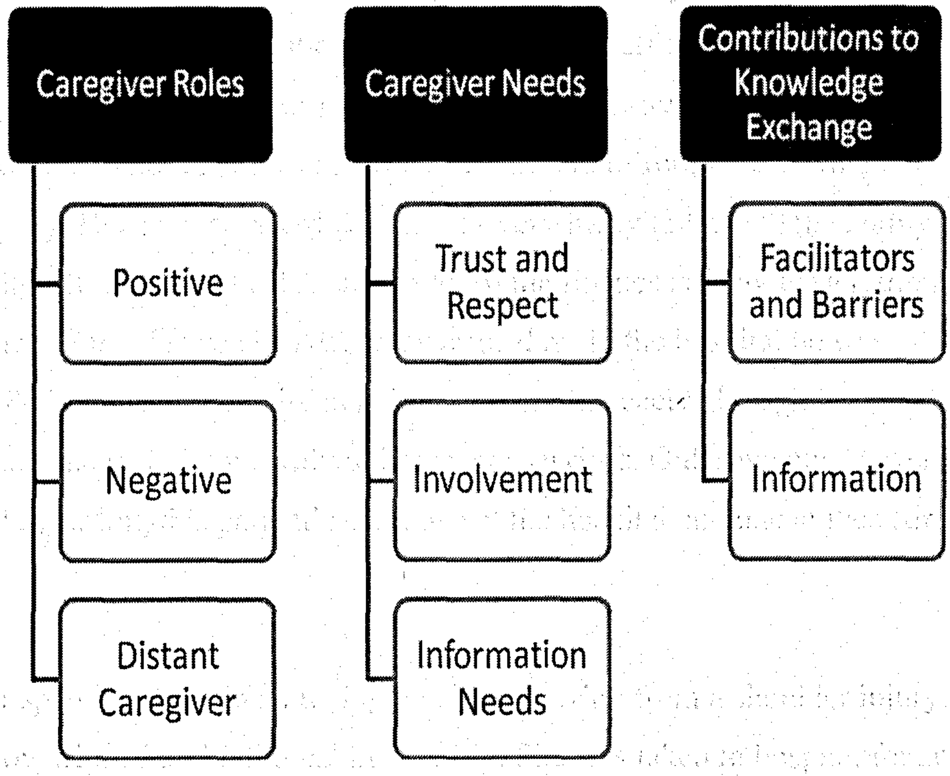

Figure 3. Findings - Roles, Needs and Contributions.

3.3.1 Getting to know the participants

The following section describes the patients, their families and the health care providers who were involved in their care, as well as a brief description of the situation they experienced.

1. Heidi – This elderly woman sadly did not survive more than a few months following her hip fracture. After falling and breaking her hip she was transferred to a nursing home to recover from surgery. According to her daughter who was very involved in her care, Heidi became very confused after her surgery and this did not improve.

Throughout the recovery and transitions, the patient's network consisted of health care providers who provided care while she was ill.

2. Todd – This older gentlemen lived on a farm in south-western Ontario. Extremely independent and living alone, he slipped and fell on the ice while getting his mail. Although his family, two daughters and a son, sounded extremely supportive, none were available for participation in the study due to their busy jobs and travelling for business. Todd expressed frustration with the hospital staff and felt that patient advocacy groups were needed for patients who couldn't advocate for themselves. He was disappointed in not only his care, but also the care of roommates which he witnessed daily. He acknowledged that he was very lucky to have a) the ability to speak for himself and to make decisions and, b) the finances to pay for a retirement home that he felt met his needs. After numerous days in the hospital he was transferred 80 km away to a retirement home where he received respite care. Following this, he went home without homecare services. Only two nurses were interviewed regarding this patient's care, one at the hospital and one at the retirement home.

3. Lily – After spending time in a nursing home recovering from a shoulder injury, this elderly widow tripped and fell breaking her hip. She was taken to hospital for surgery, and after a brief stay she returned to the nursing home for more respite care. Since she already had a bed at the nursing home her process was much simpler. Once the nurses made sure she was stable, Lily returned to the nursing home. She has two single, older sons who visited her every day. After a few months in the nursing home she finally returned home without homecare. Upon her initial return home she seemed depressed by her limitations and suggested that "it would be easier if she just wasn't here." Her two sons continued to stop by daily, bringing dinner and doing house chores. When a follow-up interview was conducted one year later, she still expressed frustration with her dependence on a walker, and explained that she does not leave the house unless she has a doctor's appointment.

Given that no one at the nursing home wished to participate in the study, the only health care provider for this patient was the nursing home coordinator who commented that she was recovering well. Contrary to what the coordinator said, Lily explained numerous times that the rehabilitation staff at the nursing home were only working on her shoulder and had not given her any exercises for her hip, nor did they have her get up from her wheelchair.

4. Abbey – Although Abbey is very elderly, she is full of energy and imagination and resided in a retirement home. This was her second hip fracture which occurred after tripping over a cord while trying to move some plants. Following the hip fracture, she was then transferred to the hospital for surgery and then to a nursing home for respite care. The retirement home did not feel they could provide adequate support during her recovery. The nursing home was some distance from her current home, but her daughter remained very much involved in her care. After her six week appointment, Abbey was told that she would need more surgery to fix some problems related to the first surgery. During this time the family made the decision to give up her retirement home and hope that a permanent spot in the nursing home would be available. Abbey had multiple health care providers involved in her care as she was transferred between many facilities on her journey.

5. Ernest – While trying to trim some branches Ernest fell out of a tree and fractured multiple bones in his body. He had surgery at a major hospital in the city and without being involved in decision was then transferred to the smaller rural hospital. Although his wife was a prior health care provider, she found the communication and transition extremely frustrating. After many weeks in the hospital, Ernest returned home where he waited days before receiving a visit from homecare staff. The frustrations with the healthcare system only heightened for his wife who was trying to care for her husband (without the right equipment).There were multiple health care providers involved in his care at each care setting that were interviewed for the study.

6. Leslie – While on the phone one day Leslie went to sit on a stool but unfortunately missed and fell to the ground. She was taken to hospital where she learned she had experienced a hip fracture and would need surgery. Leslie lived in a two-storey house quite comfortable with her husband, and was in close contact with all of her children. Her two daughters who were previously healthcare providers were involved in her care. Leslie experienced a few rough days following her surgery, but with the help of her family and rehabilitation exercises she was home within two weeks. Although she had access to homecare, her daughter was deemed capable of taking care of her mother so the homecare services were cancelled. Leslie expressed many thanks to the hospital staff for the care she received, while on the other hand her daughter reported some issues involving a mix up in medication and lack of information exchange.

7. Terri June – Terri June lived in a mobile home in a small town in south-western Ontario. Luckily, a neighbour realized she had fallen and was able to help call her an ambulance. Once she reached the hospital, the healthcare providers contacted her family who lived a fair distance out of town to notify them. The family felt it was best if they made the decisions for their mother and move her into a retirement home. Terri June was not happy about this decision but realized it was the best option. Since the family was out of town they depended heavily on phone communication with healthcare providers and they were happy with the information and involvement they received.

8. Paula – Paula was out watching a skating show with some friends from the retirement home on a Sunday afternoon. After a long day of sitting in the arena, Paula stood up to leave and unfortunately her legs buckled beneath her. She stumbled to the cement floor and instantly knew something was wrong. Paula was taken to the hospital where she learned she had fractured her hip. Although Paula has two children, her son is a long-haul truck driver who is barely home and her daughter is a single mother with two children who works three jobs to make ends meet. Her children were unable to be at the hospital to gather information and her husband is visually impaired with dementia and could not leave the retirement home on his own. After many days in the

hospital and much confusion over where she would have surgery, she finally received surgery at the large hospital in the city before being transferred back to the rural hospital. After a few weeks in the smaller hospital, and much uncertainty about her discharge, Paula was sent back to her retirement home to continue her recovery. Her daughter was only available by phone and did not have time to complete the full interview guide. The nursing staff members at her retirement home were helpful, but only worked part time and were difficult to contact.

9. Ingrid – Ingrid lived in a granny suite with her elderly husband. Over a year ago her son Peter and his wife decided to build an addition on to their home to accommodate his mother and her husband. Both Ingrid and her husband expressed their wishes to remain living at home rather than a nursing home, this seemed like a good solution. One day Ingrid was making her way to the bathroom when she tripped on a foot stool. After expressing pain, Peter took her to the hospital where they learned she had fractured her hip and would need surgery. While in emergency, they were told that she would be walking out of the hospital in great shape. Following surgery she was then told that they would need to find a nursing home for a short-term stay while she was recovering. Unfortunately the short-term stay room has turned into a permanent room for Ingrid. Although she had support from her son, they were unsure how to navigate the system and didn't feel they had support from any healthcare providers. It wasn't until they reached the nursing home that they were satisfied with her care.

10. Beatrice - Prior to breaking her hip Beatrice lived at home with her husband. After spending a few weeks in the hospital she returned home with homecare. Although her husband seemed involved in her care and expressed interest in participating, he did not end up taking part in the interview process. She had a small network of healthcare providers – initially the nurses in the hospital, then a homecare physiotherapist, followed by a physiotherapist at an outpatient clinic. When visited at her home, she seemed content and satisfied with how she was recovering.

11. William – A retired fire-fighter, this elderly man was in great health. One Sunday morning he decided to re-shingle his shed while his wife went to church. He slipped and fell, breaking his hip. After a few weeks in the hospital, the staff felt he was ready for home. With the support of his wife, he continued his rehabilitation at home.

    He received three homecare visits upon returning home and then continued his care at the outpatient clinic. Although William and his wife were happy with the care he received and felt he was doing well, the physiotherapy expressed concern with his lack of discipline. He was not using the walker or cane when he should have been.

