PATIENTS' EXPERIENCE OF OCCUPATIONAL THERAPY DISCHARGE PREPARATION

by

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ABSTRACT

Discharge planning is intended to assist hospitalized patients returning home. Occupational therapists play an important role in interdisciplinary discharge planning by assisting with the identification of potential barriers to discharge and discussing possible strategies with clients, such as recommending equipment and/or additional support and offering other interventions that can facilitate return to home. A deeper understanding of patients' perspectives of discharge preparations can be used to inform effective occupational therapy discharge interventions.

Using interpretive description, the experiences of 6 patients recently seen by an occupational therapist in preparation for discharge from acute care settings were explored in qualitative interviews. Results indicate that occupational therapy discharge preparation was perceived as valuable and client-centred by most participants. It was noted that past health care experiences, patient's pre-existing personal values, beliefs and expectations of the health care system and families' concerns all impacted the occupational therapy discharge process.

LIST OF ABBREVIATIONS USED

ADLs Activities of Daily Living

CCAC Community Care Access Centre

CMOP-E Canadian Model of Occupational Performance and Engagement

IADLs Instrumental Activities of Daily Living

ICU Intensive Care Unit

PEO Person -Environment-Occupation

TOH The Ottawa Hospital

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CHAPTER 1 – INTRODUCTION

While discharge preparation is a large focus of in-hospital occupational therapy for people diagnosed with general medical conditions, relatively little is known about the process or targeted outcomes of this intervention. The goal of this study was to improve our understanding of patients' perceptions of occupational therapy during preparation for discharge home following acute care hospital stays.

1.1 CONTEXT

Acute care hospital units are designed to treat people with severe medical illnesses. The Mosby's medical on-line dictionary defines acute care as "a pattern of health care in which a patient is treated for a brief but severe episode of illness, for the sequelae of an accident or other trauma, or during recovery from surgery" (2009). Acute care is typically provided by specialized health care professionals using complex technical equipment and materials. Unlike chronic care, this type of care is often needed only for a short time (Mosby medical online dictionary, 2009). Discharge planning assists hospitalised patients to leave acute care and return home. It is described by Shepperd and colleagues (2013) as consisting of "the development of an individualised discharge plan for a patient prior to them leaving hospital for home" (p.5). The discharge planning process is characterised as bridging the gap between hospital and community care (Bauer et al., 2009) which involves the identification of patients' needs and the organisation of suitable support to facilitate a safe return home (Grimmer et al., 2004).

The ideal discharge plan is described as meeting both the medical and psychosocial needs of the individual (Preyde et al., 2009). Therefore, discharge planning requires multidisciplinary collaboration so that an appropriate plan can be developed based on each discipline's input in order to address the patient's needs (Bauer et al., 2009, Katikireddi & Cloud, 2009). The multidisciplinary team typically includes the following professionals: medicine, physiotherapy, occupational therapy, nursing and social services (Katikireddi & Cloud, 2009). Other disciplines such as nutrition and speech therapy may also be involved depending on the patient's needs.

Hospital discharge to home can be difficult for many people for a range of reasons. In a qualitative study exploring the needs and challenges of 14 elderly women returning home following hospitalization, Leclerc and colleagues (2002) found that hospital discharge plans focused on very basic physical and medical needs. These discharge plans "[fell] short of the mark" (p. 249) in that they did not take into consideration the complexity of the women's needs, resulting in unmet physical and emotional needs and struggles with re-establishing daily routines post-discharge.

Comprehensive discharge planning is important in order to ensure that appropriate support, continuity and coordination of care is available. Effective discharge planning increases quality of life and decreases the likelihood of readmission (Crennan & MacRae, 2010). In their study of the hospital discharge process from the perspective of patient, caregiver and clinician, Foust and colleagues (2012) report that between 19-23% of recently discharged patients

experience adverse events or are readmitted to hospital within 30 days of discharge. Effective discharge planning may assist in reducing such readmissions.

During discharge planning, occupational therapists play an important role in interdisciplinary collaboration facilitating the discharge process. Occupational therapists contribute to the identification of potential barriers to returning home and possible problems that can follow return to home. Occupational therapy interventions in acute care aim to maximize safety and minimize stress for the client and family by preparing patients and their families for discharge (Smith-Gabai, 2011; Schultz-Krohn & Pendleton, 2006), in particular in relation to how a patient will manage their daily activities and routines. Occupational therapists assist in the early resolution of issues related to managing daily activities through recommendations regarding alternate discharge locations, training, equipment and/or additional support.

In the occupational therapy literature reviewed, discharge preparation has not been explicitly defined or spoken of; thus for the purpose of this study, discharge preparation will refer to the subset of interventions (such as education, activities of daily living re-training, assistive devices/equipment trial, etc.) aimed at facilitating the return back home and/or addressing the discharge barriers identified during discharge planning. Experienced occupational therapists who work with older adults in acute care settings report that they contribute significantly to discharge preparations by suggesting discharge locations, needed equipment and follow up support (Holm & Mu, 2012).

Occupational therapists evaluate patients' occupational performance to gather information that will guide discharge planning (Crennan & MacRae, 2010). Canadian occupational therapists often refer to the Canadian Model of Occupational Performance and Engagement (CMOP-E) to guide their practice (Townsend & Polatajko, 2007). Occupational performance is conceptualised as the result of the dynamic interaction between person, occupation and environment (Townsend & Polatajko, 2007); occupational therapists look at how an individual (the patient) engages in an occupation within a specific environment. Occupations are described as tasks or activities individuals do as part of their daily routine; this includes taking care of oneself (self-care), contributing to society (productivity) and enjoying oneself (leisure) (Townsend & Polatajko, 2007). Ideally, each of these aspects - that is, the person, the environment and the occupation - are examined in detail in the development of plans to support occupational engagement following discharge, thus facilitating participation in daily routine upon returning home.

A number of authors have pointed out that more holistic previously documented descriptions of occupational therapy practice around discharge may not accurately reflect current practices, as patients are now being discharged earlier, sicker and likely requiring more help with daily activities (Coffey & McCarthy, 2012; Wales et al., 2012; Bauer et al., 2009; Preyde et al., 2009; Grimmer et al., 2004). That is, there may be less time available to fully consider patients' current occupational performance and put appropriate plans in place to enhance occupational engagement post-discharge. However, given patients are

being discharged with more complex medical problems and experience shorter hospital stays, it seems that the need for such discharge preparation is greater than ever, and occupational therapists have a key role to play.

Though not uncontested (Walley Hammell, 2013), client-centred approaches guide occupational therapy assessment and intervention. Clientcentred practice is defined as a "Collaborative and partnership approach used in enabling occupation with clients... [C]lient centred occupational therapists demonstrate respect for clients, involve clients in decision making, advocate with and for clients' needs, and otherwise recognize clients' experience and knowledge" (CAOT, 1997, p.180). Current research promotes the involvement of patients in the discharge planning process to maximize positive outcomes (Foss & Hofoss, 2011). However, again, due to the limited time available to work with acute care patients prior to discharge, it is not clear the extent to which occupational therapists in this setting have the time and resources to be clientcentred. While health care trends promote patient involvement and occupational therapists strive to be client-centred, the literature focuses mainly on the perspectives of occupational therapists. Patients' perspectives of occupational therapy interventions, in particular regarding discharge planning are largely underrepresented in the literature. Which raises the question: what is the patient's perspective and experience?

In a qualitative study Maitra and Erway (2006) compared the perceptions of clients and their occupational therapists regarding client involvement in the shared decision making process, in different health care facilities. Eleven

occupational therapists and 30 of their patients were interviewed. The majority of therapists (9 out of 11) stated that they educated clients regarding the goal-setting process and eight reported encouraging their clients 'a lot' to take part in goal setting. However, 14 of the 30 clients reported being involved less than a quarter of the time in their goal setting. In general, it seems that patients and their families do not feel included sufficiently in the discharge process and the identification of post-discharge needs (Foss & Hofoss, 2011; Bauer et al., 2009; Olofsson et al., 2005; Grimmer et al., 2004). This implies that, in some cases, the patient and the therapist may not share the same focus regarding what is important to address during discharge preparation; it also raises questions concerning the application of client-centred principles in occupational therapy practice.

The present context of an aging population with greater and more complex medical needs, decreased average length of stay and budget constraints all contribute to increasing pressure on an already overburdened health care system (Preyde et al., 2009). Occupational therapists believe in and intend to provide client-centred interventions. However, the reality and demands of the current acute care environment appear inconsistent with occupational therapists' values of holistic client-centred care (Smith-Gabai, 2011). This raises the question: are patients experiencing occupational therapy services in acute care as client-centred?

The findings of Maitra and Erway (2006) seem to indicate that the type of facility where an occupational therapist provides services influences the application of the client-centred approach. Though generalizing from qualitative

research is risky, since it is not intended to be generalizable, the authors noted that occupational therapists working with hospitalized patients seemed to experience the most difficulty in their efforts to engage in client-centred practice. These occupational therapists tended to use client-centred practice the least, compared to occupational therapists working in long-term care or rehabilitation facilities, nursing homes or hospital out-patient settings. In-patient occupational therapists noted that acutely ill patients' inability to participate in goal setting discussion is a barrier to client-centred practice. Whether client-centred practice is equally applicable to the various occupational therapist work environments has been recommended as an area for further study (Maitra & Erwary, 2006).

As an occupational therapist working in a large urban Canadian acute care facility, I noticed a growing discontent amongst my occupational therapy colleagues concerning the pressure for shorter lengths of stay and the impact this pressure has on our practice. This reduced time in hospital means, at times, we as occupational therapists are expected to assist in the discharge preparation of patients who are returning home despite the fact that they are still quite frail and dependent. We are concerned with our ability to prepare these patients for discharge in the time available.

In addition to this pressure to discharge patients quickly to free beds, occupational therapy services have also been affected by budget cuts. These cuts have led to increased workloads for therapists. In some cases, these cuts have led to an increasing number of referred patients being discharged without being seen

by an occupational therapist or being seen the day before or the day of discharge – again, allowing very little time to adequately prepare them for discharge.

For me, these circumstances prompted a reflection on the role and contribution of occupational therapy in discharge preparation for patients returning home. I began asking a number of questions. How do patients experience discharge? Do patients feel well prepared to return home? How do occupational therapists respond to patients' concerns and needs related to discharge? Do patients' experiences seem consistent with client-centred care? Answers to these questions would provide valuable information to assist occupational therapist in improving discharge preparation and ensure patients' needs are being addressed prior to their return home.

A review of literature concerning patient experiences and perceptions of discharge home following hospitalization for general medical conditions demonstrated many unmet needs, needs that could be at least somewhat met through client-centred occupational therapy. The goal of this study, therefore, is to describe the patient's experience of occupational therapy intervention carried out with the goal of preparing patients hospitalized in a medical acute care setting for discharge home.

Thus the research question that was pursued in this study was: how do patients in a medical acute care setting experience occupational therapy services focusing on preparation for discharge home and how do they perceive this preparation assisted in resuming their daily routine upon return home?

1.2 LITERATURE REVIEW

To guide the development of this research project, a literature review was undertaken to look at discharge planning process, patient's experience of discharge, occupational therapists' experience of discharge and client-centredness.

1.2.1 Discharge Planning Process

The experience of returning home following hospitalization in an acute care setting has been described in the literature. Findings demonstrate that this return home is challenging for most patients and their families. In theory, proper discharge planning facilitates patients' return home. The goal of the discharge planning is to improve service coordination post-discharge by identifying patients' needs in the community (Katikireddi & Cloud, 2009).

Discharge planning is described as bridging the gap between hospital and community care (Bauer et al., 2009). Ideally, this process includes multidisciplinary collaboration so that an appropriate plan can be developed based on the client's needs and each discipline's input (Bauer et al., 2009; Katikireddi & Cloud, 2009). The optimal discharge plan meets both the medical and psychosocial needs of the individual (Preyde et al., 2009). The complex process of discharge planning includes a thorough patient assessment, the development of a thorough and efficient plan addressing identified barriers to discharge, education of patient and carers, follow up and monitoring of the need for further evaluation (Bauer et al., 2009). From an institutional perspective, discharge planning is believed to reduce length of stay and minimize unplanned re-admission (Katikireddi & Cloud, 2009). Despite being an integral part of hospital care,

discharge planning processes are variable and not entirely evidence based (Katikireddi & Cloud, 2009).

In an article aimed to help junior doctors in their daily practice,

Katikireddi and Cloud (2009), recommend that the discharge planning process
begin upon admission. They encourage junior doctors to identify potential barriers
to discharge and initiate referrals to other health care professionals accordingly.

They highlight that multidisciplinary team work is required for effective discharge
planning. This process is usually facilitated by weekly meetings to review the
different disciplines' assessment findings in relation to barriers to discharge and
patient progress. In acute care settings, medical, nursing, physiotherapy,
occupational therapy and social work services are commonly included in these
team discussions.

1.2.2 Occupational Therapy Perspective of Discharge Planning Process in Acute Care Setting

In the acute care setting, occupational therapists contribute to team discussions by assisting in the early identification and resolution of discharge barriers based on findings from the patient's occupational performance evaluation (Crennan & MacRae, 2010). During the evaluation process taking place in hospital, the occupational therapist will look at how the patient engages in his/her occupations within this environment, for example how the patient is able to take care of him/her self, contribute to society or others and enjoy him/her self. From an occupational therapy perspective, proper discharge planning involves examining in detail each of these aspects - that is the person (physical, mental and

spiritual aspects), the environment and the occupation - in the development of interventions to support discharge home to promote safe re-engagement in valued and/or necessary daily activities identified in collaboration with the patient during the evaluation process. Although occupational therapy scope of practice encourages the examination of self-care, productivity and leisure, in acute care settings, self-care is often the main focus in part due to time constraint and limited resources.

The occupational therapy evaluation typically includes an interview and formal testing and/or observation of the patient. The goals of the interview are to better understand the discharge environment (e.g., the patient's home), the resources already in place, and the patient's goals. Formal testing and/or observation of the patient engaging in routine activities (e.g., toileting, dressing, bathing, meal preparation etc.) will assist in identifying occupational performance issues based on how easily and safely the patient can engage in these activities. These occupational performance issues will be reviewed with the patient and may lead to refinement of the goals. This evaluation process can lead to recommendations concerning discharge location, equipment and/or additional services to support the patient's safe return home from hospital (Holm & Mu, 2012).

1.2.3 Older Patient's Experience of Discharge

Outside of the occupational therapy literature, there have been multiple studies of the discharge experience of elderly patients. Understanding of the discharge experience of these patients is critical due to their frailty, increased risk

for further functional decline following discharge home and higher risk for readmission (Foust et al., 2012; Foss & Hofoss, 2011; Mesteig et al., 2010; Preyde et al., 2009). Older patients and their families frequently report insufficient involvement in the identification of post-discharge needs and the discharge planning process (Foss & Hofoss, 2011; Bauer et al., 2009; Olofsson et al., 2005; Grimmer et al., 2004). However, it is not clear if discharge planning has an impact on patient outcomes.

Shepperd and colleagues (2013) completed a Cochrane review of the effectiveness of discharge planning for older adult patients returning home after an acute care hospitalization. This review included 24 randomized controlled trials with a total of over 8000 patients comparing individualized discharge plans with routine care that did not include an individualized plan. Twelve outcomes were reported including length of stay, readmission rate, complication rate, mortality rate and patient's satisfaction. The results demonstrated a small but statistically significant reduction in length of stay for older individuals admitted for a medical issue. However, there was no statistically significant difference in two trials that included patients recovering from surgery as well as patients admitted for a medical condition. A significant reduction in the three month readmission rate was noted among patients admitted for a medical condition. However, there were no differences in six or nine month readmission rates. As well, there was no evidence of lower mortality among medical patients. However, two trials noted an increased satisfaction of patients with a medical condition assigned to discharge planning.