3.3.2 Description of Experiences – What role do caregivers play during transitions following a hip fracture?

Every patient has his or her own story and experiences as they go through the rehabilitation journey following a hip fracture. Family caregivers too, have a story to share. The stories may differ based on experience, knowledge and/or relationships. The next section gives a brief overview of the roles, challenges and barriers the caregivers involved in this study experienced. As well, one description outlines the benefit of having prior healthcare knowledge as the family caregiver found it much easier to help care for her mother.

Leslie and Janet

Janet is the daughter of Leslie, who fractured her hip after falling off of a stool in her kitchen. Prior to falling, Leslie lived in a two storey house with her husband. Both Leslie and her husband experienced multiple health issues, but managed just fine on their own prior to this event. Janet is a retired nurse of over 40 years who described a sense of fulfilment when helping her mother throughout the recovery process.

> *Caregiver: But if people had families and got families involved...I think there's satisfaction for me to look after my mother..(laughter)*

Even though Janet was not from the town or the surrounding area, she was able to come to the hospital as soon as her mother was admitted for surgery. As well, she made a commitment to live with her mother for 6 weeks post-surgery, or until she felt Leslie could manage alone. When Leslie was first interviewed in the hospital following her surgery, she was disoriented, on oxygen, and had trouble completing the interview. Her goal of walking out of the hospital and back home seemed unlikely at this point. Yet, when Leslie was seen in hospital just prior to discharge it was like visiting a new person. She was incredibly energetic and in high spirits. She admits that without her family support and encouragement she probably would not have recovered.

> *Patient: But like I say it's because...maybe it's family...you know that really helps you[recover].*
>
> *Interviewer: That's true*

While in the hospital, Janet made an effort to visit her mother every day and monitor her rehabilitation. Due to her healthcare knowledge, Janet was able to help her mother with physiotherapy exercises, and ensure that she was doing them properly.

> *Patient: And then uh they will visit maybe twice a week and make sure you are doing your therapy and of course when my daughters are there they are all quite capable of doing it the second time. The first time they did it here and then in the evenings Janet who's now got to go home she said she did it very thoroughly. So that was the part to keep the morning and the evening going made it very much stronger.*
>
> *Interviewer: Good. So she helps you with your exercises?*
>
> *Patient: Oh. My daughter?*
>
> *Interviewer: Yes*
>
> *Patient: Well they loved it because she's just retired 44 years of nursing and she (voices in audible). They loved her coming in every night she was here and stayed until 9:30pm and so I don't suppose everybody had half that but that was...that was a really big help to me*

In addition, to helping her mother complete her evening exercises which contributed to her recover. Janet monitored the medications that her mother was receivin ag. She was able to ask questions and recognize when errors were made regarding types and dose of medication.

> *Caregiver: And uh...one thing we did find though...that's where the communication broke down...even though the main profile said tramacet they hadn't said don't give traveset...they still tried to give her that..I said no she's only taking extra strength Tylenol so we had to correct them more than once on that pain control*
>
> *Interviewer: So if you weren't there then she might have...*
>
> *Caregiver: She might have gotten it!*

When her mother was discharged from the hospital, the homecare workers were satisfied with the knowledge Janet had, and didn't feel that Leslie needed much more help at home. Observations of the family dynamics and admission/discharges of the patient took place as well.

June 3rd, 2010

> *It is so nice to see such a caring family taking care of their mother. Janet seems very happy that she is able to help her mother and fortunate that she can live with her mother for the next six months while she recovers. During these observations I did not feel that Janet was burdened by this. She agreed that it would be a waste of services to have someone come in to help her mother when she was very capable and willing to help her mother herself. She also had lots of support for her other siblings. Leslie was also so thankful to have her daughter and couldn't have been happier with how things turned out. Overall – she was in extremely high spirits.*

Janet commented on how important family can be, especially when the nursing staff does not know the patient.

> *Patient: That one lady said I heard her telling you I didn't need a commode*

> *Caregiver: That was the CCAC lady*
>
> *Patient: Oh my I certainly did*
>
> *Caregiver: And she doesn't understand you well enough to know..she's up 3-4 times a night, she also takes a sleeping pill and for her to manoeuvre with a walker to the bathroom was just a little unsafe..*

Although Janet acknowledged the benefit of having a nursing background, she also felt that family can be great support for the patient, and anybody can really do what she has done for her mother.

> *Interviewer: Ya and that's something we're finding really interesting. Do you feel it's easier for you to help because of your background in nursing and in the healthcare?*
>
> *Caregiver: I think so but I think anybody can do what I did, they just have to have a little bit of training...anybody can bed bath their mother or their father. That's reasonable..if you bathed a baby..you can bathe an adult*
>
> *Interviewer: Right*
>
> *Caregiver: There's nothing to that. And just to be alert as to what their families are going through. And nobody knows your family better than your family does so I mean you have nurses changing shift after shift..it's the same for me as a nurse going in and interviewing the patient for the first time..they look like..don't you know this already? Well no I've never met you before, I need you to tell me how you're feeling. If you had a family member beside them, it's so much easier to interview them. Um well for instance, the first few days mom made no sense at all, she was seeing things on the wall that weren't there, how do you interview someone like that, how would a nurse know what that patient is expressing, we have to take it at face value and think.*

Some family members however, may need more education to be able to help their family member throughout the recovery. Leslie experienced, what could be considered, a smooth recovery. Leslie had surgery, stayed in the hospital for a few weeks, returned home, continued rehabilitation and one year later, was still in high spirits. Overall Janet provided emotional support, physical support and social support for her mother. While living with her mother following the surgery, Janet cooked meals, cleaned the house, and took her too appointments, managed her medications, assisted her with physiotherapy exercises, and helped with many activities of daily living such as bathing. Not every patient was as fortunate as Leslie. Although families maybe just as supportive as Leslie's family, it could simply be that the family caregiver did not have the knowledge or expertise to help make the best decisions for the patient.

Ingrid and Peter

Ingrid, an elderly lady who fell at home and cared for by Peter, her son who lacked knowledge of the healthcare system. Ingrid lived in a granny suite which was attached to Peter's home. Prior to falling, Peter and his wife, were very much involved in the care of both Ingrid and her elderly husband. Peter and his wife cooked all the meals, cleaned, and drove them to various appointments.

When she was first admitted to the hospital she was told she would walk out better than she had ever walked before. This set high expectations for Ingrid's recovery. Lack of communication continued as Ingrid was placed in a room.

> *Interviewer: Oh ok and did you receive any information about her care? Physiotherapy? Did they explain that stuff?*
>
> *Caregiver: No, they just, no... we went off the board, we asked them what that meant*
>
> *Interviewer: Oh the sit to stand?*
>
> *Caregiver: Yeah, but other than that they didn't tell us anything.*

After a few days, the family was abruptly told that their mother would need to be placed in a long term care facility to continue recovering.

> *Caregiver: Until they called us to tell us they wanted to have a meeting to tell us they wanted to put her in a long term home*
>
> *Interviewer: How long after the surgery was that?*
>
> *Caregiver: Probably about two weeks...So we got invited to a meeting on a Friday morning, where there was the doctor, and about 8 people there*
>
> *Caregiver 2: A couple of nurses*
>
> *Caregiver: A couple of nurses, and they basically said that you know, she is going to need 3 or 4 months or more of rehab*
>
> *Interviewer: Ok*
>
> *Caregiver: So you have to now choose a facility right away*

Not only did the family feel pressured to make this decision, they were doing it based on little information and education on the whole process.

> *Interviewer: Alright, and then thinking about the time here, do you feel that you have been involved in the decision making?*
>
> *Caregiver: Um, not really, um, I don't know that I...*
>
> *Caregiver 2: Apparently she went for some x-rays and some heart tests last week and we have never even gotten any results or nothing*
>
> *Caregiver: Yeah and I'm about to ask about her medications that they are giving her, we don't know anything*

This type of situation may be experienced more among people who lack knowledge of the healthcare system. Similarly, Lily, an elderly lady, had the same experience. When she fell and broke her hip, she was already in respite care at a nursing home for a previously broken shoulder. This meant that she was in the hospital for limited time before returning back to the nursing home. The result was limited rehabilitation time with the physiotherapists in the hospital, and no continuation of therapy once she returned to the nursing home.

Ernest and Lana

It is evident that patients and their families can have very different experiences, especially based on their previous knowledge or experience in the healthcare field. It is important to note that family caregivers who may have worked in healthcare, may still not have a smooth recovery journey with the patient.

Lana is a retired nurse who lives with her husband who fell and broke his hip. She described the whole experience as quite frustrating because she did not receive adquate information about her husband's care.

> *Caregiver: Probably the nurse initially, and then I believe one of the residents at some point I spoke to, but I didn't get any information about exactly (emphasis) what had happened, about where was the fracture of the pelvis? I was concerned about that a lot too, because, you know the hip can only do so much because of where the pelvis is broken, and he's going to be a lot more limited in what he can do...But eventually I did speak to a resident, it was a long time before I spoke to a surgeon or somebody who was present at the surgery itself, but it was before the surgery that I had spoken to that resident.*
>
> ...
>
> *Interviewer: Ok, so when there were times that you wanted to know something, how did you go about finding out?*
>
> *Caregiver: Well I would speak to the nurse and if they didn't know I'd ask them to have somebody call me on the phone because I'm not there that early in the morning, 7 o'clock, I mean it's not the time visitors are usually expected to be there anyway...*
>
> *Interviewer: is when the doctors go?*
>
> *Caregiver: That's right they do their rounds fairly early before they go into surgery. But I never heard from the surgeon at all. And then eventually I did*

Not only did Lana not receive help when they returned back to their home. But she also felt that she and her husband did not receive the information or options they needed while in the hospital, regarding his next transition,

> *Interviewer: So do you think they spoke with Ernest about where he would like to go next or...*
>
> *Caregiver: I don't know that he was given any option. He ended up going to a surgical floor for a period of time, and then he was told that he would be sent either to Parkwood, or to Strathroy, being the closer to home type of hospital. Which I wasn't really as happy about, because I had heard different things about Strathroy that they don't have as good a patient care, and that the rehab for them and the physio doesn't compare to what's available through Parkwood, and that would have been I guess a preference in some ways, although it's a long drive from here, you know it's, well half to forty five minutes. So he was just sent wherever, wherever there was a bed that's where he was going to go.*

Terri June and June

Due to the rural location of this study, there are many patients who are admitted to hospital without caregivers living nearby to help them. For the purpose of this paper, these are referred to as distant families. Patients who have distant families do not have the support system who can help them make significant decisions such as where they will be placed following surgery.

Terri June was admitted to hospital after falling, and did not have any family in the area. Communication with the family was limited to phone calls. June, the daughter-in-law of Terri June explained the difficulties they had to deal with while trying to care for their mother while being located in another city. While meeting with the family the following was observed, June 4th, 2010

> *Seems to be a sense of resigned frustration from these family members – what they had been afraid of for the past few years has indeed come true and they tried to prevent it, wish they could have prevented it, still feel some responsibility in this.*

When she first broke her hip, the family received the news from a neighbour. Following this incident, the family was in contact with hospital personnel by phone, trying to make decisions.

> *Interviewer: Yeah, ok..And then did you get more news later from anybody at the hospital?*
>
> *Caregiver: Um, we called the hospital, and we were told that they were, she was being x-rayed and all that kind of stuff, and so we basically had to hear what was going to happen with the results of that.*
>
> *Interviewer: Yeah. And then how long after that, I know you guys work and...*
>
> *Caregiver: Yeah, we kept calling the hospital, and we were told that you know, she had indeed broken her hip, I believe it was later that evening, and they were expected to be doing surgery on her, but it ended up being the following day before they actually did the surgery on her, so it seemed like an awfully long time, and I know she was in a lot of pain, she told us.*

The normal process for a patient who will need to move to a long-term care facility post-hip fracture surgery involves a family meeting. In this situation, the family had limited time to make these decisions because all the communication was done over the phone.

> *Interviewer: Yeah, even though she knew she would be moving, I'm sure it happened kind of suddenly for her, when the bed actually came up?*

> *Caregiver: Yeah, and it did for us too, like we knew, we kind of had an idea that it would happen, but we certainly didn't have the time to go and check any place out, because she wouldn't allow us to do it before, you know, we never took the time to try and go around to see what was what.*
>
> *Interviewer: Yes, then this wasn't really her first choice of facility.*
>
> *Caregiver: Right, but now she says she's staying there so.*

Other Caregivers

The other caregivers that were interviewed for this study also expressed various difficulties. William and his wife were extremely independent but found the whole process tiresome and frustrating. Joanne, the wife, made herself available at the hospital all the time to try and gather as much information as possible but still did not feel she received adequate information on her husband's care. She expressed most of her frustration over the discharge process. She came into visit her husband one morning and upon arriving was told she would be taking him home. At this point she was not prepared, physically or mentally, to be taking him back home.

> *Patient: Yeah, after lunch sometime*
>
> *Interviewer: Were you given any indication?*
>
> *Caregiver: Not at that time, we weren't expecting it; I just went in for a regular visit*
>
> *Patient: They never talked about it*

For another patient, his complete rehabilitation process was experienced by himself. Although a very knowledgeable, independent man, Todd experienced difficulty when trying to voice his opinion. He was extremely upset with the hospital staff and was not happy with the decisions they were making.

> *Patient: so there was a miscommunication with them down here in the hospital...but it doesn't surprise me...what's going*

> *on...that hospital is going downhill from a year ago. I'll tell you that*
> *Interveiwer: You were in there a year ago?*
> *Patient: Yeah...for my knees*
> *Interviewer: Oh ok*
> *Patient: just...you know...I don't know...you've got a couple nurses in that hospital that are really mean*
> *Interviewer: oh that's not very good*
> *Patient: no it isn't*

....

> *Patient: Isn't there suppose to be a patient's advocate for the hospitals?*
> *Interviewer: I don't know*
> *Patient: every hospital does...that's the law*
> *Interviewer: Yeah*
> *Patient: but they don't have one at [the hospital]*
> *Interviewer: no?*
> *Patient: when I get out of here when I'm all said and done...I'll find out how to fix this*

Although his children took care of him and were involved in his care, they were very busy with their own lives and were not frequently visiting the hospital or ensuring he was receiving the care he should. Upon leaving the retirement home following respite care, he returned to his summer home without homecare and experienced daily pain.

> *Interviewer: No. Did someone talk to you about any services you may receive once you came home?*
> *Patient: No*

Lastly, Lily who became quite frail after her hip fracture did not seem to have much help while trying to recover. Although her sons visited her every day, they were unaware of how the healthcare system worked and did not know the types of questions to ask. When Lily eventually went home she became very depressed thinking about the burden she was putting on her sons.

> *Interviewer: Are you having homecare at all?*
> *Patient: Well I don't know, somebody called and they called Jeff but I don't know whether anybody is coming or not he said he thought they were supposed to call me and let me know when they are coming, so I haven't heard anything since, I don't know whether they come and see whether I can do things myself and stuff*

……………………

> *Patient: Well, yes of course, I have to use the walker now where before I navigated without it. And then of course as I say, I used to go and do my own shopping, maybe I am a baby and I should be doing more but I don't know, I don't feel like it... I don't care whether I drive or not, maybe the kids wish I would, but I don't care, I really, I just don't care*
>
> *Interviewer: It's ok*
> *Patient: I just wish I would go to bed sometime and never get up*

Overall, it is evident that family caregivers play an important role in helping patients following a hip fracture. They provide a variety of care in various ways. These roles include, but are not limited to; emotional, social and physical support, patient advocate, personal nurse, information seeker, and personal taxi driver. For example, in the case of Leslie, her caregiver took on the role of a personal nurse, helping with all aspects of her recovery. Patients who had caregivers who could fulfill the role of physiotherapist or medication manager were at an advantage. As well, caregivers who knew to take on the role of information seeker also helped the patient. Patients who didn't have caregivers fulfilling any of these roles were at a disadvantage.

3.3.3 Caregiver Contributions to Knowledge Exchange

The following section will outline some important themes that emerged from multiple sources of data. The findings look at determining the caregiver needs (emotional and informational) and then move to examining how caregivers contribute to knowledge exchange and how valuable they can be for both the healthcare providers and the patient during rehabilitation and throughout the transition process.

The needs and expectations of family caregivers are an influential component to knowledge exchange. As well, there are many facilitators and barriers affecting the involvement of family caregivers. These will be examined before understanding how family caregivers can play an integral role in the knowledge exchange process during transitions.

3.3.3.1 Family Caregiver Needs and Expectations

Trusting and Respecting Healthcare Providers

Themes of trust and respect surfaced frequently in many interviews with caregivers, healthcare providers and the patients. These words have various meanings depending on the context. When a family caregiver began to trust the healthcare providers, families seemed to feel more comfortable asking questions, making decisions and taking advice from the care providers.

> *Caregiver: She [nurse] was wonderful. I can't thank her enough. She was very good with mother, um, you know, we involved mother in everything we said or did, we didn't go behind her back or anything, and she asked us first, you know which way we wanted to go, and we thought mother should be involved, and listen to everything. And she would speak directly to mother and look at us for confirmation, you know, whatever she responded with, you know. I found that really wonderful.*

By having the trust and respect for the healthcare provider, transitions between healthcare settings and the transition back home seemed to be less of a burden on family caregivers. They were content with the information they received from the care providers and felt they could ask questions when they needed to.

> *Caregiver: I had never met her...and [I]met a few fellows on the weekend that were covering for her...so my main source of information was the nurses who gave adequate care and just, they were wonderful...the majority of them*

Only a small number of the participants felt they could trust and respect the healthcare providers that were giving care to their family member. On multiple occasions patients and family caregivers expressed frustration with the staff and regreted their lack of information sharing. For instance, family members found it tiring to chase after healthcare providers to get answers regarding the care of their family member.

Being Involved

Given that the rehabilitation process following hip fracture surgery is stressful, involving the caregivers at various transitions along the journey can help ease some of the stress that may be experienced by patients and families. This journey is complex as there are multiple transitions and different types of knowledge are needed at different transitions. For example, families transferring the patient from the hospital to long-term care need to know what they should be looking for when choosing a facility. Also, they should be involved in the transfer of information to ensure that the new destination has all the information needed to care for the patient. For families, knowing they are involved in the decision making and aware of what is happening with their family member is extremely important to them. Families appreciate being involved,

> *Interviewer: So you felt like you were involved in the decisions, and that you were able to make mum be involved in the decisions?*
>
> *Caregiver: Yes. That was definitely a bonus this time, we were very involved.*

Throughout this research project there were multiple occasions where families felt they were not involved in the decision making process. Family caregivers have expectations that they should be involved at all points of the rehabilitation journey. On some occasions even patients felt disconnected. For example, one patient expressed his lack of involvement in the decision making when it came to where he was to live following his hospitalization.

> *Patient: uh...how to be involved...is them being a little more caring where you're going...you know...like not everybody has the money to go to these places...*

For family caregivers who are not able to be at the hospital frequently or even at all, the process of being involved in decision making becomes very difficult. As many caregivers commented, when they were contacted to have a family meeting with the healthcare providers to discuss "next steps", there was no option when it came to choosing a date and time, they were told when they had to be at the hospital.