The current literature underlines how patients and their caregivers frequently report unmet medical and psychosocial needs post-discharge. When looking at patients' experiences, returning home is described as a time of uncertainty and worry (Cornwell et al., 2012; Foust et al., 2012; Yeung et al., 2011; Ellis-Hill et al., 2009; Olofsson et al., 2005; Grimmer et al., 2004: LeClerc et al., 2002; Bull, 1992). Various factors contribute to the uncertainty and worry of returning home after an acute care hospitalization.

Patients commonly report unmet informational needs. Lack of information regarding the medical condition itself, the course and management of the condition, as well as the anticipated recovery process, is commonly highlighted (Ellis-Hill et al., 2009; Grimmer et al., 2004). In a qualitative study with 9 stroke patients (in 5 cases interviews completed with near family members present) four months post-discharge, Olofsson and colleagues (2005) found that patients and their caregivers wished for increased support and information from health care providers. They sought information regarding medications and risk of possible setbacks, reassurance concerning the progress of their recovery as well as confirmation that their exercise programs were appropriate. Similar findings are reported by Ellis-Hill and colleagues (2009) in their study looking at the factors characterizing 'good' versus 'poor' discharge experiences of 20 individuals admitted to hospital following a stroke. These individuals felt they were ill informed concerning their medical conditions and they had many unanswered questions after discharge. Many participants worried about the possibility of worsening their situation or 'doing it wrong'; they did not feel that they had a

good enough understanding of their condition to overcome the new challenges they were faced with. This created a life filled with uncertainty. For some, the situation was made worse as they waited for community services to be initiated without knowing when these services would begin or how to accelerate the process.

Similarly, other studies uncovered patients' concerns that they lacked information regarding possible treatment options (Bull, 1992) and community supports once home (Cornwell et al., 2012; Yeung et al., 2011; Naylor et al., 2005; Olofsson et al., 2005). Findings from Cornwell and colleagues' (2012) qualitative study of 9 individuals with non-malignant brain tumor provide an account of patients' and carers' lack of knowledge of community resources. The authors report that all participants responded that they did not know which services were available or if they needed services. They did not recall obtaining information regarding services and support options prior or following discharge home. This lack of information about community support created a situation where many patients recently discharged home did not know who to turn to for answers.

Not only did patients identify difficulties accessing a health care provider who could respond to their concerns (Ellis-Hill et al., 2007; Olofsson et al., 2005; Grimmer et al., 2004; LeClerc et al., 2002) but of those who had health care providers, some also reported feeling uncomfortable approaching them regarding their concerns (Grimmer et al., 2004; LeClerc et al., 2002). In their longitudinal study of the experience of 100 elderly patients discharged from hospital, Grimmer

and colleagues (2004) found that some study participants did not bring to the attention of their General Practitioner important issues related to their functioning within the community. These participants perceived these physicians as too busy or unable to address the problem, or they simply prioritized their concerns to ensure that the most pressing issues (such as prescriptions) were taken care of prior to the end of the limited consultation time.

Once home, patients appear to undergo a period of transition and adjustment during which their concerns and worries may intensify. There is a need for patients to create a new reality as they adapt to physical, cognitive and emotional changes as well as the subsequent impact of these changes on their routine, relationships, roles, sense of self and their views on the meaning of life. In the early phase of discharge home, many patients identify managing activities of daily living (ADLs) and instrumental activities of daily livings (IADLs) as the most challenging areas of this new reality, rather than the management of their medical condition per se (Cornwell et al., 2012; Grimmer et al., 2004; Mistiaen et al., 1997; Bull, 1992). To meet these new demands, many patients modify their routines or turn to their caregivers, relatives or friends for additional support (Coffey & McCarthy., 2012; Ericksson et al., 2009; Preyde et al., 2009; Grimmer et al., 2004; LeClerc et al., 2002). In doing so, they alter their relationships with these individuals (Yeung et al., 2011; LeClerc et al., 2002) as well as their roles and social functioning (Cornwell et al., 2012; Yeung 2011; Grimmer et al., 2004; Rittman et al., 2004; Leclerc et al., 2002; Bull, 1992). These changes in routine and relationship also impact on the patients' sense of self and identity as they reassess their engagement and

contribution to their immediate environments as well as in their communities (Cornwell et al, 2012; Yeung et al., 2011 & Rittman et al., 2004).

Rittman and colleagues (2004) provide an example of the impact of illness on the patient's self in their study of 51 male veterans discharged home following a stroke. Their study explored how stroke survivors experienced time upon their return home after hospitalization. The authors report on how the stroke impacted on one of the study participant's sense of self and engagement in occupations: "Well, you feel bad but you have to accept it. It was just something that was natural before... I would take the car or I would walk in the city..." (p. 264). Later in the interview this participant summarized the importance of his perceived losses: "One's happiness finishes....yes, it finishes, what good is someone who is sitting in a chair? It is a bother... for a companion, how do you live?" (p. 264). For many patients the physical, cognitive and emotional changes that lead to changes in their functional status also contribute to increased concerns for the wellbeing of their carers as they may fear becoming a burden to them (Yeung et al., 2011; LeClerc et al., 2002; Bull, 1992).

Patient anxiety may arise secondary to unmet needs upon their return home (Leclerc et al., 2002; Mistiaen et al., 1997; Bull, 1992). The lack of information and disruptions in routine described above contribute to increased concerns and uncertainty about returning to 'normalcy' and maintaining one's level of independence, which results in emotional distress (Olofsson et al., 2005; LeClerc et al., 2002). Unmet information needs contribute to social isolation and uncertainty (Grimmer et al., 2004). The emotional distress experienced upon returning home may bring feelings of loneliness and isolation regardless of availability of caregiver support (Cornwell et al., 2012). As well, the

process of recovering at home can be isolating from the community (Erikson et al., 2009; LeClerc et al., 2002). Contributing to this isolation is the worry and helplessness experienced by some people relating to their new physical status and their new physical limitations (Yeung et al., 2011; LeClerc et al., 2002). For example, LeClerc and her colleagues (2002) describe how in some instances accessibility of the environment and/or lack of support can create additional obstacles to re-engagement in social activities following discharge home. All the women participating in their study were recently discharged home following a hospital admission related to an acute illness and discussed issues resuming grocery shopping, banking, and accessing follow-up appointments; these problems challenged their ability to cope and remain positive. Yeung and colleagues (2011) in their study of 15 Chinese stroke survivors report similar findings and describe how some study participants, who had previously been very active socially, wanted to reduce their social activities due to fear of judgement from neighbours and friends because of their changed physical appearance and abilities.

As discussed above, when looking at discharge preparation as a whole, the literature highlights that patients identify many unmet physical, emotional and informational needs upon returning home. Very few studies have investigated patients' experience of discharge preparations relating to occupational therapy interventions focusing on facilitating the discharge process. Therefore it is currently unclear if patients' would report similar experiences and unmet needs following occupational therapy discharge preparation.

1.2.4 Occupational Therapists' Contribution to Discharge Preparation

Currently in Canadian acute care settings, occupational therapists regularly participate in discharge preparation in collaboration with other health professionals such as physicians, nurses, physiotherapists, and social workers. Multidisciplinary collaboration is considered beneficial in that an appropriate discharge plan can be developed based on each discipline's input in addressing the patient's key goals (Bauer et al., 2009; Katikireddi & Cloud, 2009). As client-centredness is a core value guiding occupational therapy interventions (Townsend & Polatajko, 2007; Radomski & Trombly Latham, 2008), occupational therapy assessment and intervention ideally respect the values and consider the specific needs of each patient. Occupational therapists address issues in occupations or daily activities by looking at the relationship between the person, environment and occupation as described by the Person-Environment-Occupation (PEO) Model (Law et al., 1996) and the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend & Polatajko, 2007). Occupational therapists are expected to work with each patient and his/her carers to assess current functional status and identify needs and supports required in preparation for return home (Wales et al., 2012). Discharge preparation is perceived as a primary responsibility of acute care occupational therapists. Through assessments and interventions, occupational therapy in acute care focuses on maximizing safety and minimizing stress for the client and family by preparing patients and their family members for discharge (Smith-Gabai, 2011; Schultz-Krohn & Pendelton, 2006).

Occupational therapists believe their occupation-based perspective is important in facilitating safe discharge home following hospitalization in an acute care setting (Clark

& Dyer, 1998). In acute care settings, three general processes used in occupational therapy discharge preparation have been described by Schultz-Krohn and Pendleton (2006): education, implementation of the initial rehabilitation process, and consultation, which includes discharge planning. Unfortunately they say very little about what these general process involve. Given their occupation-based client-centred approach, occupational therapists appear well suited to play an important role in preparing patients to manage functional challenges post-discharge and facilitate re-engagement in meaningful activities in the community.

Current literature is scarce regarding the contribution of occupational therapists to the discharge process. The majority of studies to date on the experience of discharge take a nursing perspective or look at the multidisciplinary team as a whole in the discharge planning process. In addition, few studies have focussed on the patients' perspectives of occupational therapy prior to discharge home from an acute care setting. Wressel and colleagues (2006) conducted a pilot randomized controlled trial to determine whether occupational therapy intervention in acute care improved older patients' perceptions of their ability to manage at home post-discharge. The experimental group received occupational therapy and the other received standard care which did not include occupational therapy. Questionnaires were completed prior to discharge as well as approximately three months after discharge regarding difficulties in ADLs and IADLs and management of the post-discharge period. At discharge, the control group had higher anxiety and planned healthcare contacts. At three months post discharge follow-up, the experimental group were more likely to have transportation service and in-home alarms. However, there were no differences in reported coping. Nonetheless, these authors

concluded that occupational therapy interventions in acute care may positively impact older patients' ability to manage at home.

Despite the paucity of literature focussing on the contribution of occupational therapy to the discharge process, there is considerable literature on the barriers that seem to influence discharge preparations and occupational therapy practice relating to facilitating patients' return home after hospitalization. In the current health care environment, some authors note that discharge from an acute care setting may appear to be driven more by the facilities' need for beds than the patients' readiness to return home (Ellis-Hill et al., 2009; Clark et Dyer, 1998). Ellis-Hill and colleagues (2009) conducted a qualitative study exploring patients' and caregivers' experiences of discharge from hospital following a stroke. Some participants felt that their discharge was linked to the facility needing beds rather than for clinical reasons. Clark and Dyer (1998) studied the experience of older people from the UK in the process of returning back home for whom equipment and/or adaptations were recommended by occupational therapists. They report that hospital procedures appeared to be led more by the pragmatic need for available beds than by a policy objective of moving care to the community; this led to patients feeling ill-prepared for discharge home.

In acute care settings, where the focus is on obtaining medical stability for prompt and safe discharge home (Smith-Gabai, 2011; Schultz-Krohn & Pendleton, 2006; LeClerc et al., 2002), it is not uncommon for occupational therapists to only have one visit with a patient, at times on the day of discharge (Schultz-Krohn & Pendleton, 2006). This implies that during this single encounter, the occupational therapist needs to review her/his role, identify discharge needs with the patient and caregiver, and provide both education and

recommendations to maximize positive discharge outcomes. These sessions can run anywhere between 30-120 minutes based on various factors such as caseload demands, issues identified, availability of resources and time of discharge. This time pressure adds to the challenge of providing holistic client-centred discharge planning and preparing the patient and caregivers adequately.

1.2.5 Challenges to Discharge Planning

The pressure to do much in a very short period of time can negatively affect the discharge process and preparation to return home. Immediate medical and physical basic needs may be prioritized over post-discharge needs or patient concerns (LeClerc et al, 2002; Clark & Dyer, 1998). In a study exploring elderly patients' perceptions of their post-discharge experience over a 6 month period, Grimmer and colleagues (2004) found that participants did not feel involved in the discharge planning. They felt that hospital staff did not help them to better understand their conditions and/or changes in health status. They also felt they were not sufficiently prepared to address practical situations that would arise upon their return home.

The limited time available for discharge planning and preparing patients and families for the upcoming discharge may result in an inconsistency between the anticipated needs addressed prior to discharge and the actual needs experienced once home (LeClerc et al., 2002). Due to lack of education on the medical health condition and/or change in health status, as well as limited time for discussion of the patient's concerns, it may be difficult for patients to identify possible problems and anticipate future needs. As a result, patients and their

families are ill prepared to face the challenges and adjustments related to returning home. Clark and Dyer (1998) add that the increased demands being placed on the health care system and the increasing time pressures create a situation where it has become apparent that promoting independence comes second to safety. This means that discharge planning and discharge preparation are more geared towards short term needs related to the acute medical condition or intervention that led to hospital admission, rather than the long term needs related to ongoing chronic conditions.

The notion of promoting 'safety' at discharge was further explored by Moats and Doble (2006) who bring to light two very different approaches of addressing safety: risk avoidance *versus* autonomy. In the risk avoidance approach, the emphasis is placed on the elimination of risk factors that could contribute to physical injuries (such as falls) and risk associated with certain behaviours. Safety takes precedence over engaging in significant occupations. This risk avoidance approach highlights an underlying expectation that individuals being discharged from hospital will follow recommendations from their health care providers post-discharge. In contrast, the autonomy approach includes patients in the decision process concerning risks that might be considered in the interest of maintaining engagement in a meaningful activity. The autonomy approach seems well-aligned with Canadian occupational therapists' value of client-centred care. However, translating this principle into clinical practice situations can be quite challenging particularly given the current emphasis on early discharge which doesn't provide sufficient time for the hospitalised

individual to recuperate and engage in rehabilitation. Tensions often arise between acceptance of patients' decisions and occupational therapists' values in client-centredness and autonomy promotion when concerns about the patient's safety are brought up related to a decision, especially if cognitive issues are identified.

Given patients are often discharged weaker and frailer and community supports are scarce, there is a tendency for health care professionals to place greater emphasis on safety then autonomy; this likely also applies to occupational therapists. It is not yet clear how patients experience these tensions.

1.2.6 Patients' Participation in Discharge Planning and Client Centredness

Current research promotes the involvement of patients and caregivers in the discharge planning process to maximize positive outcomes (Foss et al., 2011; Preyde et al., 200 9). Health care professionals support this approach (Grimmer et al., 2004; Townsend & Polatajko, 2007; LeClerc et al, 2002; Lane, 2000). Such involvement of patients is consistent with client-centred practice (Townsend & Polatajko, 2007; Lane, 2000). However, as mentioned previously, research demonstrates that patients do not feel included sufficiently in the discharge process. As discussed earlier, in a qualitative study comparing the perception of involvement of clients and their occupational therapists in the shared decision making process, Maitra and Erway (2006) interviewed both occupational therapists and clients to explore client-centred practice in different health care facilities. The study results highlighted that occupational therapists and patients do not share the same perception on the use of and client participation in client-centred practice. Ten of the 11 occupational therapists involved in the study reported discussing goal options with their clients and 9 out of 11 reported taking clients' suggestions into

account when setting goals. A different perspective emerged in response to similar questions to the clients. Only 7 of the 30 clients stated they participated in the setting of all of their goals, 8 reported participating in setting half or more of their goals and 14 felt they contributed a quarter or less of the time to the goal setting process.