> *Caregiver: They kind of hit us with this one morning we were told uh to come in and have a meeting with the doctor. It was at 8 o'clock on a Wednesday morning or something*
>
> *Interveiwer: And there was no flexibility with that meeting?*
>
> *Caregiver: None*

The patients are aware of the commitment their families are making by being involved in their care. Even patients expressed frustration with the lack of flexibility for families to participate when choosing a time to meet to discuss the patients' options.

> *Interviewer: Ok, and how about your family? Was your family involved in the discussion?*
>
> *Patient: Well somehow or other they were notified. I wish they wouldn't leave it to me to, because she said Wednesday morning at 8 or 8:30 we're to have a meeting, and my family representative and whoever else, I didn't think I was supposed to be involved, were to be at this meeting at 8 or 8:30 in the morning! Well I thought Holy smoke, my girls just can't drop everything, and 8:30 in the morning, as a matter of fact I was still eating my breakfast.*

Again, once the decision had been made to transfer the patient, the patient was told what the decision was, without much choice.

> *Interviewer: Yeah. So were you involved in the decision of where to go next, after the hospital?*
>
> *Patient: Um, they just said it would be either here or [the other hospital]*

The same thing happened when patients were at a point in their recovery when going home was an option. Often, they were not asked if they wanted to go home, or if they felt like they would be comfortable going home, they were just told. As well, caregivers were only sometimes approached to determine if they felt ready to handle their family member once discharged home.

> *Interviewer: ok, and were you involved in the decision to go home?*
> *Patient: no, no they just told me*

It is evident that when healthcare providers, patients and families build a relationship based around mutual trust and respect they can work together to figure out the best care needed for the patient. Furthermore, determining the needs of the caregiver and satisfying these needs also promotes a better relationship.

3.3.3.2 Understanding Caregiver Information Needs

Throughout the document review, observation of the settings, and interviews with caregivers, it was evident that caregivers required additional information to adequately support and care for their family member. Caregivers expressed the need for additional information on topics such as rehabilitation procedures/techniques, what to expect when their family member returns home, what aids should be in place before the patient is discharged from the hospital, what medications will be needed, what home care services are available, and who to call for assistance once discharged. Several caregivers expressed that any sort of pamphlet or information guide would have been beneficial.

> *Caregiver: No booklet or pamphlet but the people that were in the next bed got a booklet because they were scheduled for surgery*
>
> *Interviewer: Oh*
>
> *Caregiver: So they had the pre-op things. So I borrowed their booklet, took it home and copied it*
>
> *Interviewer: OK*

> *Caregiver: I didn't know about how he was supposed to bend and not bend.*
> *Interviewer: OK and was the booklet helpful for you?*
> *Caregiver: Yes*
> *Interviewer: Yeah, ok*
> *Caregiver: We still have it here*
>
> ……………………………………
>
> August 19th, 2010
>
> *While conducting the interview this afternoon I got the impression that she was surprised that no information brochure was given. She did some problem solving and borrowed someone else's – she seemed to find this very helpful. Overall they seemed content with the care they received in the hospital so far. They both were capable of communicating information and answering any questions I asked.*

As well, many times caregivers expressed concern because they did not receive information about how the patient was doing. Caregivers commented that they were unsure of whom to ask when questions arose. The lack of information about the patient caused unneeded stress.

> *Caregiver: Apparently she went for some x-rays and some heart tests last week and we have never even gotten any results or nothing... and I'm about to ask about her medications that they are giving her, we don't know anything*

Overall, many patients and caregivers expressed the need for more information from the healthcare provider. By satisfying these caregiver needs and expectations, caregivers are more suited to help the patient during recovery.

3.3.3.3 Facilitators and Barriers for Knowledge Exchange

Facilitator: Prior Nursing Experience

The whole issue of lack of knowledge becomes very apparent throughout the caregiver process. It was very evident that family caregivers who had prior healthcare knowledge were able to navigate the system much easier than people who did not have this knowledge. Three of the family caregivers had previous healthcare experience and were at a noticeable advantage when taking care of their families. They were all retired nurses and were able to use their prior healthcare experience to help with rehabilitation, medication and most importantly system navigation. Although three of the caregivers had prior knowledge, two of them still struggled during the transition process. For the other caregiver, her mother was only making the transition from hospital to home which went smoothly for them. Healthcare providers were confident in this caregivers' ability to care for her mother while at home.

> *Caregiver: But mom I think they were satisfied in the fact that they knew that you had professional care at home*
>
> *Patient: Oh ok...alright*
> *Caregiver: Other people aren't able to have that kind of care*

When moving from the role of healthcare provider to the role of family caregiver, these caregivers still experienced the burdens that go along with caregiving regardless of the nursing experience they had. For instance, Lana was very stressed when her husband returned home because she was unaware of the physiotherapy limitations he had. This was due to the fact that she was not involved in his physiotherapy sessions at the hospital.

> *Interviewer: Yeah, so you called for information.*
>
> *Caregiver: Yes, I did. And I was letting them know I was a little concerned that he didn't seem to be getting as much physio as I thought would be in his best interest. And, uh, to be sure what and how he could move, you know, they recommended that he needed to have the pillow between his legs to move, to keep the legs moving in unison, because of the pelvis mostly. But I don't know whether any precaution was really advised as far as the amount of flexion or anything...because it sounded like he would be able to lift and bend his knees you know as an exercise, but not by very much because the muscle and the incision needed to heal first too.*

It is evident however, that due to the caregivers' prior healthcare knowledge, she knew exactly what to do to get information and ensure that her husband was getting the rehabilitation care that he needed to recover.

Barriers: *Lack of Knowledge and Trust*

When families are entering a vulnerable time, trust is extremely important as previously discussed. This was especially noticeable through our observations of situations where families lack knowledge of the healthcare system and are ultimately depending on healthcare providers to help make the best decisions.

October 12th, 2010

> *After meeting with this family a few times now, it is easy to see how involved they are in caring for their mother. The son was becoming quite distressed while explaining the difficulties he has had to overcome. He felt that he was given the wrong information numerous times. He shared many stories where he felt he was misguided. He was let go from his job just days before. He felt the pressure as he was trying to deal with finding a home for his mother while packing up his office.*

Many caregivers questioned if they had been given adequate information to make the best decision for their family member.

> *Caregiver: But my point is it gets costly and it gets time consuming which it's hard at times you are trying to do other things you know. We like to...normally we bowl on Tuesdays but we've kind of given that up. You know we would have liked to at least compared you know what could we do for her at home if we have someone come in you know 3 times a week bathe her...and this and that. We could help feed her. We were already cooking all her meals anyways towards the end there before she fell.*

Many of the caregivers were not happy with the information they received from healthcare providers and in some cases were told information that they later realized was not accurate,

> *Caregiver: So that was nobody's fault so you know we went from thinking you know she'll be in there for a week and walking home in a week to that was July, 17. I don't think that's [walking] been very normal since*
>
> *Interviewer: No?*
>
> *Caregiver: And that's not anybody's fault I certainly you know I don't blame anybody for that but a lot of the events that happened in between were certainly very questionable...along the way*

Caregivers not only lacked trust in the staff they were dealing with, but they also lost trust in the healthcare system as a whole. The experiences they had throughout this process has only created disappointment with the changing focus in our current system,

> *Caregiver: I think those were the main ones. I think that the...the sorrowing part that I see is that it's just all about money it's just...that's all it seems to be uh you know...we probably have one of the best healthcare systems in the world but it's cracking at the seams and you can see it. If this experience taught me anything it was that our healthcare system is in jeopardy now.*

In addition to the conversations with the patients and families, observations also took place. The observations recorded data that complimented what was being said in the interviews. Families seemed very distressed by the situations they were experiencing.

April 23rd, 2010

> *She became animated a few times, which will be apparent in the interview transcript. These occasions were in discussing pain relief for her husband, and in explaining frustration over her need to seek out information so that she would feel prepared in taking on her role as caregiver once he returned home.*

Caregivers who had no prior experience either working in the system or even being a patient in the system had difficulty knowing which questions to ask the healthcare providers and were unsure what to expect during the rehabilitation journey. Their experiences reveal frustration, anxiety, and anger over the lack of appropriate information provided to them during their family members' recovery journey.

Rural Setting

The rural setting can be both a facilitator and a barrier to knowledge exchange. In some cases the rural setting can be of benefit to the healthcare providers because usually they have knowledge of the community and are thus able to better advise patients and families of available community services, what the retirement homes/long-term care facilities offer, cost etc.

> *Health care provider: ...because we're a small hospital ... we know the staff, you get to know the patients. And a lot of us live in the community as well.*

But for the family caregiver the rural setting, which may translate into far distances, only creates more stress when attempting to help family members recover. Distant families also experience stress related to not knowing how the patient is doing, feeling unable to assist as much as they would like, and can only depend on the telephone communicate with their family member and healthcare providers.

> *Caregiver: Yeah, we kept calling the hospital, and we were told that you know, she had indeed broken her hip, I believe it was later that evening, and they were expected to be doing surgery on her, but it ended up being the following day before they actually did the surgery on her, so it seemed like an awfully long time*
>
> *Interviewer: And how soon after that were you able to come and visit?*
>
> *Caregiver: We couldn't come down until Saturday*

Another barrier of the rural community is the isolated living situation for some patients when they are discharged home. For example, one healthcare provider stated,

> *Health care provider: we can get into some nightmares, you know just because, okay so they can't go home, they live alone, they can't go home, you know they're in the middle of nowhere, they have no transportation, families don't live close, it's a two storey old farmhouse, you know just those sorts of things*

It is important to acknowledge these facilitators and barriers that are present during care transitions of older adults. By overcoming the barriers and promoting the facilitators, knowledge exchange can occur more easily.

3.3.3.4 Family Caregivers' Contribution to Knowledge Exchange

In most cases, families can play a major role in providing the healthcare provider with information such as past medical history, previous ability to complete activities of daily living and so on. In cases where the patient has difficulty communicating, or in the frequent case when information is not received by a healthcare provider in the new setting from his or her peer in the previous setting, families are vital for ensuring this information is obtained. Although many families view themselves as helpful to the healthcare providers some healthcare providers suggest they would much rather just deal with the patient as the caregiver is too difficult. Sometimes healthcare providers tended to suggest that family support was lacking and in some cases the family was viewed as "useless" when asked about the amount that families help them do their job.

> *Interviewer: Ok, and do family members make your work more difficult?*
>
> *Health care provider: Sometimes they hinder it and you have to ask them to please leave the room.*

Some healthcare providers acknowledge that family members may not be helping or providing information, due to the stressful situation that the family is experiencing.

> *Interviewer: In general do family members ever make your work more difficult?*
>
> *Health care provider: Um they can. And it's not always their fault it's sometimes that they're anxious or maybe they haven't had a chance to talk to the doctor or maybe they just don't understand...*

However, in most cases, family caregivers are viewed as a good source of information for the healthcare providers as they sometimes depend on families to provide patient history and current living situation, especially if the patient is unable to give that information themselves or if they don't receive adequate information from the previous setting.

> *Interviewer: Ok, and what information is provided by the family caregivers to you?*
>
> *Health care provider: Just basically what they've done at home, um, some people families will tell us that yes they were independent, mobile at home on their own, other families will say no they didn't do much walking or they went from a bed to a wheelchair and that's basically it, they basically tell us about their ADL's at home*

Knowledge exchange between family caregivers and healthcare providers is equally important at any point during the transition. Physiotherapists agree that family caregivers make important contributions by helping the patients with their exercises and providing valuable patient information.

> *Health care provider: I always try and get the family involved. In this case the wife was very interested.*
>
> *Interviewer: Yeah she was. And does the caregiver ever provide you with information?*
>
> *Health care provider: Of course. Again in this case very valuable.*

In order to successfully gain full advantage of the knowledge caregivers can share with healthcare providers, a relationship built on trust and respect needs to be established first. By doing so, this allows healthcare providers and family caregivers to work together. This will help to provide the best possible care and experience for the patient.

3.4 Discussion

Ensuring that the correct and adequate information is exchanged between healthcare providers and family caregivers is vital during any care transition. This helps to guarantee that the transitions between and within healthcare settings and home are done smoothly. However, even though people have studied the importance of family caregivers, this study specifically looked at the role caregivers play during transitions following hip surgery.

Overall family caregivers are involved in multiple roles throughout the recovery process. As revealed by our multiple sources of evidence, family caregivers are valuable sources of information. They communicate previous medical history and functional status to the doctors, and communicate current information about the care to the family member. As well, families can help motivate the patient to complete daily exercises and follow physiotherapists' orders when needed. When the decision to transition to a new care facility is being made, families are seen as an integral part in this process. All these examples of caregiver roles have been supported by Nahm (2010) who states, "Caregivers play an important role in both physical care, such as helping with eating and drinking, and emotional support by providing encouragement and social interaction" (p.255). In terms of the participants in this study, many family members wished they could have taken part in the physiotherapy appointments so they could learn how to better assist the patient once at home. Simple practical involvement such as this not only helps the patient recover, but also eases the stress of family members because they will feel more prepared to manage the patient's needs at home.

Although there are national caregiver support programs set up to assist caregivers, many caregivers who were interviewed did not know about these programs or did not use them. Consequently, there was limited information about these initiatives passed on from healthcare providers to the family caregivers. This may be due to the fact that healthcare providers may not be knowledgeable about the types of programs that are offered to assist caregivers. Support programs may be of great benefit for families, but caregivers expressed a need for help in the form of something as simple as a pamphlet. They stated that just a small brochure outlining what to expect following surgery or describing the types of assistive devices they may need to rent for use at home would be extremely helpful to plan ahead for transitions and discharges. Hickey (1990) acknowledged that care provided by the family may be enhanced if information is given to the caregiver in an understandable way. Written information is often a useful format as caregivers may have trouble remembering all of the information that is shared with them. Contact information of their physician and/or nurse practitioner is also useful information.

A portion of the study also analyzed what the caregiver information needs are and what contributions these family caregivers could make to knowledge exchange with healthcare providers. Knowledge exchange can be in many different forms, between many different people throughout care transitions. Some patients and families experienced a lack of knowledge exchange which ultimately affected their trust in the healthcare providers and the health system.

Withholding knowledge from caregivers creates more frustration and difficulty throughout the rehabilitation process. The process of communication and knowledge sharing between healthcare providers and caregivers was infrequent. As previously discussed, healthcare providers sometimes use family caregivers as a source of knowledge about the patient, however, when knowledge sharing does not occur care providers may not receive the information they need about the patient. Frustration was expressed by many patients and families because of the inability to have family meetings scheduled at times that were convenient for family caregivers. This is one example of hospital driven care rather than patient driven care. In order to shift to patient/family driven care it is imperative to involve the family and patient in all decision-making and care from the start. Following an acute event such as a hip fracture, family members search for information about the patient care. It is evident that when the healthcare providers and the family caregivers work together to share knowledge, transitions and rehabilitation can occur much more smoothly (Fleury, 1999).

Caregivers who had no prior experience either working in the system or even being a patient in the system had difficulty knowing which questions to ask the healthcare providers and were unsure what to expect during the rehabilitation journey. In order to facilitate better communication between caregivers and healthcare providers, building trusting relationships is essential. When care providers take time with patients and their families, and provide consistent care, more trust evolves in the relationship. Communication allows for mutual sharing of information, and a development of trust which also helps healthcare providers understand family dynamics, family history and future roles. All of these are beneficial to helping the patient recover (Fleury, 1999). Although some caregivers may have had prior knowledge of the healthcare system and knew the types of questions to ask, some still struggled during the transitions, demonstrating how difficult healthcare system navigation can be.

Lastly, the findings outlined both advantages and disadvantages to living in the rural area. For healthcare providers, working in a rural hospital allows them to become familiar with the community and residential accommodations in which most of their patients live. This can be of benefit when determining if a patient's residence would be suitable for them post-discharge. As well, the staff at smaller rural hospitals would become familiar with patients the more they are admitted to hospital. Disadvantages of living in a rural community are felt most by family caregivers who may have to drive greater distances to visit their family member. During the rehabilitation journey, making use of the advantages of a rural community while decreasing the disadvantages contributes to better transitions.

In summary, satisfying the needs and expectations of family caregivers is important. As well, involving the family caregivers and allowing them to contribute to the knowledge exchange process is essential as they can share vital information. By accomplishing these two steps, and focusing on knowledge exchange facilitators, while minimizing the barriers, smoother transitions are more likely.

3.4.1 Knowledge Exchange Definition

As reviewed in this thesis, the CIHR knowledge translation definition is one that is internationally recognized and widely used. Although the definition incorporates terms such as exchange, synthesis, and the dissemination of evidence-based information into practice, the definition fails to acknowledge the exchange of information that happens at the care setting level. That is, the exchange of information from healthcare providers to the patients and family caregivers, as well as the information exchange from patients and families to the healthcare providers. Since 2000 when the term was defined by CIHR, a few other definitions have been developed. The World Health Organization (WHO) and the National Institute on Rehabilitation Research (NIDRR) adapted the definition in 2005 and developed their own definitions. Both of these definitions also fail to recognize the exchange of information at the micro level, between healthcare providers, patients and their families.

3.4.2 Strengths and Limitations

There were some strengths as well as some limitations to this study. Addressing the strengths first, a large amount of data were generated through the study processes. Although this may also seem like a limitation, as there was much information to analyze, the range of data supported a good representation of patients' diverse experiences during transitions across healthcare settings. As well, there was a wide range of participants in the study. Patients of many ages, different forms of family caregivers (spouse or child), and many types of healthcare providers (physiotherapists, surgeons, etc.) ensured that many different experiences were observed. As well, many different points of view contributed to these findings.

In addition to these strengths, there were also some limitations that need to be acknowledged. The interview guide was created for the use of the larger study. Based on the focus of this thesis, other questions were subsequently developed and posed during the interviews. These questions varied between interviews. Adding these new questions to the interview guide ensured that all the participants were asked the same questions for consistency purposes. In terms of collecting the data, a few limitations also arose. First, some of the family caregivers could not be interviewed for various reasons (out of town/busy). These other perspectives could help enrich the data even further. Also, because the study site was outside of London, it was difficult to always be at the hospital during the admission and discharge of patients. Every effort was made to get to the hospital in reasonable time, but in some cases it was a few days before the participant was interviewed in their new location.

Lastly, although this study made reference to the impact of the rural setting on several occasions, it is important to note that only one rural hospital and the health planning region is represented in these findings. Thus, the findings here are not generalizable across all healthcare settings.

3.5 Conclusions

This study has contributed to the literature by attempting to understand the role that family caregivers play during care transitions, as well as outline the importance of knowledge co-creation between healthcare providers and family caregivers as patients undergo hip fracture recovery. Sharing knowledge is an effective way to ensure that patients are receiving the best possible care while ensuring that family caregivers have the knowledge and resources to help their family member recover. Most successful and smooth transitions are experienced when both the family caregivers and healthcare providers build trusting relationships. It is then likely that healthcare providers will chare their research-based and clinical knowledge and caregivers will share their experiential knowledge so that new knowledge can be co-created that benefit the patient. When everyone involved has all the information they need and are involved in all aspects of the transition process, care transitions will be smoother, the quality of care better and the patient's recovery faster.