The present context of an aging population with greater and more complex medical needs, decreased average length of stay and budget constraints all contribute to increasing pressure on an already overburdened health care system (Preyde et al., 2009). Occupational therapists believe in and intend to provide client-centred service. However, the reality and demands of an acute care environment appear inconsistent with occupational therapists' values of holistic client-centred care (Smith-Gabai, 2011). This raises the question: are patients experiencing occupational therapy services in acute care as client-centred?

1.3 RESEARCH QUESTION

The main objective of the current study is to describe the patient's experience and the perceived impact of occupational therapy intervention carried out with the goal of preparing patients hospitalized in an acute care setting for discharge home. The proposed research seeks to answer the following question: how do patients in a medical acute care setting experience occupational therapy services focusing on preparation for discharge home and how do they perceive that this preparation assisted in resuming their daily routine upon return home? Secondary questions include: do patients perceive that occupational therapy services addressed their informational, functional and emotional needs in preparation for returning home? To what extent do the patients feel the

occupational therapist sought their concerns, views, feelings and goals in preparation for their discharge home?

CHAPTER 2 – METHODOLOGY

2.1 METHODOLOGICAL PERSPECTIVE

Creswell (2007) states that qualitative research requires that researchers make their assumptions, paradigms and framework explicit, as these inform decisions concerning the study design and analysis of the data. A constructivist paradigm is proposed for this study, as the intent is to better understand patients' experience of occupational therapy discharge preparation. This paradigm was selected because it was reasoned that there is no one objective reality of this experience, but rather, multiple realities formed by the interplay of multiple factors. From a constructivist perspective, realities are mental constructs that can take various meanings (Appleton & King, 1997). The researcher engages in conversations with the study participants to collect data; the findings are created during the process of the study (Appleton & King, 1997). A number of approaches, typically described as qualitative methodologies, are suited to investigate the meaning individuals or groups assign to human experiences, behaviours and interactions and social issues (Creswell, 2007; Kielhofner, 2006). Interpretive description, which will be used in this study, is consistent with this perspective.

2.2 Interpretive Description

Qualitative research designs were examined to identify the method most appropriate to answer the proposed research questions. Phenomenology was initially identified as a possibility. However, the intent of the proposed study was not to look at the 'essence' or 'basic truth' of the experience of receiving

occupational therapy prior to discharge but rather to explore patients' experience of how occupational therapy contributes to discharge preparation to return home following hospitalization in an medical acute care setting. Interpretive description as described by Thorne (2008) is well suited to answer this question that emerges from clinical practice.

Interpretive description is a qualitative inquiry of smaller size studying a clinical aspect of importance to a discipline with the intent of "capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding" (Thorne et al., 2004, p.5). Data collection methods commonly used in interpretive description include interviews, participant observation and document analysis (Thorne et al., 2004). Thorne (2008) states that the development of this method originated from a need to have a methodological approach better suited to addressing issues related to "complex experiential clinical phenomena" (p. 26-27) for health disciplines rooted in applied health knowledge. Thorne and colleagues (2004) describe interpretive description as a "qualitative approach to clinical description with an interpretive or explanatory flavor" (p.3).

Interpretive description evolved in nursing secondary to the realization that traditional qualitative research methods (such as grounded theory, phenomenology, ethnography) were not well suited for certain clinical questions; that is, these methods did not allow researchers to address questions emerging from the clinical field in a practical and easily applicable way. Furthermore, when researchers in applied health fields borrowed or adapted from traditional

qualitative research traditions, they did so without following faithfully the rules and structure of these traditions. This raised concerns relating to the quality of such studies as the epistemological perspectives and methodological aspects of these traditional approaches were not always respected. Thus interpretive descriptions was developed, "retaining the coherence and integrity of a theoretically driven approach to knowledge development while supporting defensible design variations according to the specific features of context, situation, and intent" (Thorne 2008, p. 27). As a result, interpretive description emphasizes research design logic to ensure sound qualitative description of phenomena important to the practice of health care. Given occupational therapy is not rooted on a single well developed theory, the conceptually-driven approach that served as a foundation to this research project includes concepts such as the value of client-centred practice and enabling as well as the value of interdisciplinary collaboration.

The proposed study consisted of in-depth interviews of patients recently discharged from an acute care setting and seen by an occupational therapist in preparation for their return home. The interviews took place in patients' homes and were conducted within 7-14 days post-discharge. This time frame was chosen with the view that it would provide participants time to begin settling back home while maximising the likelihood that these individuals would still recall the occupational therapy discharge preparation and their concerns prior to discharge. This is consistent with previous related studies where participants were

interviewed 1-2 weeks post-discharge (Cornwell et al., 2012, Ellis-Hill et al., 2009, Naylor et al., 2005, Grimmer et al., 2004, Bull, 1992).

2.3 INCLUSION CRITERIA

The participants were among adults hospitalized in acute care who were referred to occupational therapy for discharge preparation. The inclusion and exclusion criteria are specified below:

Inclusion:

- At least 18 years of age.
- Admitted for a medical condition to The Ottawa Hospital (TOH).
- Referred to and seen by occupational therapy for discharge planning.
- Discharge location is own home.
- Speaks and understands French or English.
- Judged by the referring occupational therapist to be likely able to provide own consent.

Exclusion:

- A patient of the student researcher.
- Previously seen by occupational therapy for treatment during this hospitalization.

- Admitted for orthopedic or psychiatric condition.
- Planned discharge home for end of life care.

To eliminate the possibility of undue influence or coercion, no potential patient participant was under the care of the student researcher. Patients admitted for treatment of orthopedic or psychiatric conditions were excluded as the focus of this study was occupational therapy for discharge preparation following treatment for medical conditions. As well, a large proportion of patients hospitalized for orthopaedic conditions are there for a planned surgery and their experience may be different as they will have had the opportunity to consider discharge concerns prior to their admission. Patients hospitalized for psychiatric conditions may have very different experiences, concerns and needs around discharge. As well, patients discharged home for end of life care were not considered for inclusion. In addition to likely having some unique discharge concerns, the range and intensity of post discharge resources accessible to these patients are different.

The decision concerning the sample size was based on the research question and the information being sought. The vast majority of interpretive description studies are conducted on a relatively small sample size (between 5 and 30 participants) although the method can be applied to larger sample sizes (Thorne, 2008).

In qualitative research, investigators commonly plan to collect data until saturation is achieved. Saturation may be judged to have been achieved when new findings are no longer obtained from additional participants, indicating to the

investigator that no further variation in the experience is likely to emerge. Thorne (2008) argues that the use of saturation is problematic when it comes to understanding a clinical phenomenon as it is questionable that one can ever be assured that sufficient data has been collected to fully understand all that is potentially relevant to the human experience being studied. As a result, she advocates for justification of sample size based on the research question and phenomenon explored. Thorne (2008) suggests that for phenomena commonly occurring clinically, a small sample size with individuals familiar with the experience of the phenomena is suitable. As the phenomenon under investigation was medical patients' subjective experience of occupational therapy in preparation for discharge home, a smaller sample size was proposed. A purposive sample of 6-10 patient participants including both men and women was sought; in the end, 6 patient participants were interviewed.

2.4 RECRUITMENT

Following approval from Research Ethics Boards at Dalhousie University and The Ottawa Hospital (TOH), occupational therapists working on medical units at the General (medicine, oncology, cardiology, nephrology, ICU) campus were invited by the researcher through an e-mail to a presentation on the study during a monthly discipline meeting at each campus. Here they were asked to identify potential patient participants meeting the inclusion/exclusion criteria. As some potential participants were admitted off service (that is, patients admitted for medical conditions who stay on other wards), all occupational therapists were encouraged to attend. As many as a dozen occupational therapists were involved

in the identification of possible patient participants. On average, these therapists received between 30-60 referrals per month.

The occupational therapists providing service to medical units noted above identified potential participants who met the inclusion criteria. The treating therapist informed potential participants that there was a study of discharge experiences being carried out by reading a script provided to them by the researcher. In order to be judged as likely able to provide their own consent, potential patient participants needed to demonstrate to the therapist that they understood the goal of the proposed research and what would be required of them after reading or having listened to the script describing the study. The occupational therapist then requested the individual's permission to share their contact information (name, room number) with the student researcher. If the potential participant agreed, the student researcher visited the patient in the hospital, explained the study and sought informed consent.

To obtain informed consent, the student researcher reviewed the study procedures and confirmed that potential participants understood these as well as the potential risks and benefits. Potential participants were informed that they could withdraw from the study at any point with no consequences to them prior to the data analysis (Spring 2015) after which no data could be withdrawn. They were informed of the various ways by which confidentiality would be maintained. Upon consent, participants were contacted by phone 3-5 days post-discharge in order to schedule the home visit for the interview. Verbal confirmation of continuing consent was sought during the telephone contact concerning the home

visit as well as to access the occupational therapy discharge report from their most recent admission. The information contained in the discharge report was used solely to inform the researcher as to the occupational therapy interventions provided as part of the discharge preparation to the patient participants. The recruitment process was more challenging and took more time than anticipated; approximately 6 months to recruit the six patient participants. Some barriers to recruitment included the level of frailty of the patients upon discharge as evidenced by the fact that four individuals were contacted to set up an interview but declined participation reporting being 'too unwell' to participate. As well, several patients had some level of cognitive impairment which either interfered with consent and/or was perceived to possibly impact on their ability to recall the occupational therapy discharge preparation. The quick pace of acute care setting led to therapist meeting with some potential patient participant less than 24 hours before discharge which created challenges for the student researcher to review the study with these individuals prior to their discharge. Again, several occupational therapist reported to the student researcher 'having forgotten' to read the script presenting the study to potential participant due to time pressure and high demands placed on them.

2.5 DATA COLLECTION

The data collection method consisted of in-depth patient participant interviews. Prior to these interviews, the occupational therapy discharge report was consulted to find out about the occupational therapy involvement and interventions provided while in hospital. This was thought to be useful in helping

patients remember the occupational therapist intervention and facilitate the elaboration of more specific questions.

Three to five days post-discharge, the student researcher called each participant to set a time to meet with the individual to conduct an interview designed to elicit the participant's experience of the occupational therapy intervention and its impact on their discharge experience. Semi-structured interviews occurred in the participant's home or location of their choice. This home visit took place within 7-14 days of discharge. Semi-structured interviews are the most commonly used interviewing technique for qualitative studies such as interpretive description. Semi-structured interviews are usually designed to include a few open-ended questions exploring the topic under investigation (DiCicco-Bloom & Crabtree, 2006). Other questions emerged as the conversation evolved between the research subject and researcher. At the beginning of the interview the student researcher gathered information such as age, diagnosis, living arrangements, and support at home for socio-demographic purposes. A picture of the occupational therapist that provided discharge preparation intervention to the patient participant was also presented to facilitate recall. The semi-structured interview of the patient participants included the following questions:

> 1. Please tell me about what you recall from the few days prior to your return home? Could you describe to me what were your main concerns then regarding returning home? What kind of information were you looking for?

- 2. How did the occupational therapist respond (or not) to your need for information?
- 3. How did you feel about returning home and getting back to your routine? How did the occupational therapist help (or not help) in getting you ready physically to return home? Did the occupational therapist make any suggestions/recommendations? If so, can you tell me what you thought of these recommendations?
- 4. How did the occupational therapist find out about what was important to you about going home? How involved did you feel in the discussions about going home?
- 5. Based on what you recall from your interactions with the occupational therapist, how would you describe your experience? Could you tell me what you found useful? What was less/not useful?

The interviews lasted approximately 60 minutes. There were 6 patient participants. The interviews were audio-recorded and interviews were transcribed verbatim for later analysis. Two interviews were transcribed by the student researcher and the remainders were transcribed by a transcriber.

2.6 DATA ANALYSIS

Interpretive description (Thorne, 2008) drawing on thematic analysis as described by Braun and Clark (2006) guided the process of data analysis. This method assisted in identifying, analysing and presenting themes within the data as

well as assisted in the interpretation of various aspect of the research topic.

Thematic analysis is not associated with any particular theoretical framework, thus is applicable to interpretive description employing an occupational therapy disciplinary lens. It is recognized that the occupational therapy professional training and clinical experience of the student researcher shaped and guided the information sought and the analysis. Thematic analysis can serve different purposes such as reporting experiences, meanings and the reality of the subjects under study which relates to the aims of the current study. Braun and Clark (2006) propose and describe six phases to thematic analysis, which were followed:

- 1. Familiarization with the data. This phase involved immersing one's self in the data, becoming well versed with the breadth and depth of its content. It included transcribing verbatim the data from the audio-recorded interviews. It is suggested that researchers transcribe the data themselves as a way to become familiar with the content. Do to time constraint two interviews were transcribed by the student researcher and the others were transcribed by transcribers. The transcripts were reviewed against the audio recording to ensure accuracy. Active reading (and re-reading) of the data to search for meaning and patterns occurred in addition to preliminary notes taking and listing of ideas for coding.
- Generating initial codes. This phase consisted of bringing to light initial codes to organize the data into meaningful elements. It was initially done on paper and later Atlas.ti program was used. The

entire data set was systematically reviewed, giving equal attention to each element of the raw data to identify repeated patterns (or themes). Initial codes were discussed and reviewed with the thesis committee to ensure accuracy, deepen the analysis and suggest alternate interpretations.

- 3. Searching for themes. Codes analysis at a broader level was undertaken, combining some codes to bring forth overarching themes. As described by Braun and Clark (2006), thematic mapping was used as a helpful way to begin delineating the various relationships between codes, themes, and discriminating between themes and sub-themes.
- 4. Reviewing themes. In this phase themes were refined. Themes were broken down into separate themes, merged into one or discarded due to a lack of support from the data. The content of each theme was reviewed to ensure coherence and that each theme was distinct from the others. Feedback for the thesis supervisor was sought to ensure accuracy, deepen the analysis and trustworthiness.
- 5. <u>Defining and naming themes</u>. Each theme was analysed separately to get to the essence and see how it fitted in the broader context of the 'story' emerging from the data. The data was further reviewed to ensure each theme was accurately depicted and supported by narrative accounts.

6. <u>Producing the report</u>. Finally the researcher reported the 'story' emerging from of the findings in a manner that demonstrated the quality of the analysis, providing evidence to support the story.

2.7 TRUSTWORTHINESS

In qualitative studies, rigor can be evaluated by carefully assessing the trustworthiness of the research (Krefting, 1991). To enhance the quality of the proposed qualitative research several techniques were drawn upon.

Reflexivity has been suggested as a strategy that assists the investigator to evaluate the influence of her own background, interests, perceptions and behaviours on the research process (Thorne, 2008; Kielhofner, 2006; Krefting, 1991). Thus a field journal was kept. It is suggested that it contain three types of information: the schedule and logistic aspect of the study, the 'diary' of the investigator's thoughts and feelings and thirdly the methods log (Krefting, 1991). The 'diary' component of the field journal included thoughts, feelings, ideas, observations, questions, frustrations and possible hypotheses experienced at the various stages of the research process. Prior to the data collection and throughout the research, the diary also facilitated exploration and reflection on the student researcher's expectations, beliefs and experiences (both from a personal and professional point of view) about discharge preparation. Through the process of completing the field journal the student researcher became aware of beliefs, values or external influences. This increased awareness assisted in minimizing biases and recognising the possible influence these thoughts, feelings, frustrations etc. may have on the student researcher's approach and decisions relating to the

study (Krefting, 1991). Discussions with the supervisory committee also assisted in this process. As the student researcher shared her ideas with the committee, committee members asked questions facilitating the analysis process by raising new interpretations and deepening reflections.

The method log also served as an audit trail. Decisions (and the rationale) related to the research and data analysis was recorded for future reference (Thorne, 2008; Kielhofner, 2006; Thorne et al., 1997; Krefting, 1991). This informed the student's supervisor of the student researcher's rationale and thought process during the data analysis.

To enhance plausibility of analysis and interpretations (Thorne, 2008; Walley Hammell, 2002) expert peer review of data, coding and analysis was undertaken by the student's supervisor. The student researcher regularly reviewed and discussed the decisions relating to coding and analysis with her supervisor to maximise trustworthiness.

2.8 ETHICAL CONSIDERATIONS

2.8.1 Recruitment and Consent

Recruitment proceeded as described above, ensuring capacity to provide informed consent. Signed consent to participate was confirmed by telephone when setting up the interview, at which time consent to review hospital discharge records was also obtained. During the interview, pictures of the occupational therapists that provided the discharge preparation intervention were used to promote recall; the student researcher sought consent from the occupational therapists for the use of these pictures prior to the data

collection. The TOH consent for photo release form was used to obtain consent from all the consenting occupational therapists servicing medicine, oncology, cardiology, nephrology, ICU units at both campuses.

2.8.2 Confidentiality

Confidentiality was maintained through the implementation of various strategies. The audio recording of the interview was downloaded to an encrypted USB stick immediately after the interview and this stick was used and provided to the transcriber. The electronic file of the interview was deleted immediately after the interview had been transcribed and checked by the student researcher. All identifying information was removed from the interview transcripts. Patient participants were assigned a fictitious name that was used in transcribed interviews and the thesis instead of their real name. Any correspondence with the student researcher's committee members containing the now de-identified study data was done through password protected e-mails. No hard copy containing identifying information was kept. The transcripts with identifiers removed were kept in a locked cabinet in a locked occupational therapy room (limited access) at TOH. The file containing contact information and linking real names to pseudonyms was kept on the researcher's personal password protected Ipad until data collection was completed. As data collection is completed, this information will be kept for 5 years in a sealed envelope in a locked cabinet in the locked office of the occupational therapy Chief along with any written consent from patient participants and occupational therapists. Should any presentation, report or published research article occur the fictitious names will also be employed. The specific patient participant interview content was not shared with the treating occupational therapist to maintain confidentiality. Finally, all

occupational therapists discussed in participant interviews will be referred as 'she' in order to reduce the identifiability of therapists.

2.8.3 Potential Risks

The interview process may have induced fatigue and/or emotional distress for the patient participant. As an experienced clinical occupational therapist, the student researcher was able to recognize the signs of fatigue or any emotional distress manage them and refer as appropriate. Should concern have arisen as to a participant's ability to manage at home and potential need for increased services, the researcher would have discussed and directed the patient participants to their primary care provider, walk in clinic or CCAC case manager as applicable. This did not arise. Nor was there any need to break confidentiality to report suspected abuse or neglect.

2.8.4 Potential Benefits

No direct benefits from participating in this research were identified. However, indirect benefits may be future improvements of occupational therapy discharge preparations based on the findings of this study.

CHAPTER 3 – FINDINGS

The objective of this study was to explore patients' experience of occupational therapy provided to aid in discharge preparation following a hospital stay for treatment of an acute medical illness. The analysis demonstrated that the context of the current hospital stay and previous hospitalizations were major factors in how participants experienced discharge planning. Following a brief description of the study participants, a summary of issues related to context in which participants' experience of occupational therapy appeared to be embedded will be described. Finally, participants' experience of occupational therapy, with special attention to the results of discharge preparation and client-centredness will be outlined.

3.1 PARTICIPANTS AND DEMOGRAPHICS

Six individuals participated in this research project. Half of the participants were in their 60's and half were in their 70's. They were three men and three women. All were recruited from one of a dozen medicine units in one of Ottawa's acute care hospitals. The reasons for their admissions included: pneumonia, pulmonary embolism, history of falls, failure to cope due to weakness and non-healing wound. In addition, these individuals had various comorbidities such as diabetes, hypertension, cardiac or pulmonary issues, peripheral neuropathy, iron deficiency, macular degeneration, and a history of cancer and cancer related treatment. Therefore these individuals were all seriously ill and many were frail. Half of the study participants lived alone and the other half lived with a spouse.

Overall, 5 occupational therapists facilitated the occupational therapy discharge preparations for these 6 individuals. None of the participants were seen by multiple

therapists. Interviews were conducted 1-2 weeks post discharge (Table 1). All patient names are pseudonyms chosen by study participants.

Table 1 Participant characteristics

Joe	Man in his late 70's
	Seen by occupational therapist A
	Living with spouse
	Interviewed 15 days post discharge
Pamela	Woman in her late 70's
Joy	Seen by occupational therapist B
	Living alone/widowed
	Interviewed 12 days post discharge
David	Man in his mid-60's
	Seen by occupational therapist C
	Living alone
	Interviewed 8 days post discharge
Ellen	Woman in her late 60's
	Seen by occupational therapist D
	Living with her spouse
	Interviewed 13 days post discharge
Archie	Man in his early 70's
	Seen by occupational therapist E
	Living with his spouse
	Interviewed 8 days post discharge
Mary	Woman in her early 60's
	Seen by occupational therapist D
	Living alone
	Interviewed 7 days post discharge

3.2 OVERALL CONTEXT INFLUENCING OCCUPATIONAL THERAPY DISCHARGE PREPARATION

The experience of occupational therapy discharge preparation is unique to each individual. Hospital discharge preparation is a complex process that usually involves a

team of health care professionals working together with the patient to facilitate and prepare them for their return back home. Although this study aimed at getting a better understanding of the patient's experience of occupational therapy discharge preparation, it became apparent that this experience was marked by the context of the hospital stay and discharge needs. The hospital environment, the patient's experience of the current hospital stay, family concerns, the patient's own concerns and past experience of the health care system all contributed to and shaped the patient's experience of occupational therapy discharge preparation.

3.2.1 The Hospital Environment and Experience of Current Hospital Stay

Most study participants found the discharge process overwhelming and chaotic. Some of these difficulties related to the process of discharge itself and uncertainty related to returning to and managing at home. Several participants spoke of poor communication regarding the expected discharge date, and confusion related to who to talk to in order to get clarifications related to medications, course of treatment, and management of symptoms or issues once home. Several participants were unclear as to the roles of the various health care professionals in the discharge process, and this led to confusion relating to whom to address questions. As well, concerns were voiced by half of the participants relating to whether communication actually occurred between the various health care professionals, especially if teams or services from other units (e.g., Supportive and Palliative Care Team, Surgery) were involved. Participants reported receiving conflicting information which added to their worries. Most study participants found that the high number of health care professionals involved in their care made it challenging to

remember the role of each one and to know where they should direct questions. Ellen commented that the hospital environment consisted of a 'flurry of activity'.

In addition, several study participants reported difficult or unpleasant experiences around the time of discharge. These included issues with roommates or staff, restrictions placed on their ability to leave their rooms due to infection control precautions, room and unit changes, and difficulties sleeping due to the noisy hospital environment.

Consequently, most study participants had experienced some level of emotional discomfort at the time the occupational therapy discharge preparation took place.

Ellen, as well as Archie, reported several room changes in addition to a transfer to a different unit. They found these changes unsettling. The change of unit was particularly confusing as it led in most cases to getting acquainted with new physical surroundings and a new team of nurses, and other health professionals. This is how Ellen recalled these changes:

(...) people were running around like crazy, didn't know what to do, where to put me, they changed me into three different rooms in a matter of maybe three hours. I was out in the hall and they kept moving me to different rooms all over the hospital. And then they kept telling me he's not your doctor anymore, he is, or he's not your doctor anymore, he is; you're going to be working with her now. So like by the time it was over, I didn't have a clue.

For Joe, it was three successive roommates who created an unpleasant environment. He recalled having "the room from hell". He described his first roommate as emotionally unstable, which led to a transfer to the mental health unit. His next

roommate was very noisy with constant visitors and finally his last roommate passed away. His roommate's death created a situation where he unintentionally overheard his roommate die, the pronouncement of the death and other hospital procedures that occur at a death.

Two other participants described unpleasant experiences due to being on "contact precautions" because of an infection. Hospital protocol in such cases requires patients to remain in their rooms except for tests or medical procedures. Both participants felt isolated because of this restriction. In addition, they found the sign indicating the precaution status outside their room to be upsetting as well as confusing. In one case the patient felt it was unnecessary and in the other case the individual felt it was not explained properly to him and his spouse.

As highlighted previously, half of the participants questioned the communication between the various health care professionals on their unit and the diverse team or other services included in their care. In most cases, these experiences strengthened their desire to return home as soon as possible despite their worries concerning home management of their illness. They sought a more peaceful and predictable environment.

For half the individuals interviewed the uncertainty related to the discharge process stemmed in part from poor communication of the targeted discharge date. These participants reported having very little advance notice with regards to discharge date or felt frustrated that the date had been postponed, in some instances several times, without their input. In addition, two study participants reported not feeling ready for discharge. David, for example, felt his circumstances were not taken into consideration when

establishing the target discharge date. He reported having no shoes and no means of transportation around the time of discharge due to very limited social support. He felt these circumstances had no bearing on how the initial discharge date was determined despite his attempts at voicing these concerns to his doctors and other team members. Archie, who was hospitalised for several weeks, described feeling "on standby" as he did not know what the anticipated course of his recovery was. He recalled feeling discouraged during his lengthy hospitalization as the doctors and nurses did not speak to him about discharge for a long time. He stated "they couldn't say anything positive" about his condition, prognosis or functional potential which led him to doubt his ability to return home.

3.2.2 Patient's Own Concerns Regarding Discharge

For all participants their primary goal was to return home. When asked about their concerns regarding managing at home, four participants reported having none. For others, the question of whether they would be alright at home hung in the air; it was either a question they were asking or their family members were asking. During the home interview Joe described having no concerns. Looking back, he described himself as "insanely confident" at the time of occupational therapy discharge preparation. He reported falling in his wife's bathroom a few days after discharge, which he interpreted as a sign of being overly confident in his abilities. David on the other hand, felt he could return home where he lives alone but believed that "I can't do it the way I used to". He reluctantly discussed beginning to think that he may need to reconsider his living arrangements and perhaps move to a residence in the near future. To him this was a very difficult thought as David had witnessed his father's death three months after moving to a

nursing home. David seemed to associate moving to a retirement or nursing home as a form of defeat as it would mean he could no longer take care of himself. He also recalled visiting a 'residence' for himself and feeling "disrespectful" by the individual managing it.

The two other study participants, Mary and Pamela Joy, both living alone prior to their admissions, expressed concerns regarding their safety and ability to resume their daily routines upon discharge. Mary discussed her concerns related to her ability to manage her regular routine after discharge due to "not knowing her boundaries". She felt it was difficult to anticipate and grasp what her new reality would be within her home environment and this created some anxiety. She discussed some of her concerns with her family as evidenced by her reporting that her brother in law went to her home to fix her hand rail leading to the second floor. Pamela Joy perhaps best described the mixed emotions she felt upon thinking about her return home when she reported her main goal was to return home "but in the back of your mind there is the nagging feeling – will I manage?"

As noted above, returning home was very important to everyone interviewed. However for the three participants living alone, there seemed to be additional pressure and concern associated with personal values regarding independence and remaining self-sufficient in order to successfully manage at home. These participants appeared to take great pride in being autonomous and it was essential to them to continue to be so. As Pamela Joy stated, "comes a point when the door closes and you're alone. You need to be able to look after yourself". Mary expressed a similar view: "It's my health, and I live alone. I'm not going to depend on a lot of people." For David, being independent seemed

to be a core value, something he could not compromise. He explained, "I want to do it myself; I refuse help most of the time, I'm a proud Indian. I was taught to try, do things on my own." As his daughter had expressed concerns to health care team members regarding his capacity to live home independently on a past admission, he was acutely sensitive about and reluctant to engage in any discussion about his concerns and home support.

3.2.3 Family Concerns Regarding Discharge

As highlighted previously, four participants reported no concerns regarding their ability to manage after discharge, and returning home was their main goal. All these individuals acknowledged that a family member had expressed concerns at some point. When Joe was asked at the beginning of the interview if he had any concerns relating to returning home he stated "No, I was very much looking forward to it". Joe reported that his wife had expressed concerns relating to his safety in the bathroom prior to discharge, which he seemed to appreciate, although he himself felt confident and well equipped to manage bathing. "My wife keeps reminding me that the tub is a very dangerous place for me (...) so it was on my mind". Later Joe added "My wife was afraid that I would not be able to function at home, was not able to move." As mentioned above, he described himself as "insanely confident" at the time of the occupational therapy discharge preparation.

David reported that on a previous admission, at a different hospital a few months prior to the current admission, his daughter had expressed concerns to the care team relating to his safety living alone in his small apartment. He disagreed with his daughter's

assessment of the situation and appeared concerned that her opinion could impact on the current discharge plan.

During the interview, Ellen emphasized her desire to be discharged home quickly and mentioned expressing this to her care team and spouse. She and her husband had different perspectives as she stated that he expressed concerns relating to her breathing status and felt that she was too unwell to be discharged. "I was the one pushing to leave; they [husband and health care team] wanted me to stay".

Archie reported no concerns, admitting it was difficult to anticipate his future needs; "cause a lot of things we didn't even know what to expect." He focussed on returning home at all costs. However he stated his wife was preoccupied with their ability to cope as a couple with daily routine activities given his health status at the time.

3.2.4 Past Health Care Experiences

Though it was not an intended focus of the research or the interviews, five of the six participants spontaneously mentioned previous health care experiences during their interviews, either as a patient or as a health care worker. These experiences also appeared to have mediated their experiences of the current occupational therapy discharge preparation process in important ways. Two participants, Ellen and David, had experienced negative hospital discharges in the past; they appeared to have low expectations and expressed distrust in the health care system as well as the discharge process. During a past hospital stay (in a different facility) Ellen had experienced difficulties dealing with the team. She spoke of an unpleasant meeting with an intern who she felt was unaware of her situation and unreceptive to what her husband had to say.

This led to her seeking the removal of the intern from her care team. She described the previous hospital stay as generally unpleasant and reported that discharge was difficult and upsetting in part due to the quickness of it, adding "I would rather die than go back there." As a result of this experience, she appeared quite distrustful of the health care system and expressed hopelessness and helplessness relating to whether she would receive effective care during the most recent hospital stay and whether the discharge process would be smooth or helpful to her at the start of our interview. It was evident that her perception was that her medical team would not seek her input and include her in the decision making process.

David's situation was different. As mentioned previously, during a previous admission his daughter had expressed concerns to the care team relating to his safety and ability to manage living alone in his small apartment. At the time, this led to a discussion among David, his daughter and the care team about the possibility of moving to a nursing home or seniors' residence. From David's perspective, this was an unacceptable option based on the deep value he placed on his independence, his perception of his father's stay at such a facility and his negative experience with the residence manager upon visiting one during a previous hospitalization. He was discharged home from the previous facility shortly after his refusal to move to this residence. He felt that this discharge was rushed because of his refusal to consider moving from his apartment. This experience appeared to have left him apprehensive and guarded regarding the hospital discharge process.