3.6 Acknowledgements

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4 DISCUSSION

4.1 General Discussion

The aim of this thesis was to understand the role of caregivers during transitions following hip fractures, to determine caregivers' information needs and to identify the contributions they make to knowledge exchange. Improved understanding was accomplished through conducting in-depth interviews with patients, family caregivers and health care providers at the many care settings that patients experienced after undergoing hip fracture surgery. This was done using an ethnographic approach which included face-to-face interviews, document review and many hours of observations. In this final chapter, a brief summary of the findings is outlined, followed by a discussion on reflexivity. The chapter ends with discussions on future directions and how this study contributes to the fields of caregiving, knowledge exchange and musculoskeletal research.

> First, it is important to note that a clinicians' perspective may be that they cannot provide certain patient information to others without that patients' expressed consent. Although this was not the case for any of the participants in this study, family caregivers who interact with healthcare providers may perceive this as a lack of information causing distrust between them and those healthcare providers. For a real team to work, these things such as trust and respect need to be satisfied. Furthermore, the roles identified by family caregivers may be intertwined with their perceptions and reality.

With these caveats in mind, analysis of the data explored the role of caregivers, and identified some of the facilitators and barriers to information exchange between caregivers and healthcare providers. The results were organized based on the PARiHS framework, creating an adaptation of the figure (Figure 4). This figure illustrates the essential components that are needed to co-create knowledge that will benefit the recovery of patients with a hip fracture and ensure smooth transitions for both the patient and caregiver. As noted earlier, three domains make up the PARiHS framework, evidence, facilitation and context. In order to create an adaptation of the figure, the findings were applied to these domains. The context of the study is the rural healthcare setting. The evidence domain is satisfied by the sources of knowledge, in this case, knowledge about the hip fracture, knowledge from the caregiver and knowledge from the healthcare provider. All of these sources of knowledge help to co-create knowledge that will benefit the patient's transition process and rehabilitation journey. Lastly, it was acknowledged that by building trusting relationships, more knowledge is shared – this satisfies the last domain, facilitation.

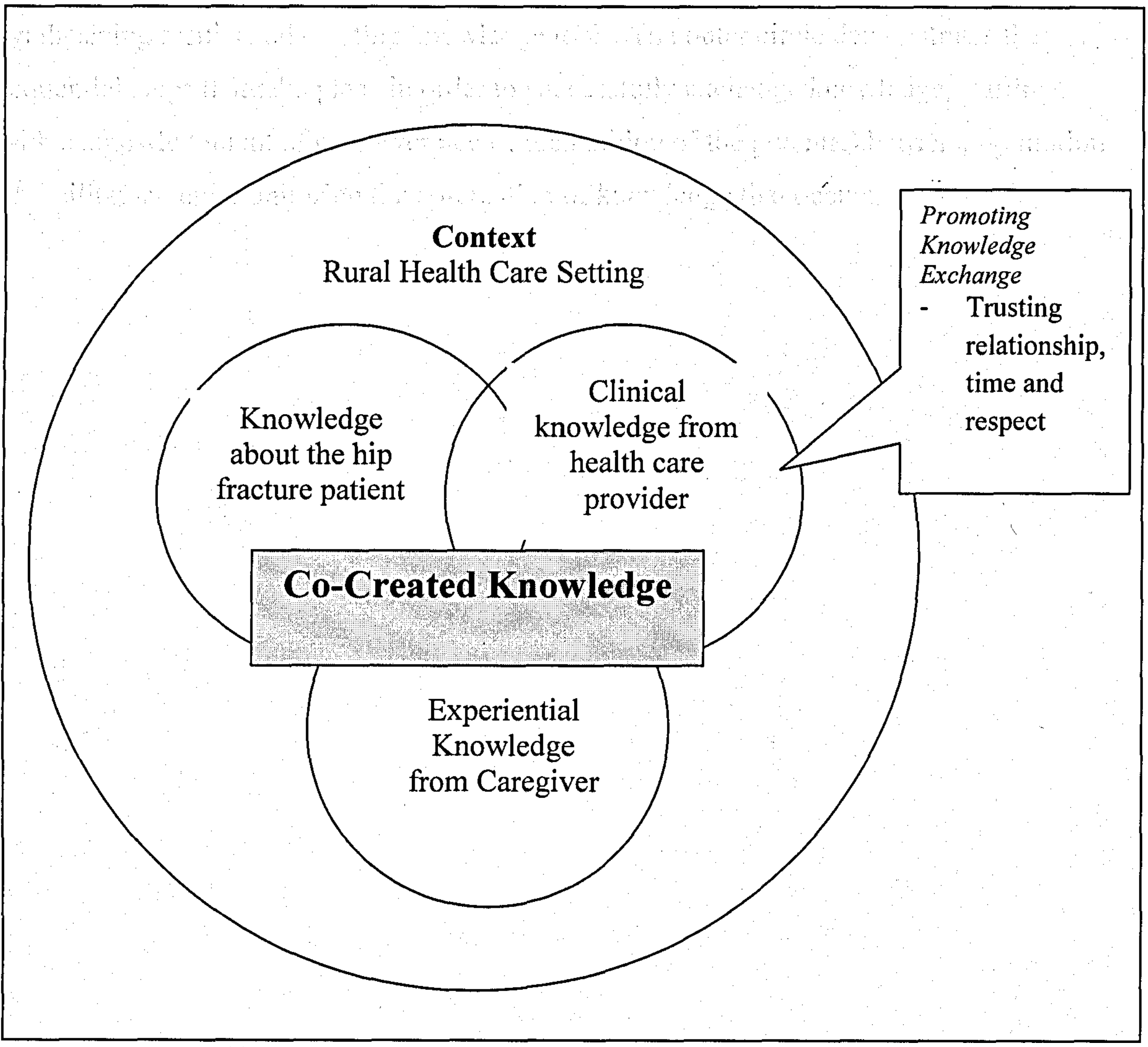

Figure 4. Adaptation of the PARiHS Framework – Co-Creating Knowledge

Alternatively, the Knowledge –to – Action model can also be modified to illustrate the importance of knowledge exchange between healthcare providers and family caregivers. The model takes into account the co-creation of knowledge that evolves from the PARiHS framework, and takes it a step further by acknowledging the importance of mutual problem solving and teamwork that includes healthcare providers and family caregivers. Figure 5 outlines an adaptation of the KTA model created from the results found in this study. The inner section illustrates that knowledge exchange depends on teamwork between healthcare providers, patients and their family caregivers. The triangle represents various steps of creating knowledge, from asking questions, to synthesizing results and creating knowledge tools. The outer circle demonstrates the sequential steps that take place in order to successfully exchange knowledge, starting with acknowledgment of caregiver needs, recognition of the potential barriers, promotion of facilitators and monitoring the co-creation of knowledge that occurs.