During his most recent admission David appeared to try to present himself as a 'good patient', accepting the team's recommendations for post discharge services despite feeling these services were unnecessary to ensure his return home: "I sort of waved the

white flag - you know and said go ahead, you know. Yeah, if you say I need them, okay, right, okay." The symbol of the white flag, signalling surrender suggests he felt powerless and had no voice in the decision making during the discharge preparation process.

Pamela Joy on the other hand, had previous hospital stays that were very positive. She had had past encounters with occupational therapists and found occupational therapy very helpful in supporting her return home as illustrated by this quote: "I've had a fair amount of occupational therapy over the last couple of years and I have come to really appreciate what they can do for you." Thus she was quite happy to meet with an occupational therapist again and was receptive to the various suggestions. Her earlier positive experiences predisposed her to engage enthusiastically in the current occupational therapy discharge process, believing that occupational therapy could contribute to an easier return home.

For Mary, it was not a past patient experience that influenced her hopeful anticipation of the occupational therapy discharge process, but rather her work related experience. Her work had provided her with some knowledge of adaptive equipment and its potential benefits: "I do have the advantage because of the work that I do, I deal with occupational therapists. I know a bit what is available and that it's [equipment recommendations] based on the person's injury, if they live alone (...)." This led her to be positively disposed towards considering equipment, assistive devices and community support that could be of assistance to her. In turn, her experience of discharge planning with the occupational therapist was perceived as valuable and a collaborative process.

Some study participants perceived the role of the health care professionals as facilitators, supporting them through the process of regaining health and returning home. In contrast, other study participants seemed to see the health care professionals and health care system as a potential barrier to their return home. For example, David and Ellen's negative past health care experiences led them to hold negative beliefs and views towards the health care system, which created an atmosphere of apprehension, mistrust and doubt. Ellen commented about her difficult discharge preparation and what she perceived as a lack of team communication:

I'm saying that I don't think it'll ever change, because it's far too big an animal for everybody to be on the same page, you know. It's like one minute they tell you one thing and then somebody else comes in and says something totally different, and when you question it, it's like they don't know. That's what I was told, 'I haven't a clue'.

The participants' recollections of their experience with occupational therapy discharge preparation brought to light that the occupational therapy discharge preparation was embedded within a broader discharge process involving the patient, family and multiple health care providers. For some, such as David, this led to a fearful and guarded approach to all team members, including the occupational therapist. For others, there was a marked difference between how they experienced the overall discharge process and the occupational therapy discharge preparation. This was particularly evident with Ellen, who after describing at length how the health care system had failed her several times, reported being pleased that the occupational therapist demonstrated and offered to let her

try equipment that might be beneficial to her upon her return home, during the last few minutes of the home interview with the student researcher.

As well, the findings highlighted above suggest that the occupational therapy discharge interventions occurred in a much broader context than the current admission for these study participants. Knowledge of the health care system as well as past health care experiences appear to have led study participants to generalise and translate this information into beliefs and expectations. Participants also drew attention to the impact personal values (such as autonomy, being a 'proud Indian') played in the discharge preparation process. This may be best illustrated by David's reluctance to accept community services stating: "I was taught to try, to do things on my own". Hence the interactions and relationship between these various elements provided a unique context for the occupational therapy discharge preparation for each participant.

3.3 EXPERIENCE OF OCCUPATIONAL THERAPY DISCHARGE PREPARATION AND CONTRIBUTIONS

3.3.1 Recollection of Occupational Therapy Service

Half of the participants had a clear recollection of the occupational therapy discharge preparation. Mary, Pamela Joy and Archie talked at length about the occupational therapy contribution to their discharge preparation and they generally spoke in positive terms about their experience. In contrast, other participants recalled little of the occupational therapy discharge process. For example, Joe remembered reviewing and trying equipment but had little recollection of other aspects of the occupational therapy discharge preparation for which he blamed his poor memory. Toward the end of the

interview, when discussing his general experience of the occupational therapy discharge preparation process, he commented that "the occupational therapist was okay 'cause I wanted to see her again, so obviously she did a good job." In addition, as discussed previously, he reported having no concerns upon discharge and being "insanely confident" which may have led him to be less attentive during the process, feeling that the information given was not pertinent to him.

At the beginning of the interview, Ellen also had poor recollection of the occupational therapy discharge preparation. However after sharing her story about her confusing and problematic discharges (most recent and past hospitalization) she was able to discuss briefly how she reviewed equipment with the occupational therapist. Prior to reflecting on her experience with occupational therapy, she seemed to need someone to hear the story of her journey through the health care system. The experience of this longer journey appears to have overshadowed other aspects of her last hospital stay. Finally, David had little recollection of his occupational therapist and his work with her. He reported, "I don't know what she did. (...) all she did was talk to me and then that was it." David was concerned that he may not be returning home after discharge, and the fear of possibly not returning home may have led him to not engage in the occupational therapy discharge process, resulting in poor recollection of it. Thus, for at least two participants, contextual issues (related to previous and current hospitalizations) seemed to overshadow the details of their interactions with the occupational therapist.

3.3.2 Occupational Therapy Facilitation of Discharge Home

For most participants, and within the contexts of the current and previous health care experiences, occupational therapy discharge preparation did seem to facilitate

discharge home through demystifying the discharge process, educating patients on the possible functional impact of their current health status, providing opportunities to try equipment and sharing information related to community resources. Together, all of these activities assisted participants in seeing possibilities and options for managing at home post discharge.

3.3.2.1 Information provision, education and review of equipment

Five of the six participants felt the occupational therapist responded to their information needs and provided education relating to equipment, services, ways to manage once home and the discharge process itself. Mary discussed how the occupational therapist assisted in the identification of possible concerns related to managing at home. She felt occupational therapy helped her anticipate possible needs, while providing the opportunity to problem solve by trying equipment that might be useful within her home environment. She greatly appreciated the information booklets offered to her as she found them to be a valuable source of information at the time of admission and once home. She was provided with several occupational therapy booklets but mentioned that the booklets on energy conservation techniques and safety in the bathroom were especially useful. She appreciated being able to re-read these booklets upon her return home. The information allowed her to problem solve as she identified concerns while attempting to resume her daily tasks and routines. She pointed out that she initially fatigued quite easily as she resumed engaging in her daily activities so she referred to the booklet on energy conservation provided by her occupational therapist: "It's a fair size kitchen but in one booklet it tells you to sit down if you are cutting vegetables. So I did that the first couple of days and thought 'ya, it does make sense'." She later added that "There was something

in each one [occupational therapy educational booklets] that I would have never thought of." She felt the occupational therapist "went further" than responding to her immediate needs, assisting with identifying scenarios that could be problematic based on her living environment and routine. For example, she was appreciative that her occupational therapist took the time to review how to safely transfer from her couch upon finding out that she liked to rest there during daytime, and that the therapist explored community access with her given she did not drive and had poor walking endurance.

Pamela Joy, whose hand function was limited due to her illness, was appreciative of the assistive aids and hand exercise program her occupational therapist provided.

These gave her confidence that she could resume her self-care activities and be self-sufficient again. She found that occupational therapy input was instrumental to her successful return home:

(...) on the whole, I don't know what patients would do without occupational therapy. Because so many of us are, especially nowadays with the population aging, we're so set in our ways that we don't think of things that are new and different. And by providing us with that information and giving us tips as to what we can and can't do, it's very helpful.

Joe noted that the equipment trial and verbal instructions were helpful in ensuring that equipment would adequately meet his needs at home. He reported that he had considered additional equipment for his home setting: "I knew I would need this someday or maybe right away." Having the opportunity to try the equipment at the hospital offered him the benefit of experiencing the positive aspects of using these items which confirmed

in his mind that it was the right time to start using this equipment at home. Even though Ellen only talked about occupational therapy at the very end of the interview, she also reported that she felt the equipment trial was useful and stated she was pleased she was provided with this opportunity. Finally, Archie echoed other participants stating the occupational therapist helped guide him through the discharge process, informing him as to what to expect; the occupational therapist also helped him try equipment and practice skills, such as wheelchair transfers, that would help him manage at home. He stated that he and his wife were unclear about the discharge process in general, and they were not aware of the possible equipment and resources that could benefit him home. Therefore, he reported being very grateful for the occupational therapist's guidance and recommendations as highlighted by this statement: "She really helped us a lot 'cause we didn't know very much, but then she came in and was willing to help us. So I was very, very pleased at anything which she could do."

Four of the six study participants found the equipment recommendations particularly useful and had implemented them all or in part. Joe and Pamela Joy reported daily use of the equipment recommended to them, finding it helped them safely engage in their daily routines. Mary said she had considered the recommendations made to her by the occupational therapist and that she had applied some as suggested, adapted others to meet her specific needs within her home context, and decided against adopting others. She stated that upon her return home, she applied several of the energy conservation principles and made small changes to the layout of her dining room/kitchen area to make it easier to access. She reported having discontinued the use of the walker inside her home as she spent most of her time in a smaller area of her house, felt stronger and had a

small portable oxygen tank which she could carry without the use of the walker. She was pleased she was able to make her own decisions based on the information provided to her while in hospital. She mentioned that the discussion about equipment was a collaborative process and she reported that she felt no pressure from the occupational therapist to obtain specific equipment. She commented about the information presented to her: "(...) I didn't feel, what is the word I am looking for, undermined. (...) now it's [the information] in a file to go back to it (...)" Archie also made some changes to one recommendation based on his home environment; he changed the setting of the commode chair (over the toilet *versus* stationary) to better suit his needs.

The remaining two participants were Ellen and David. Ellen appreciated the equipment trial and recommendation, but she had hired private help and felt she would not use the equipment so she did not order it. Finally as discussed earlier, David did not find the equipment and support recommended useful as he felt he could manage his daily routine without any change to his environment; he seemed to perceive that using adaptive equipment would be a concession that he was no longer as capable of independence, potentially leading to further loss of autonomy. However, he agreed with equipment recommendations while in hospital in hopes that this would convince providers not to try to talk him into residential care.

3.3.2.2 Link to community resources

Half of the participants were appreciative of the occupational therapist's contribution to organizing community support after discharge. Archie and Pamela Joy found referrals to the Community Care Access Center (CCAC) as well as the Going Home Program very useful in easing return home, allowing them to reengage in their

daily routines or establish new ones. They found comfort in knowing there would be some help and follow up from health care professionals after their discharge home. CCAC is a provincially-funded community service coordinating agency, organizing services within the home for eligible patients. Based on patients' needs, health care professionals such as nurses, physiotherapists, occupational therapists, and personal care attendants may provide home services. As well, individuals are assigned a community case manager who can assist with re-evaluating services should need change. The Going Home Program is another provincial program to assist seniors returning home following hospitalization. For a period of 10 days post hospitalization and based on their needs, individuals can access a variety of services such as meals on wheels, assistance with light housekeeping, personal care support, and transportation home. Both CCAC and the Going Home Program are publically funded. Pamela Joy felt these services increased her confidence upon returning home where she lives alone.

3.3.2.3 Occupational therapy discharge preparation as a source of renewed hope

As highlighted previously, the equipment trial was a significant part of the occupational therapy discharge preparation for most study participants and was viewed very positively. Several participants expressed that the equipment represented much more than simply allowing them to complete a task safely. For many, it contributed to increased confidence and hope that returning home was feasible. It also represented maintaining valued independence, autonomy and re-engagement in meaningful activities. Archie was most grateful for the introduction of a wheelchair. His hospitalization was long and he had been confined to his room for a period of time in part due to an infection control procedures. Afterwards, weakness and difficulty walking due to a leg wound

further restricted his mobility. The wheelchair afforded him freedom and new hope. For him, being provided with a wheelchair meant that he was getting better, and could eventually move around himself and possibly return home. When asked to comment on the importance of trying the wheelchair he stated "without it [the wheelchair], I'm screwed".

Mary found that seeing and trying different pieces of equipment was very reassuring as it allowed her to consider what would work within her home environment and identify options available to her. This new knowledge and experience contributed to an increased sense of confidence. She stated "(...) the way it was presented to me: you may need this, or you may like that. So that was very good that way, to me that spoke volume because you need to be sensitive to people's needs. It gave me confidence." Pamela Joy had a similar experience. She reported that the equipment provided her with the feeling that she "could cope when home"; the education related to various assistive devices provided by the occupational therapist gave her confidence that resuming her routine and remaining self-sufficient was possible. Archie and Pamela Joy added that the occupational therapists' attitude and vision also contributed to their increased sense of confidence. Pamela Joy commented that the occupational therapist demonstrated a 'can do attitude' which she felt was contagious and led her to increased self-confidence. In other words, because the therapist seemed convinced she could succeed at home after discharge, Pamela Joy also began to believe this. For Archie the occupational therapy discharge preparation was a turning point during his hospitalization; he recalled being discouraged, hopeless and consequently isolating himself prior to occupational therapy

intervention. He found that the occupational therapist "brought new hope" through her work with him and "she never gave up on me" which was encouraging to him.

When Mary was asked about the value of the information and options presented to her by her occupational therapist during the discharge preparation, she stated: "For me it was fantastic. If I had to put a value on that it would be 10/10". Several times during the interview, Archie expressed deep gratitude to the occupational therapist for providing him with a wheelchair, which he felt was a crucial contributor to his renewed sense of hope. He also perceived the occupational therapist as being a constant presence guiding him and his spouse though the discharge process. When asked if occupational therapy discharge preparation was helpful he spontaneously replied: "Fantastic. (pause) I'll give her 120%!"

3.4 CLIENT-CENTREDNESS

A further goal of this study was to explore whether patients experienced occupational therapy services in acute care as client-centred despite the limitations on time and services. As previously discussed in Chapter 1, client-centred approaches guide occupational therapy assessment and intervention. Occupational therapists believe in and attempt to provide client-centred interventions. An occupational therapist practicing using a client-centred approach would demonstrate respect for this individual, involve him or her in decision making, collaboratively identify goals to be addressed, advocate with and for the person's needs, in addition to recognizing his or her experience and knowledge. However, given the limited time available to work with acute care patients prior to discharge – sometimes an hour or two the day before discharge - it is not clear whether occupational therapists in this setting have the resources and time required to provide

client-centred interventions. The patients' experience of the occupational therapists' approach and ways in which the occupational therapist facilitated discharge form the study participants' perspective will be reviewed below in order to establish if a client-centred approach was indeed used.

3.4.1 Respectful Approach

Most patients described their occupational therapist as pleasant, nice, kind, accommodating, reliable and professional. Pamela Joy particularly appreciated that the occupational therapist and the physiotherapist came together on the first visit, which avoided having to repeat information. She found this gesture very considerate. Archie expressed his gratitude several times during the interview and spoke in very positive terms. He described his occupational therapist as a "nice person" adding that she was cooperative, helpful and easy to talk to. He felt she explained her interventions and the use of equipment very well.

Mary reported feeling that the therapist understood her predicament and living environment and was therefore able to respond to her various needs: "I got what I asked and even more". She also added that the therapist promptly followed through on the established plan and provided her with the printed information she requested. Pamela Joy also commented that her specific needs were well addressed during the discharge preparation. Pamela Joy and Archie were appreciative that the occupational therapist took the time to "check in" to ensure their needs were met prior to discharge. This was particularly significant to Archie who added that his occupational therapist "never gave up on me"; he experienced her as constant source of support to him and his wife and very reliable.