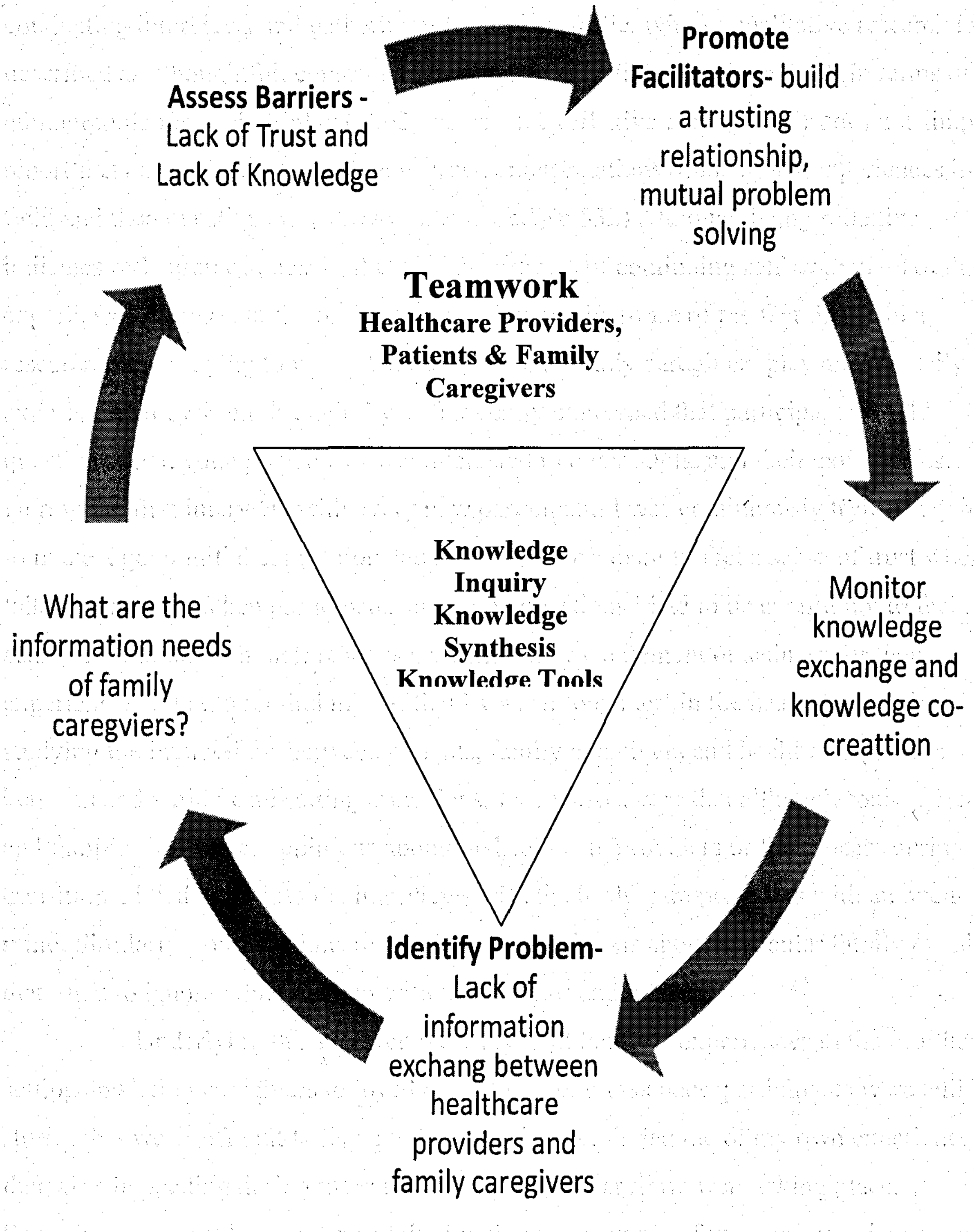

Figure 5. Adaptation of the Knowledge to Action Model - Teamwork

4.2 Reflexivity

When using qualitative research it is important to be reflexive when conducting interviews and gathering information. Reflexivity in qualitative research is described as "thoughtful, conscious self-awareness" (Finlay, 2002, p.532). In terms of ethnographic research, Finlay (2002) states, "the reflexive ethnographer does not simply report facts or truths but actively constructs interpretations of his or her experiences in the field and then questions how these came about" (p.532) Although being reflexive indicates reflection of oneself, it is also the process of continuing self-awareness of the experiences throughout the research. I was constantly aware of the fact that I am a research trainee trying to understand the role that family caregivers play and the daily experiences they went through. I was frequently concerned that participants would question why a young person was so interested in older adults and their experiences. During the first interview with every new participant, I was continuously trying very hard to make a good initial connection and allow the participant to feel a sense of trust when talking with me. When participants answered questions I had to be careful not to feel a sense of emotion with their response, whether it be excitement or sadness for their experiences. I had to remind myself that I was an 'outsider' in the healthcare setting, studying the interactions between patients, family caregivers and healthcare providers between and within care setting transitions. I was also aware that although some patients and families had certain opinions about the healthcare providers or the process during transitions, I had to go into the interviews with the healthcare providers with an open-mind. Similarly, some healthcare providers had opinions about particular family members that I had to ignore while dealing with the families and patients.

Underlying this research were my own family's experiences in the healthcare setting and being caregivers to loved ones. In several instances, participants were telling stories that were difficult to listen to because they reminded me of my own experiences that were happening during the same time that the interviews were taking place. Sometimes I was able to embrace this situation, share some of my own experiences and use it as a building block in the conversation to help relate to the caregivers. I believe that this made them feel that they could open up more and share their stories rather than looking at me as just a 'researcher'.

Lastly, this experience was my first introduction to qualitative research. Throughout my undergraduate degree I worked with quantitative data. At times I found the transition to qualitative research a struggle because I was unaware of what to do in certain situations. Each interview, observation and analysis of data was a learning experience but over time proved to be easier. At times I just needed to step back, re-group, ask questions of people who had qualitative knowledge and then proceed forward. After the interviews were complete, I had beliefs in my head based on the perspectives of many participants. By reading through the interviews multiple times I was able to determine which ideas were expressed strongly by many of the participants. These ideas helped to create the themes that were discussed in this thesis and create an understanding of the importance of caregivers during transitional care.

4.3 Future Direction and Contributions to the Field

4.3.1 Contributions to Knowledge Exchange

As a result of the study, an adaptation of the PARiHS framework was created to visually demonstrate the importance of co-creating knowledge with all of the people involved when recovering from hip fracture surgery (Figure 4). The current body of knowledge exchange literature often focuses on information exchange between healthcare providers or moving research into practice. The importance of engaging family caregivers in the whole process and respecting and using their experiential knowledge was identified through this study.

As well,. the information gained from this research was also adapted into the Knowledge – to – Action framework (Figure 5) which illustrates the steps to creating knowledge exchange through teamwork and mutual problem solving between patients, healthcare providers and family caregivers.

4.3.2 Policy and Educational Implications

Based on the outcomes and findings of this research, much has been revealed about the need to further caregiver education, both for caregivers and healthcare providers who are working with caregivers. In terms of policy implications, this research aims to help make changes to the current process. A significant part of creating smooth transitions comes from building trusting relationships and involving family caregivers as equal partners in the healthcare team. Their experiential knowledge about the patient, family circumstances, and support network makes a significant contribution to the co-creation of knowledge useful to the patient. By making every effort to ensure this occurs will slowly help to improve the system.

Regarding educational implications, teaching healthcare providers about family caregivers early on in their education would have the most benefit. Implementing course work on knowledge exchange, family caregivers and transitional care could lead to a more optimal health system and more effective use of family caregivers.

4.4 Conclusions

This study represents a good first step in recognizing not only the important roles that caregivers play during the rehabilitation process, but also the contributions they can make to knowledge exchange. In order to continue filling this gap in knowledge, further studies need to be conducted that specifically focus on examining the process of knowledge exchange and co-creation of knowledge between caregivers and healthcare providers. These studies should again follow the families, healthcare providers and patients throughout the full journey and at each location. The process of creating smooth transitions can be improved when all people involve work together and build trusting relationships. When the focus is on the facilitators and the barriers are removed, improvements can be made.

4.5 References

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APPENDICES

APPENDIX A Patient Interview Guide

inforehab Canadian Institutes of Health Research Instituts de recherche en santé du Canada Western Health Sciences

Interview Guide for Patients

*(**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

Background Information about Patient

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): ____________

Background Information about Care recipient

When did you fracture your hip?
How did you fracture your hip?
Was this your first hip fracture?
Was this your first fracture? Have you ever broken any other bones / had any other fractures?
Have you been having any help from your family / friends at home?

What has your friend/relative done to assist you? What kinds of help have you been receiving?

How long have you been receiving help?

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 _____ this will 'not' be applicable in acute care because the patient had surgery here. At _____[2] 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 _____? Should we ask about from the time the ambulance arrived and then the admission?

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

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

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, did you actually receive from health care providers to help you care for your hip fracture before/after moving from the previous care setting?

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

Did you receive information about your own needs while at ___________[3]?

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___________, who did you speak to about your care?

Did you receive any information about your care prior to leaving? What kind of information did you receive about your care before your discharge?

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_________[4]?

---

[2] Blank spaces indicate de-identification for this thesis document

[3] Blank spaces indicate de-identification for this thesis document

[4] Blank spaces indicate de-identification for this thesis document

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....

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

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?
What kinds/types of information did you receive about your care once you arrived home?
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 walking or with your exercises?* If yes, how did you do this?
What did you find difficult about doing your exercises? Or walking / transfers / mobility – what about stairs?
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? Tell me more about that?

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):

Concluding Questions

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

APPENDIX B Healthcare Provider Interview Guide

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Canadian Institutes of Health Research
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Interview Guide for Health Care Providers
*(**Ensure the study ID is recorded with the interview.)*

1. General Background Information
Please describe your position here at [INSERT LOCATION, e.g. SMGH or FCHS]?
How many years have you been employed in this position?
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
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
When a patient comes to this setting (e.g. unit):
What information is generally received from the previous setting (e.g. unit)?
Who is responsible for sending/ getting the information to this unit?
(***Probe: who gives this information?*)
How is this information received?
(***Probe: forms, informal communication with health care providers, formal communication or meetings, family caregivers, key person etc.*)
Are there any specific forms that are sent from the previous setting (e.g. unit)?
(***IF YES*), can we have a blank or de-identified copy of this form(s)?
Is there information that you need from the previous setting that you do not receive?
(***IF YES*) Can you give me an example of this?
Why do you think you didn't receive this information?
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?*)
What information is collected once the patient is on this unit?
How is this information collected?
(***Probe for forms, etc.*)
Who is this information collected from?

(***Probe: patient, family*)

4. Patients/Caregivers Involvement

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

Who provides this information?

How is this information provided?

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

What information is provided by family caregivers?

What information is provided by clients?

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

Do family members make your work more difficult?

(***IF YES*) How?

Do family members help your work?

(***IF YES*) How?

Do your clients ever make your work more difficult?

(***IF YES*) How?

Do your clients ever help you in your work?

(***IF YES*) How?

5. Discharge

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).

What steps are taken to prepare clients?

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

When is this information provided?

How is this information provided?

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

Who provides this information?

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

6. Concluding questions

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

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

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

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?

Who else do you think we should speak with? *(This is the sampling question, make sure to get name, unit, job title and possible e-mail)*
If we only interview two people on this unit regarding hip fracture patients and the flow of information, who should they be?

APPENDIX C Family Caregiver Interview Guide

Western
Health Sciences

inforehab

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Interview Guide for Family Caregivers

*(**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.)*

Background Information about Caregiver

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): ________________

Background Information about Care recipient

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?

Exploring Current Situation

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 D Consent to be Contacted Form

inforehab

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Western
Health Sciences

Consent to be Contacted Form

InfoRehab: Enhancing MSK Rehabilitation Through Better Use of Health Information

Principal Investigator:
Dr. Bert M. Chesworth, School of Physical Therapy,
The University of Western Ontario

I agree to provide my name and phone number to Ms. Helen Johnson, a research staff member who will contact me to further explain the project and discuss my participation.

______________________________	______________________
Name of potential participant (Print)	Phone number
______________________________	______________________
Signature of potential participant	Date
______________________________	
Name of legally authorized representative (Print) (If appropriate)	
______________________________	______________________
Signature of legally authorized representative (If appropriate)	Date
______________________________	
Name of person obtaining consent (Print)	
______________________________	______________________
Signature of person obtaining consent	Date

APPENDIX E Letter of Information/Consent Form

inforehab Canadian Institutes of Health Research Instituts de recherche en santé du Canada Western Health Sciences

Letter of Information for Patient With a Hip Fracture

InfoRehab: Enhancing MSK Rehabilitation Through Better Use of Health Information

You are being invited to participate in a research study to identify how hip fracture patients, their families and care providers participate in and experience the exchange of health care information when moving across health care settings. Health care transitions from one care setting (e.g. a hospital) to another (e.g. a home) are common when someone fractures his or her hip.