3.4.2 Collaborative Decision Making and Goal Identification

Five participants reported feeling the occupational therapy discharge preparation was a collaborative process. They described feeling listened to, respected and comfortable discussing their situation with their occupational therapists. They felt it was a dialogue, as the therapist sought information relating to their home environment, talked about their daily routine and inquired about their concerns related to returning home in order to establish occupational therapy goals. Ellen and Mary found the various suggestions useful in assisting them to reflect on and prepare for their return home, and Ellen described her therapist as "attentive". They felt included in the discussion and did not feel equipment was being imposed on them, which they appreciated.

Several participants characterized the approach used by the occupational therapist as flexible, open and collaborative. Most study participants reported they felt listened to and that their specific home environments as well as life situation were taken into account when discussing discharge with the occupational therapists. As discussed earlier, Mary was appreciative that her occupational therapist took the time educate her on ways to facilitate resuming her daily activities and explored community access. She felt valued as an individual as the therapist sought to meet her unique needs. She commented: "the occupational therapist understood exactly what I needed." This seemed to encourage her to remain engaged in the discharge process. These individualized interventions assisted her in gaining confidence in the occupational discharge preparation and her ability to cope after her return home as her specific needs were explored.

Several patients also described a sense of encouragement and hope brought through working on discharge preparation with their occupational therapist. The

personalised feedback patients received regarding the discharge process, equipment, community services available in addition to working towards optimizing their independence based on their life situation and home environment all contributed to a more positive outlook concerning returning home. All these elements suggest that the occupational therapy interventions were perceived by patients as client-centred which fits with occupational therapy professional values, and probably the intent of individual therapists, despite the broader context discharge which was perceived by many study participants as lacking client-centredness.

David's general experience of discharge appeared to be different. He could barely recall the occupational therapist. He emphasized the importance of independence. He was aware that his current care team knew of his daughter's concerns regarding his safety should he return home and that the possibility of living in a retirement home might come up. Moving to such a facility remained an unacceptable option to David in part based on his father's experience. Consequently, it appears he perceived the team as a potential threat to his return home and felt vulnerable and unsafe. This suggests the inherent power imbalance between patient and health care providers can hinder therapeutic relationships regardless of the approach taken by the current occupational therapist.

In the context of this study, positive experiences of feeling supported were described by those participants who seemed to have developed a sense of partnership with their occupational therapist and/or care team. For some participants such as Joe, Mary, Archie and Pamela Joy, it appears they perceived the occupational discharge preparation as facilitating the process of returning home although Archie, Pamela Joy – and to some extend Mary – expressed some difficulties with the overall hospital

discharge process. As mentioned previously, from a global discharge process perspective, most study participants felt they were insufficiently included in the discharge discussions thus demonstrating a lack of client-centredness. In contrast, the findings suggest that specifically concerning occupational therapy discharge preparation, the patients felt that the occupational therapist sought their input thus demonstrating greater client-centredness.

3.5 Limitations of occupational therapy interventions and the health care system

Many participants highlighted that they would have liked to spend more time with the occupational therapist but recognised that there were limitations to occupational therapy resources and time. All study participants except David reported finding the occupational therapy discharge preparation useful in some way. Many appeared to have low expectations of the health care system and spontaneously offered reasons or excuses for the gaps in services they perceived while hospitalized.

Three study participants commented that the occupational therapist did as much as possible given the current limitations and pressure on the health care system. For example, Joe reported feeling there was "unfinished business" related to the occupational therapy discharge preparation but could not recall what he felt was left pending. He added that a number of health care professionals were involved in his care and he did not feel more could have been done to facilitate his discharge. He shared his thoughts about the "conflicting role" of the emergency department; the fact that they should listen carefully to individuals to ensure proper care is available, but their ultimate goal is "to get you out of there quickly." Pamela Joy expressed some disappointment related to the fact that the

occupational therapist did not come back to see her despite mentioning that there might be other assistive devices that could be useful. Nonetheless, Pamela Joy was very appreciative of the time spent with her occupational therapist and felt it was not a concern that the therapist didn't come back: "Would have been nice to see her but it's a big hospital and one needs to make allowance". She later added, "We had very little time together and I'm mindful of the fact that (...) it's a large hospital and she [the occupational therapist] does what she can." She felt that despite the limited amount of time with the occupational therapist, she was provided with all the information and equipment required to meet her needs: "she covered my specific needs; maybe they need more occupational therapists". Mary also recalled the occupational therapist as being occasionally rushed but felt that as she regularly went for tests and thus was unavailable herself at times, it was not solely the therapist's fault; both therapist and patient had to be flexible and understanding.

A couple of times she [the occupational therapist] was rushed but that's the job. She'd apologize "I'm so sorry" but I'd say "don't worry, it's not like I'm going anywhere..." And then there were also a couple of time where she would come in and I'd be pulled away for a test so you know... That's the nature of the hospital.

These study participants were very gracious and worked at seeing their occupational therapist as helpful well-intended individuals. They attributed any shortcomings in their occupational therapy discharge preparation to an over-stretched health care system. Their perceptions appeared to be that the occupational therapists were caring professionals doing their best given limited resources.

CHAPTER 4 – DISCUSSION

This qualitative study aimed at gaining insight into patients' experiences of occupational therapy carried out with the goal of preparing people hospitalized in an acute care setting for discharge home, with specific emphasis on perceived contributions of this intervention and whether care was perceived as client-centred. This section will discuss these issues as well as the influence of the broader context on occupational therapy discharge preparation in light of previous literature. Then, study limitation and strengths will be addressed. Finally, relevance of the findings to occupational therapy practice and implications for future research will be proposed.

4.1 OVERALL DISCHARGE CONTEXT INFLUENCING OCCUPATIONAL THERAPY DISCHARGE PREPARATION

The literature describes patients' experiences of preparing to return home from an acute care hospital as a time of uncertainty and worry (Cornwell et al., 2012; Foust et al., 2012; Yeung et al., 2011; Ellis-Hill et al., 2009; Olofsson et al., 2005; Grimmer et al., 2004: LeClerc et al., 2002; Bull, 1992). The findings of this study are consistent with this description. Most study participants expressed concerns and uncertainties surrounding the current hospitalization, the discharge process itself or their ability to cope with their daily activities upon return home. Four of the six study participants reported unpleasant experiences during their hospital stays related to one or several of the following circumstances: difficult roommate situations, multiple room changes, being confined to their rooms due to infection control procedures, poor communication between team members or the busyness of the hospital setting which was not conducive to rest and healing.

Although it was not an intended aim of the research, most study participants spontaneously discussed past health care experiences during their interview. This brought to light that the current occupational therapy discharge preparation was only one of the many experiences related to the broader discharge process for these individuals. This demonstrates that the occupational therapy discharge preparation is not solely occurring in 'the moment' of the occupational therapist meeting with the patient during the current hospitalization but rather in a much broader and more personal context. Participants' personal experiences and understanding of the health care system appeared to have led each of them to generalise and translate this personal knowledge into beliefs and expectations regarding the health care system which affected the discharge process. The possible impact of past health care experiences was also discussed briefly in Huckstadt's (2002) study of older patients' perceptions of the hospitalization process. She completed unstructured interviews with 8 patients of a large metropolitan hospital admitted to a general medical or surgical unit. One of the categories that emerged from the data analysis is titled "memories" and describes how patients involved in her study compared past health care experiences (the patient's own previous illness and hospitalization or those of a loved one) with the current one. She reported that it appeared that these past experiences influenced significantly the participants' perception of their current hospitalization. This is similar to Cheah and Presnell (2011) findings in their research on how occupations are affected in older adults following an acute hospitalization. They reported that study participants who had past experiences of hospitalization often used the knowledge and insight gained from this lived experience to instruct their current hospital experience. Based on comments made by participants, they suggested that this past

knowledge of the health care system served as a benchmark, a point of reference from which patients could compare and interpret their current situation.

Figure 1 Elements affecting patients' experiences of occupational therapy discharge

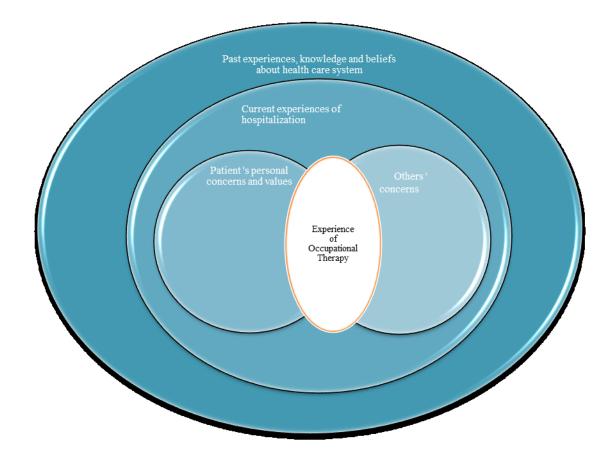


Figure 1 provides a graphic representation of all the interacting elements that seem to affect the experience of the occupational therapy discharge preparation. The experience of the occupational therapy discharge process stems from the interactions between the patient's concerns as well as pre-existing values related to discharge and others' concerns (such as caregivers or family members) which takes place in the context of current experience of hospitalization. In addition, this process occurs in an overarching context which includes knowledge and beliefs held by patients concerning the health care

system and past health care experiences. Hence the interactions and relationships among these various elements provide a unique context for the occupational therapy discharge preparation.

David's experience will be used to illustrate the interactions of the various elements and their impact on his experience of the discharge process. In David's case, his past experience of both the health care system and discharge preparation led him to be apprehensive and mistrustful; he seemed to believe that health care professionals could prevent him from returning home as he wished. Based on his observations of his father's experience he also had a negative view of supported living environments. Additionally, his experience of the current hospitalization perpetuated his negative perceptions as he reported not feeling included in the discharge discussion and found the hospital environment very busy. His concerns and his daughter's concerns were very distinct with very little overlap. Through the interview, it became apparent that personal values such as autonomy played an important role in his discharge preparation process as illustrated by his reluctance to accept community services: "I was taught to try, to do things on my own." The process was also clearly shaped by his fear of moving to a retirement or nursing home: "I don't want to end up - like being placed in a nursing home or whatever and thrown away, 'cause I've seen what happens when you end in a nursing home." All these elements may account for his taking on a 'good patient' role; he seemed to choose to go "with the flow" and surrender to the team's recommendations for equipment and home support so as to not draw too much attention to himself. Given his fear of the health care team recommending his moving to a supported living environment (such as a retirement home) David may have remained too apprehensive to actively engage in the

occupational therapy discharge preparation process, regardless of whether his occupational therapist used a client-centred approach or not.

In comparison, Archie had a somewhat different overall experience. He had limited past health care experiences but his current admission was equally unpleasant due in part to a lengthy admission and being restricted to his room due to infection control procedures. He also highlighted poor communication from his team and felt discouraged as his health care team 'could not say anything positive' and did not address discharge for several weeks. His wife expressed concerns relating to his discharge and he desperately wanted to return home but began being doubtful this would be possible. He described the occupational therapy discharge preparation as a 'turning point' in his hospitalization which instilled hope, as he could see possibilities and the potential for regaining some autonomy. He developed a partnership with his occupational therapist and engaged fully in the occupational discharge preparation. He expressed gratefulness toward the occupational therapist who worked with him on discharge preparation and he spoke of his experience of occupational therapy discharge preparation in positive terms. For both men, personal values that highly treasured autonomy were central; but for one the discharge preparation process carried threat to that autonomy, which for the other the process promised restored autonomy.

Thus from an occupational therapy clinical perspective the findings from this research provide valuable information as it brings to light the importance of appreciating the patient's values, journey and past experiences when engaging the patient and addressing discharge preparation in a client-centred manner.

4.2 EXPERIENCE OF OCCUPATIONAL THERAPY DISCHARGE PREPARATIONS AND CONTRIBUTIONS

For most study participants, occupational therapy discharge preparation seemed to facilitate return home through demystifying the discharge process, educating patients and caregivers on the possible functional impact of their current health status, providing opportunities to try equipment, and sharing information related to community resources.

Together, all of these activities supported participants in seeing possibilities and options for managing at home post-discharge.

4.2.1 Information Provision, Education and Review of Equipment

Patients' concerns related to lack of information regarding the course and management of their condition, lack of preparation concerning the anticipated recovery process (Ellis-Hill et al., 2009; Grimmer et al., 2004) as well as poor knowledge of possible community supports once home (Cornwell et al., 2012; Yeung et al., 2011; Naylor et al., 2005; Olofsson et al., 2005) have been documented previously in the literature. Four study participants in the current study also reported being generally poorly informed, or at the very least inconsistently informed, regarding the course and management of their illnesses by their medical team. They highlighted feeling that there was poor communication between the professionals involved in their care, especially if team or services from other hospital specialities were consulted during their hospitalization. At times, having multiple services involved in their care lead to conflicting information being presented to the patients which added to the confusion.

Driscoll (2000) studied patients' and carers' perceptions of the adequacy and utilization of information provided as part of the discharge planning process, drawing on the experiences and recommendations of 45 patient and family member dyads. Results suggested that providing printed information on the patient's activity level and complications that may arise at home could decrease the incidence of medical problems occurring at home post-discharge, thus decreasing the need for re-admission or other additional medical attention. Of 21 individuals who were provided printed information, 10 patients mentioned still referring to the information 2 weeks post-discharge and overall, 16 found the printed material useful. Provision of information also had emotional benefits for the patient and caregivers as it eased their concerns.

In the current study, several participants were thankful for the written information provided which included educational occupational therapy booklets on energy conservation and safety in the bathroom. Foust and colleagues (2012) in their study looking at the process of being discharged from hospital to home from the perspective of patients, caregivers and health care professionals recommended that printed, clear and specific instructions related to the patient's condition be provided to facilitate return home. In their participatory action research exploring older adult care adjustments following returning home after hospitalization Zakrajesek et al. (2013) noted the need for specific individualized resource material to optimise patient understanding of their recovery and identify ways in which they can take a more active role while positively impacting on the recovery process. These authors stressed the need for clear, specific and

individualized information based on patients' specific situations to facilitate the understanding and application of the information. The findings from the latter study highlights that although there is a need for information, many study participants expressed concerns relating to the amount of educational material provided and their inability to integrate it all.

Occupational therapy pre-discharge interventions occurred in the context of hospitalization in an acute care hospital prior to discharge home. Occupational therapists evaluate patients' occupational performance to gather information that will guide discharge planning (Crennan & MacRae, 2010). In this study, occupational therapy discharge interventions aiming at facilitating discharge home focussed on provision of equipment and assistive devices to facilitate resuming self-care routines, education relating to the impact current health care status could have on the ability to engage in meaningful daily activities, and information and referrals to community support. Similar to Wressle et al.'s (2006) findings, the aim of the occupational therapy discharge preparation in this study was to anticipate and solve practical issues that could arise on return home. Although the findings from this study highlight that indeed, patients' ability to participate in self-care activities was a very important part of the occupational therapy discharge preparation, the occupational therapists involved with the study participants also looked at productivity through focusing on instrumental activities of daily living (IADLs) such as meal preparation and homemaking in addition to community access. Efforts were made to see the individuals more holistically in order to support them in resuming meaningful activities upon their return home. As a

result, most study participants seemed to feel that the occupational therapist answered their functional and informational needs relating to ways to re-engage in their daily routines.

4.2.2 Link to Community Resources

With regards to community services, most participants involved in this study felt the occupational therapist provided valuable information and facilitated referral to community services during the discharge preparation. This was perceived as a very useful component of the occupational therapy discharge preparation. Mary, Pamela Joy and Archie felt that without the community support returning home would have been very challenging or even impossible. This is consistent with other studies (Cornell et al., 2012; Grimmer et al., 2004) which highlighted the importance of educating and linking patients and their caregivers to community support as part of the discharge preparation for successful return home and facilitation of re-engagement in previous occupations while supporting patients to remain in their own homes.