Despite the frequency of transitions between and within healthcare settings, little is known about how to ensure that the right personal health information is collected and made easily available, *and* interpretable, for those who need it as a patient is transferred from one healthcare setting to another. The results from this study will be used as part of a larger scale study that aims to improve the quality of life for persons with musculoskeletal (MSK) disorders through the better use of available personal health information. The purpose of this letter is to provide you with the information you require to make an informed decision about participating in this research.

We are asking you to take part because we wish to find out what information is the most important to hip fracture patients, families, health care providers and health administrators and/or managers to optimize recovery from a hip fracture. We are giving this letter of information only to persons who are being treated for a hip fracture at either site of the ____________________ or ____________________.[5] If the above situation does not apply to you, we ask that you not volunteer to take part in the study. This study will require 32 people.

The study is being conducted by Dr. Bert Chesworth, who works at the School of Physical Therapy at the University of Western Ontario. He will supervise the study along with co-investigator Dr. Dorothy Forbes, who works at The School of Nursing at the University of Western Ontario. Collaborators on this project include the administration of the ________________ and ________________, Manager of Rehabilitation Services for the ______________, and ______________, Senior In-Patient Occupational Therapist at the ___________________________.

---

[5] Blank spaces indicate de-identification for this thesis document

If you agree to participate in this project, you will be contacted by ______________ or one of her clinical staff members at ______________, who has been providing you care, or ______________ or one of her clinical staff members at ________________ who has been providing you care. These persons will introduce you to Ms. Helen Johnson, a research staff member who will help with data collection for this project. Ms. Johnson will arrange a convenient time to visit you at the health care facility where you are receiving care or at your home to conduct an interview with you.

You will be interviewed at discharge from acute care, and at admission to and discharge from every subsequent health care setting you are transferred to after surgery. You will also be interviewed at admission to home care and 4-6 weeks later.

If you consent to being a study participant, we will collect the following information, some of which may be obtained from your medical chart at ___________________or at _____________________[6]: your Year of Birth, gender, Country of Origin, City of residence, Relationship to the person receiving care (i.e. experiencing the hip fracture), living arrangements with the care recipient (i.e. living with or without), dwelling type (house, apartment, condo). We will also collect your first and last name, your address and your phone number so that we can arrange visits with you to conduct the interviews and also make reminder phone calls to you about these visits.

In the interview we will ask you background information about your hip fracture injury, previous fracture history and mental health status. We will ask you about your understanding of your trajectory of care that resulted from this hip fracture injury. We will ask you about your perception of the admission process, details of the information exchange during admission, how family members and the patient are involved in this process and similar questions about the discharge process. We will also ask for your opinions of the strengths and challenges of sharing information between health care settings and you and your family members or friends and ask for suggestions on how to improve the flow of information between these health care settings and patients and their family members or friends.

The interviews will be done in the health care facility where you are currently receiving care, or at your home, and will take approximately 60-90 minutes of your time. These interviews will be recorded on audio tape and transcribed verbatim. The audio tape recordings and the transcription of these recordings will not include your name. They will contain a study ID number that can be linked to your name on a Master List that is stored in a secure and separate location from the tape recording.

There are no known risks to you in participating in this project.

---

[6] Blank spaces indicate de-identification for this thesis document

There will be no personal benefit to you. However, your participation will help health care providers determine the most important health information needs that are required to improve the quality of life for persons with a hip fracture as they transition through healthcare settings during their recovery from surgery. Upon request, a written summary of the results will be mailed to you once the study is complete.

Your participation in this project will not involve any additional costs to you, and you will not receive compensation for your participation.

Your confidentiality will be respected. Your first and last name and your address and phone number will be taken off-site when necessary so that we can arrange the visits for the interviews and a reminder phone call about the interview visits. This information will always be kept in a locked briefcase, a locked car and a locked cabinet when kept at Ms. Johnson's home. This information will have no other information associated with it and it will not have any interview results associated with it. No information that discloses your identity will be released or published, without your explicit consent to the disclosure. All records will be given a code number to be used on all data collection forms. All of the information collected will be kept in locked filing cabinets. After the study has been completed and the data have been verified, your name and contact information will be deleted from the files and the remaining de-identified information will be kept indefinitely.

The Research Ethics Board at the University of Western Ontario may contact you directly to ask about your participation in the study. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your explicit consent to the disclosure.
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future care. You do not waive any legal rights by signing the consent form. If you agree to participate in this project, please sign the attached consent form, complete the contact information requested and return it to the person who gave this letter to you.

You may keep this letter of information. A copy of your signed consent form will be made for you. If you have any questions about this study, please contact Dr. Bert Chesworth at _____________, extension _________.

If you have any questions about your rights as a research participant or the conduct of the study you may contact The Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca.

Primary Investigator

Bert M. Chesworth

BA, BScPT, MClSc, PhD

Assistant Professor

inforehab Canadian Institutes of Health Research Instituts de recherche en santé du Canada Western Health Sciences

CONSENT FORM

InfoRehab: Enhancing MSK Rehabilitation Through Better Use Of Health Information

Principal Investigator:
Dr. Bert M. Chesworth, School of Physical Therapy, The University of Western Ontario.

I have read the Letter of Information, have had the nature of the study explained to me and I have agreed to participate. All questions have been answered to my satisfaction.

Name of participant (Print)

---   -------------------------
Signature of participant   Date

Name of legally authorized representative (Print) (If appropriate)

---   -------------------------
Signature of legally authorized representative (If appropriate)   Date

----
Name of person obtaining consent (Print)

---   -------------------------
Signature of person obtaining consent   Date

APPENDIX F Observation Forms

inforehab   Canadian Institutes of Health Research   Instituts de recherche en santé du Canada   Western Health Sciences

Date: ____________________   Time: ________________

Observer name:

____

Location:

____

Individuals being observed (*check all that apply*):

☐ Patient
Study ID:

☐ Nurse
Study ID:

☐ Doctor
Study ID:

☐ Occupational Therapist
Study ID:

☐ Physical Therapist
Study ID:

☐ Patient's family member(s)
- Please list (e.g. daughter, son, sister, brother):

  ____

  ____

Study ID:
Study ID:

☐ Other: ____

Study ID:
Study ID:

Location of interaction (*check all that apply*):

☐ Patient home
☐ Acute care facility
☐ Long-term care facility
☐ Hospital

☐ Other: ____________________

Location in transition point (*check one only*):

☐ Discharge (i.e. pre-transition)
☐ Admission (i.e. post-transition)
☐ Nature/purpose of interaction (e.g. family conference):

Notes about participants (e.g. mood, communication ability):

a) Please describe the *mood* of the participants?

b) Please describe the *communication skills/ability* of the participants?

Information being shared (e.g. referrals to other services, discharge locations, medications, follow-up programs such as exercise regimens):

Specific documents being provided/exchanged:

Additional observations (e.g. did information appear to be understood/opportunity for questions):

APPENDIX G Ethical Approval

Office of Research Ethics
The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Western

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. B.M. Chesworth
Review Number: 16334E **Review Level:** Expedited
Review Date: July 22, 2009
Protocol Title: InfoRehab: Enhancing MSK Rehabilitation through Better Use of Health Information
Department and Institution: Physical Therapy, University of Western Ontario
Sponsor: CIHR-CANADIAN INSTITUTE OF HEALTH RESEARCH
Ethics Approval Date: July 29, 2009 **Expiry Date:** December 31, 2010
Documents Reviewed and Approved: UWO Protocol, Letter of Information (patient with hip fracture), Letter of Information (caregiver), Letter of Information (health care provider), Consent.
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:
a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert

Ethics Officer to Contact for Further Information			
☐ Janice Sutherland (jsutherl@uwo.ca)	☐ Elizabeth Wambolt (ewambolt@uwo.ca)	☑ Grace Kelly (grace.kelly@uwo.ca)	☐ Denise Grafton (dgrafton@uwo.ca)

This is an official document. Please retain the original in your files.

cc: ORE File

APPENDIX H Copyright Permission: Knowledge to Action Process (Figure 2)

Subject: Re: Urgent: copyright permission

On 07/18/11, **Curtis Olson/UW/JCEHP** < > wrote:

Dear Ms Elliott,

Permission is granted to use Fig 1 from Graham et al's 2006 article for the purpose described below. Thank you for your interest in scholarly works published in JCEHP.

Curt Olson
Editor-in-Chief
JCEHP

--Sent from my Android device

----- Reply message -----
From: "Jacobi Elliott"
Date: Mon, Jul 18, 2011 4:06 pm
Subject: Urgent: copyright permission
To:

Dear Mr. Olson,

I am a Master's student at The University of Western Ontario, in the process of writing my thesis containing my research results. I am looking to obtain copyright permission to reprint the Knowledge to Action figure that was used in Graham et al., *Lost in knowledge translation: time for a map?* (2006).
The figure would be used in my thesis but would not be published in any articles submitted for publication. I would, of course, properly cite the origin of the figure within the text.
I appreciate you taking the time to consider this request and I hope to hear from you in the very near future.

Kindest regards,

Jacobi Elliott

--
Jacobi Elliott, BA Kin (Hon), MSc Student
Health & Rehabilitation Sciences - Health & Aging
The University of Western Ontario
Elborn College, 1201 Western Rd.
London, Ontario, Canada N6G 1H1