4.2.3 Occupational Therapy Discharge Preparation as a Source of Renewed Hope

The equipment trial was a significant part of the occupational therapy discharge preparation and represented much more than simply allowing patients to complete a task safely. For many, it contributed to increased confidence and hope that returning home was feasible. It also represented maintaining valued independence, autonomy and reengagement in meaningful activities within their home environment. Through their participation in occupational therapy discharge preparation they regained hope.

In summary, for most participants occupational therapy discharge preparation appeared to facilitate returning home through demystifying the discharge process, educating patients on the possible functional impact of their current health status, providing opportunities to try equipment and sharing information related to community resources. Together, all of these activities assisted participants in seeing possibilities and options for managing at home post discharge. Figure 2 summarises the contribution of the various components of the occupational discharge preparation to patient's overall discharge process.

Figure 2 Contributions of the various elements of the occupational therapy discharge preparation patients' experience of the discharge process.

Provision of Education/information

- •Contributed to demystifying the discharge process.
- •Assisted with identification of possible needs in the areas of activities of daily living (ADLS) and instrumental activities of daily living (IADLS) as well as community access.
- Facilitated problem solving around patient's concerns regarding resuming daily activities.
- •Increased confidence regarding ability to resume daily routine or establish new ones.
- Promoted hopefulness that managing home is possible.

Assistive Devices and Equipment Trial

- Facilitated prolem solving around patient's concerns regarding resuming daily activities.
- •Increased autonomy in daily activities.
- •Increased confidence regarding ability to resume daily routine or establish new ones.
- Promoted hopefulness that managing home is possible.

Community Support Referral

- •Eased returning home as help and follow up from health care professionals was available.
- Increased confidence regarding ability to resume daily routine or establish new ones.
- Promoted hopefulness that returning home is possible.

4.3 CLIENT-CENTREDNESS

A secondary question this research project sought to gain insight into was: are patients experiencing occupational therapy services in acute care as client-centred?

Occupational therapists value and intend to provide client-centred interventions.

However, it is unclear if patients experience occupational therapy discharge preparation as client-centred particularly given the reality and demands of the current acute care environment.

In Canada, client-centred approaches guide occupational therapy assessment and intervention. Client-centred practise involves respecting the client's knowledge and experience and involving them in the decision making process (CAOT, 1997). Current research promotes the involvement of patients in the discharge planning process to reduce the likelihood of adverse events (Foss & Hofoss, 2011). Sharing the discharge planning process with patients suggests a balance in power between the therapist and the patient. The current literature has highlighted barriers relating to the implementation of clientcentred approaches in an acute care setting such as short length of stay, scarce resources and use of a paternalistic medical model, thus raising the question whether patients and therapists share the same focus regarding what is important to address during the discharge preparation (Durocher et al., 2015; Foss & Hofoss, 2011; Maitra & Erway, 2006). In the current study, most patients reported not feeling very involved in the general discharge process. However, when discussing occupational therapy discharge preparation, several participants discussed feeling the occupational therapist sought to understand their particular needs and environment therefore allowing patients' and therapists' focus to be more attuned.

Most participants expressed confusion regarding their dates of discharge. They felt the decision with regard to the targeted date of discharge was made with minimal, if any, input from them. This is consistent with previous findings; older patients and their caregivers frequently report minimal involvement in the identification of post-discharge needs and the discharge planning process (Foss & Hofoss, 2011; Bauer et al., 2009; Olofsson et al., 2005; Grimmer et al., 2004).

For many participants, there was a marked difference between how they experienced the overall discharge process and the occupational therapy discharge preparation. Most recalled the overall discharge process as confusing and chaotic, in part due to poor communication from the health care team and the hectic hospital environment. In contrast, most of these individuals described the occupational therapy discharge preparation as a useful collaborative process and reported that their needs had been met. They reported the occupational therapist was respectful and accommodating and sought to understand their unique circumstances and needs in order to facilitate discharge preparation. They recognised however some limitations to the occupational therapy discharge preparation. Joe and Pamela Joy would have liked more occupational therapy services and two other participants mentioned feeling the therapist was rushed at times.

The greater context, including past health care experiences seemed to impact on the occupational therapy discharge preparation and patient engagement. It suggests that ideally a client-centred approach should also take onto account the patient's past journey and beliefs related to the health care system in addition to their experiences of the current

hospitalization. Gaining further insight as to how to best address past health care experiences with patients would likely be beneficial to optimize discharge preparations.

4.4 LIMITATIONS

The design of this study is such that participants shared their recollections of their occupational therapy discharge preparation retrospectively. How patients recalled the intervention immediately following contact with the occupational therapist may have been different from how they recalled it several days later. However, the current design could also be considered a strength as it made it possible to appreciate to which extent the contributions of the occupational therapy discharge preparations had an ongoing impact (i.e., that it was remembered and seen as important even after study participants returned home).

This study provides insight into the experience of a very small number of individuals who met with an occupational therapist for discharge preparation. The participants were recruited from the same metropolitan acute care hospital and they had all been admitted to one of the medicine units. As well, all the study participants were being discharged home. Consequently, the findings may not be transferable to other settings and services and may have excluded other experiences. For example, this study excluded the experience of patients being discharged to retirement homes, long term care or rehabilitation facilities or to hospital or community-based palliative care programs. As well, patients hospitalized in more rural settings may also have a different experience of the discharge process due to variation in resources and support.

All the participants were either in their 60's or 70's thereby excluding the experiences of other age groups. This study was also limited to those communicating in French or English thus excluding experiences of people who communicated primarily in other languages.

As well, due to the quick pace of the acute care setting, in some cases therapists meet with potential study participants less than 24 hours before discharge. These potential participants could not be enrolled in the study because there was not enough time to review the study with these individuals and obtain consent prior to their discharge. These individuals may have a very different experience of occupational therapy discharge preparation that was not captured in this study.

Another limitation relates to the possibility that the occupational therapists may have, consciously or unconsciously, avoided recruiting potential participants who they perceived might not have reported good experiences of occupational therapy. This included potential participants who were 'doing very well' and might not have gained much from occupational therapy. Alternately, potential participants who were reluctant to engage with the occupational therapist or who had difficulty engaging due to frailty, anxiety or severe illness, may also have reported very different experiences than the six study participants.

Finally, it is possible that participants reported their experience of occupational therapy discharge preparation more positively due to the fact that the student researcher is herself an occupational therapist. Although this is a possibility, participants seemed genuinely interested in sharing their experiences, both positive and negative, in order to

improve discharge preparation and planning; thus it is believed that the researcher being an occupational therapist had little impact if any.

4.5 STRENGTHS

This study is one of the few study to explore patients' experiences of occupational therapy discharge preparation. By doing so, it brought to light the contribution of occupational therapy interventions to the discharge process and patients' return home from the perspective of clients. As well, it highlighted how the occupational therapy discharge process is imbedded within the dynamic interactions between the patient's experiences of the current hospitalization, the patient's own concerns, the family's concerns and the patient's pre-existing personal values and health care beliefs and expectations. As discussed earlier, interviewing people at home after discharge was strength as it allowed participants to reflect back on their experience and report what they felt the intervention contributed to their experience of returning home.

Regular discussion with thesis supervisors and committee assisted in strengthening the trustworthiness of findings. The use of qualitative research methodology assisted in providing more depth to the findings. As well, the occupational therapists who facilitated the discharge preparation had a wide range of clinical experiences ranging 5 years' to over 20 years' experience.

4.6 RELEVANCE TO OCCUPATIONAL THERAPY PRACTICE

The findings of this study suggest that discharge from an acute care setting remains a challenging experience filled with uncertainty and worry. Most study participants experienced the occupational therapy discharge preparation as valuable in

assisting them with returning home. Not only did the occupational therapy discharge preparation assist in identifying potential issues in re-engaging in daily activities, but occupational therapists also facilitated the general discharge process by explaining the process, providing information and education, reviewing equipment, linking to community resources and giving patients a renewed sense of hope.

This study highlights that patients continue to report a lack of involvement in the general discharge process and wish for greater collaboration in discharge preparation and decision making. However, based on the patients' experience of occupational therapy discharge preparation discussed previously, this study suggests that occupational therapists working in an acute care setting can implement a client-centred approach when addressing discharge preparation despite the various challenges and barriers. The findings confirm that patients are interested in being more involved in the decision making and discharge process. Patients appreciated being asked about their home environment and their personal life situation to guide the discharge planning. Occupational therapists should continue to favor approaches that facilitate collaboration between the team and the patient as most patients identified being poorly involved in the overall discharge process. They should also continue to take an active role in advocating for their patients, ensuring patient voices are heard during acute care discharge preparations. Enhanced communication and involvement of the patient in the discharge process would likely assist in decreasing the confusion and anxiety related to hospital discharge and thus facilitates a more successful return home for patients and caregivers. Occupational therapists are in a privilege position to facilitate within their team a client-centred collaborative practice to discharge preparation.

This study also highlights that although the occupational therapy discharge experience takes place in the context of the current hospitalization, the broader context — the influence of past and current health care experience, beliefs and expectations regarding the health care system, and patient and family member concerns — also impact patients' engagement in discharge preparations. It brings to light the possible benefits of exploring and appreciating the personal health care journey of each patient prior to engaging in occupational therapy discharge planning.

4.7 RECOMMENDATIONS FOR FUTURE RESEARCH

Further research exploring patients' experience of occupational therapy discharge preparation with a larger sample of patients including people from different age groups, and different socioeconomic, linguistic and cultural backgrounds is recommended to provide greater understanding and insight into patients' experience. It is recommended that patients admitted for treatment of a wider variety of conditions, to both rural and urban hospitals who are being discharged to different kinds of settings be explored to ensure that as many discharge experiences as possible are investigated.

As well, further research evaluating the impact of addressing the broader discharge context with patients at the beginning of the acute care discharge preparation on the experience of acute care occupational therapy is recommended. If this is found to have a positive impact on outcome, research on how to best address the impact of previous health care experience, as well as beliefs and expectations that patients hold for the health care system is suggested as a further step to improve and enlighten occupational therapy discharge preparation.

Finally exploring the patients', therapists' and caregivers' perspectives over time would provide greater understanding of the context in which the discharge preparation takes place and the impact it may have on the experience of discharge preparation.

CHAPTERS 5 – CONCLUSION

This research aimed at gaining insight into patient's experience of occupational therapy discharge preparation following an acute care admission. Findings demonstrate that the discharge process is challenging for most patients and their families. A review of the literature concerning patient experiences and perceptions of discharge home following hospitalization for general medical conditions demonstrated many unmet needs, needs that could be at least somewhat met through client-centred occupational therapy discharge preparation. However, currently there is limited information available on the contribution of occupational therapy to the discharge process.

The study suggests that occupational therapy discharge preparation was perceived as valuable by most participants completing an acute care hospital stay for a medical condition. Not only did occupational therapy discharge preparation assist in identifying potential issues in re-engaging in daily routines; it also facilitated the broader discharge process by educating patients on the possible functional impact of their current health status, providing opportunities to try equipment and sharing information related to community resources. Together, all of these activities supported participants in seeing possibilities and options for managing at home post discharge. The occupational therapy discharge process also assisted in fostering a renewed sense of hope as the participants were provided with options and regained confidence in their ability to remain autonomous. Study participants' comments suggest that they perceived that their occupational therapist acted in a client-centred manner. Participants felt that their therapist sought their input and took into account their personal life situation and home environment. They perceived the discharge preparation process with the occupational

therapist as flexible and cooperative in nature. This suggests that the patient generally found the discharge preparation client-centred despite the broader hospital discharge context which lacked client-centredness.

Although this was not an intended focus of the research, it was noted that past health care experiences influenced participants' experiences of occupational therapy discharge process. The influence of patient's pre-existing personal values, beliefs and expectations of the health care system, often themselves based on past health care experience, on the occupational therapy discharge process was also evident. These findings highlight the complexity of factors that influence patients' perceptions of the occupational therapy discharge preparation process. Further research should be carried out to determine the possible benefits of addressing the broader discharge context during occupational therapy discharge preparation.

BIBLIOGRAPHY

- Acute Care. (2009) Mosby Medical Dictionary. 8th ed. Elsevier. *The free dictionary*. Retrieved 15 September 2013, from http://medical-dictionary.thefreedictionary.com/acute+care
- Appleton, J. V., & King, L. (1997). Constructivism: A naturalistic methodology for nursing inquiry. *Advances in Nursing Science*, 20(2), 13-22.
- Bauer, M., Fitzgerald, L., Haesler, E., Manfrin, M. (2009). Hospital discharge planning for frail older people and their family. are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing*, 18(18), 2539-46. Retrieved from /z-wcorg/ database.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. Retrieved from /z-wcorg/ database.
- Bull, M. J. (1992). Managing the transition from hospital to home. *Qualitative Health Research*, 2(1), 27-41. Retrieved from http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=1992145291&site=ehost-live
- Bull, M. J., & Jervis, L. L. (1997). Strategies used by chronically ill older women and their caregiving daughters in managing posthospital care. *Journal of Advanced Nursing*, 25(3), 541-547. doi:http://dx.doi.org.ezproxy.library.dal.ca/10.1046/j.1365-2648.1997.1997025541.x
- Canadian Association of Occupational Therapists. (1997). Enabling occupation: An occupational therapy perspective. *Ottawa, Ontario*.
- Cheah, S., & Presnell, S. (2011). Older people's experiences of acute hospitalisation: An investigation of how occupations are affected. *Australian Occupational Therapy Journal*, 58(2), 120. doi:10.1111/j.1440-1630.2010.00878.x
- Clark, H., & Dyer, S. (1998). Equipped for going home from hospital. *Health Care in Later Life*, *3*(1), 35-45. Retrieved from http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=1998046916&site=ehost-live
- Coffey, A., & McCarthy, G. (2012). Community supports used by older people post hospital discharge. *British Journal of Community Nursing, 17*(4), 170-176. Retrieved from http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2011553581&site=ehost-live

- Cornwell, P., Dicks, B., Fleming, J., Haines, T. P., & Olson, S. (2012). Care and support needs of patients and carers early post-discharge following treatment for non-malignant brain tumour: Establishing a new reality. *Supportive Care in Cancer*, , 1-16. Retrieved from Embase database.
- Crennan, M., & MacRae, A. (2010). Occupational therapy discharge assessment of elderly patients from acute care hospitals. *Physical & Occupational Therapy in Geriatrics*, 28(1), 33-43.
- Creswell, John W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. Thousand Oaks: Sage Publications.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Med Educ Medical Education*, 40(4), 314-321. Retrieved from /z-wcorg/ database.
- Driscoll, A. (2000). Managing post-discharge care at home: An analysis of patients' and their carers' perceptions of information received during their stay in hospital. *Journal of Advanced Nursing*, 31(5), 1165-1173. doi:jan1372
- Durocher, E., Kinsella, E.A., Ells, C., & Hunt, M. (2015). Contradictions in client-centred discharge planning: through the lens of relational autonomy. *Scandinavian Journal of Occupational Therapy*, 22(4), 293-301. doi:10.3109/11038128.2015.1017531
- Ellis-Hill, C., Robison, J., Wiles, R., McPherson, K., Hyndman, D., & Ashburn, A. (2009). Going home to get on with life: Patients and carers [sic] experiences of being discharged from hospital following a stroke. *Disability & Rehabilitation*, 31(2), 61-72. doi:10.1080/09638280701775289
- Eriksson, M., Asplund, K., & Svedlund, M. (2009). Patients' and their partners' experiences of returning home after hospital discharge following acute myocardial infarction. *European Journal of Cardiovascular Nursing*, 8(4), 267-273. doi:10.1016/j.ejcnurse.2009.03.003
- Foss, C., & Hofoss, D. (2011). Elderly persons' experiences of participation in hospital discharge process. *Patient Education and Counseling Patient Education and Counseling*, 85(1), 68-73. Retrieved from /z-wcorg/ database.
- Foust, J. B., Vuckovic, N., & Henriquez, E. (2012). Hospital to home health care transition: Patient, caregiver, and clinician perspectives. *Western Journal of Nursing Research*, *34*(2), 194-212. doi:10.1177/0193945911400448
- Grimmer, K., Moss, J., & Falco, J. (2004). Experiences of elderly patients regarding independent community living after discharge from hospital: A longitudinal study. *International Journal for Quality in Health Care : Journal of the International Society for Quality in Health Care / ISQua, 16*(6), 465-472. doi:10.1093/intqhc/mzh071

- Holm, S. E., & Mu, K. (2012). Discharge Planning for the Elderly in Acute Care: The Perceptions of Experienced Occupational Therapists. *Physical & Occupational Therapy in Geriatrics*, 30(3), 214-228.
- Huckstadt, A. A. (2002). The experience of hospitalized elderly patients. *Journal of Gerontological Nursing*, 28(9), 25-29.
- Katikireddi, S., & Cloud, G. C. (2009). Planning a patient's discharge from hospital. *BMJ. British medical journal*, 338(7692), 472-476.
- Kielhofner, G. (2006). Research in occupational therapy: Methods of inquiry for enhancing practice. Philadelphia: F.A. Davis.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, 45(3), 214-22.
- Lane, L. (2000). Client-centred practice: Is it compatible with early discharge hospital-at-home policies? *British Journal of Occupational Therapy*, 63, 310-315. Retrieved from /z-wcorg/ database.
- Law, M. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9-23. Retrieved from /z-wcorg/ database.
- LeClerc, C. M., Wells, D. L., Craig, D., & Wilson, J. L. (2002). Falling short of the mark: Tales of life after hospital discharge. *Clinical Nursing Research*, 11(3), 242-263. Retrieved from http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2002131169&site=ehost-live
- Maitra, K. K., & Erway, F. (2006). Perception of client-centred practice in occupational therapists and their clients. *The American journal of occupational therapy*, 60(3), 298-310.
- Mesteig, M., Helbostad, J. L., Sletvold, O., Rosstad, T., & Saltvedt, I. (2010). Unwanted incidents during transition of geriatric patients from hospital to home: A prospective observational study. *BMC Health Services Research*, 10, 1. Retrieved from MEDLINE database.
- Mistiaen, P., Duijnhouwer, E., Wijkel, D., de Bont, M., & Veeger, A. (1997). The problems of elderly people at home one week after discharge from an acute care setting. *Journal of Advanced Nursing*, 25(6), 1233-40. Retrieved from /z-wcorg/database.

- Moats, G., & Doble, S. (2006). Discharge planning with older adults: Toward a negotiated model of decision making. *Canadian Journal of Occupational Therapy*, 73(5), 303-311.
- Naylor, M. D., Stephens, C., Bowles, K. H., & Bixby, M. B. (2005). Cognitively impaired older adults: From hospital to home. *The American Journal of Nursing*, 105(2), 52-61; quiz 61-2.
- Olofsson, A., Andersson, S., & Carlberg, B. (2005). 'If only I manage to get home I'll get better' -- interviews with stroke patients after emergency stay in hospital on their experiences and needs. *Clinical Rehabilitation, 19*(4), 433-440. Retrieved from http://ezproxy.library.dal.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=2009029671&site=ehost-live
- Preyde, M., Macaulay, C., Dingwall, T. (2009). Discharge planning from hospital to home for elderly patients: A meta-analysis. *Journal of Evidence-Based Social Work,* 6(2), 198-216. Retrieved from /z-wcorg/ database.
- Radomski, M.V., Latham, C. A.T. (Eds.). (2008). Occupational therapy for physical dysfunction. Philadelphia: Lippincott Williams & Wilkins.
- Rittman M., Faircloth C., Boylstein C., Gubrium J.F., Williams C., Van Puymbroeck M., & Ellis, C. (2004). The experience of time in the transition from hospital to home following stroke. *Journal of Rehabilitation Research and Development, 41*(3A), 259-68. Retrieved from /z-wcorg/ database.
- Schultz-Krohn, W., & Pendelton, H. (2006). Application of the occupational therapy practice framework to physical dysfunction. *Pedretti's Occupational Therapy for Physical Dysfunction*, 38.
- Shepperd, S., Lannin, N. A., Clemson, L. M., McCluskey, A., Cameron, I. D., & Barras, S. L. (2013). Discharge planning from hospital to home. *The Cochrane Database of Systematic Reviews*, *1*, CD000313. doi:10.1002/14651858.CD000313.pub4 [doi]
- Smith-Gabai, H. (2011). *Occupational therapy in acute care*. Rockville, MD: AOTA Press.
- Thorne, S. E. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.
- Thorne, S., Kirkham, S.R., & MacDonald-Emes J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169-77.
- Thorne, S., Reimer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1). Article

- 1. Retrived [May 23, 2013] from http: //www.ualberta.ca/~iiqm/backissues/3 1/pdf/thorneetal.pdf
- Townsend, E.A., & Polatajko, H.J. (2007). Enabling occupation II: Advancing an occupational therapy vision for health, well-being & justice through occupation. Ottawa: Canadian Association of Occupational Therapists.
- Wales K., Clemson L., Lannin N.A., Cameron I.D., Salked G., Gitlin L., Rubenstein L., Barras S., Mackenzie L., & Davies C. (2012). Occupational therapy discharge planning for older adults: A protocol for a randomised trial and economic evaluation. *BMC Geriatrics*, 12 Retrieved from /z-wcorg/ database.
- Walley Hammell, K. (2002). Informing client-centred practice through qualitative inquiry: Evaluating the quality of qualitative research. *British Journal of Occupational Therapy*, 65(4), 175-184.
- Whalley Hammell, K. R. (2013). Client-centred occupational therapy in Canada: Refocusing on core values. *Canadian Journal of Occupational Therapy.Revue Canadianne d'Ergotherapie*, 80(3), 141-149.
- Wressle, E., Filipsson, V., Andersson, L., Jacobsson, B., Martinsson, K., & Engel, K. (2006). Evaluation of occupational therapy interventions for elderly patients in Swedish acute care: A pilot study. *Scandinavian Journal of Occupational Therapy*, 13(4), 203-210. Retrieved from /z-wcorg/ database.
- Yeung, S., Ming, Y., & Mok, E. (2011). Holistic concerns of Chinese stroke survivors during hospitalization and in transition to home. *Journal of Advanced Nursing*, 67(11), 2394-2405. doi:10.1111/j.1365-2648.2011.05673.x
- Zakrajsek, A,G., Schuster, E., Guenther, D., Lorenz, L. (2013). Exploring older adult care transitions from hospital to home: A participatory action research project. *Physical & Occupational Therapy in Geriatrics*, 31(4), 328-344.

APPENDIX A - SCRIPT PRESENTING STUDY

For use by the occupational therapist working on discharge preparation with the potential patient participant

An occupational therapist working here is doing a research study looking at patients' experience of occupational therapy discharge preparation following hospitalization as part of her Master of Science Degree through the School of Occupational Therapy at Dalhousie University in Halifax.

The purpose of this study is to better understand the patients' experience of occupational therapy discharge preparation before returning home.

This study is an interview with people who have been hospitalized for a medical reason and were seen by an occupational therapist for discharge preparation before returning home. If you chose to participate, the interview will take place in your home or location that you choose. The interview will be audio taped and may take approximately 1 hours. During the interview you will be asked about yourself and about your experience while at the hospital. This is voluntary and separate from the work we are doing together. Your choice to participate or not will have no impact on what will happen here at the hospital.

Could I give your name and room number to the occupational therapy researcher doing this research so that she can tell you more about the study?

Thank you very much,

Martine Trudelle

M. Sc. Candidate

School of Occupational Therapy

Dalhousie University

(613) 737-8899 ext 71460

APPENDIX B – PARTICIPANT INFORMATION and CONSENT FORM









Study Title: Patients' experience of occupational therapy discharge preparation

Principal Investigator: Martine Trudelle, OT Reg. (Ont.)

Masters Candidate, Dalhousie University

Tel: 613-737-8899 ext. 71460

Supervisor: Mary Egan

School of Rehabilitation Sciences

University of Ottawa

451 Smyth Rd.

Ottawa, Ont.K1H 8M5

Tel: 613-562-5800 ext. 8043

And

Brenda Beagan

School of Occupational Therapy

Dalhousie University

Room 205, Forrest Building

Dalhousie University

Halifax, Nova Scotia B3H 3J5

Tel 902-494-8804

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the study team as many questions as you like.

Introduction

You are being asked to participate in this research study because you were recently admitted to The Ottawa Hospital for a medical issue. You must have been seen by an OT before going back home.

Purpose of the study

Martine Trudelle is a graduate student at Dalhousie University and an Occupational Therapist (OT) at The Ottawa Hospital (TOH). This study is part of her Post-Professional Occupational Therapy Master of Science degree. The purpose of the study is to look at how participants, who have been admitted to an acute care hospital, experience preparing to return home and how they see the role of OT as they get ready to go back home (that is, as they prepare for discharge).

Study Designed

We estimate that 6-10 people who were admitted to TOH for a medical health issue will be enrolled in this study. We will interview people after discharge in their homes or in a public place of their choice.

If you agree to participate in this study, you will be asked to take part in one interview, conducted by Martine Trudelle, that will last about 1 hour. It will happen a week or so after you return home from the hospital. The interview can be stopped and continued on a later day if you become tired. The questions you will be asked will be about your experience of getting ready to return home form hospital and how things were once you got home. The session will be audio recorded and later written out. You may request that the recording stop at any time during the interview.

If, during the talk, we have reason to suspect abuse or neglect of a child, we have the legal duty to report it to Children's Aid. If we suspect danger to you, we will ask your permission to report this to the police or a physician. If we suspect abuse or neglect of an adult who is not able to protect themselves, we must report that to the police or a physician

How long will I be involved in the study?

The entire study will last approximately 6 months. Your participation in the study will last approximately 1 day. Over this time, you will be required to meet with the principal investigator once in your home or a public location of your choice.

Possible risks and discomfort

There are no risks to participating in this study. Some of these questions may be personal and could upset you. You may choose not to answer a question and may end the interview at any time. If you become upset, the person talking with you will remain with you or make sure someone you choose is with you until you feel better. In the research report, we may quote your words, but we will not use your name. Details about you or your health may be altered if needed, so that no one can figure out who you are. Your privacy will be protected.

Possible benefits

There are no direct benefits to you from your taking part in this study. However, we may be able to improve how OTs help patients like you get ready to return home in the future.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the medical care or other services to which you are entitled or are presently receiving at this institution.

If you withdraw your consent, the study team will no longer collect your personal health information for research purposes

Will I be paid for my participation or will there be any additional costs to me?

You will not be paid to participate in the study. There will be no added costs to you for participating in this study.

Confidentiality & anonymity

- All information collected during your participation in this study will be identified
 with a unique study number, and will not contain information that identifies you,
 such as your name, address, etc.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents or samples leaving the Ottawa Hospital will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- For audit purposes only, your original study records may be reviewed under the supervision of Martine Trudelle's staff by representatives from:
 - o the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
 - o the Ottawa Hospital Research Institute
- Research records will be kept for 10 years, after this time they will be destroyed.
- The audio version of the interviews will be transferred to a password protected computer in the researcher's home. It will be copied to an encrypted USB stick and given to the transcriber. All recordings will be erased at the end of this study.

Questions

If you have any questions about this study at any time, please contact Martine Trudelle at 613-737-8899 ext. 71460.

If you have any questions about your rights as a research participant, you may contact Catherine Connors, Director of Dalhousie University's Office of Research Ethics for assistance: ethics@dal.ca (902-494-3423) or the Chairperson of the Ottawa Health Science Network Research Ethics Boards at 613-798-5555, extension 16719.









Study Title: Patients' perception of occupational therapy discharge preparation

Consent to Participate in Research

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name Investigator/Delegate's Signature Date

APPENDIX C – PHOTO CONSENT



Clinical Education, Teaching and Documentation		aging for
I hereby give my consent to have photographs, vide of myself (or name of patient)	eotaped images or other in	nages made
I understand and agree that these images may be use more of the following purposes, provided that reason anonymity. Check applicable purpose(s): O Documentation of patient care or document Teaching of hospital staff Medical education and/or Purpose of clinical research	onable steps are taken to e	
I understand and agree that The Ottawa Hospital w photographs, videotapes, digital or other images. I understand and agree that these images will be sto	1 0	
I understand and agree that any image that identify outside the Hospital only upon written authorizatio maker. I understand that I may withdraw my conse	n from me or my substitut	
Patient or substitute decision maker/Employee (print name)	Signature	Date
Name of witness	Signature	Date

2. Authorization to Release Photographs or Other Images

I hereby authorize The Otta covering period of health c	•	my photographs or other imag	ges
From	(date)To		(date)
For the purpose of:			
Patient or substitute decision (print name)	on maker/Employee	Signature	Date
Name of witness		Signature	Date

APPENDIX D – INTERVIEW GUIDE for PATIENT PARTICIPANTS

Questions in this guide are open-ended with prompts to gather information around the patient's experience, feelings, values, and beliefs. Prompts will be given to gather more information about the experience or for clarifications.

Introduction:

Thank-you for accepting to participate in this study. During our conversation, I hope to better understand what it's like for patients who were admitted to hospital such as yourself to be seen by an occupational therapist for discharge preparation. I will ask you some general and some specific questions. I would like to remind you that it is your experience that is important when answering the questions; there is no 'right or wrong'.

I would also like to remind you that it is your right to decline to answer any question. The interview will be taped on this tape recorder. If you want me to turn off the tape recorder at any point I will do so.

For demographic purposes patient participants will be asked their name, age, marital status, living situation and diagnosis. A picture of the occupational therapist involved in the discharge preparation interventions will be presented to them if they can't remember who their occupational therapist was.

The semi-structured interview of patient participants will include the following questions:

- 1. Please tell me about what you remember from the few days before your return home? Could you describe to me what were your main concerns you had then regarding returning home? What kind of information were you looking for at the time?
- 2. How did the occupational therapist respond (or not) to your need for information?

I looked at the discharge report your occupational therapist wrote and I notice that you discussed/practiced (identify the intervention e.g. bath transfers). What do you remember about it?

- 3. How did you feel about returning home and getting back to your routine? How did the occupational therapist help (or did not help) in getting you ready to return home? Did the occupational therapist make any suggestions or recommendations? What do you think of these recommendations?
- 4. How did the occupational therapist find out about what was important to you about going home? How much did you feel part of the discussions about going home?
- 5. Based on what you recall from your meetings with the occupational therapist, how would you describe your experience? Could you tell me what was useful? What was less/not useful?

Thank you for taking the time to talk with me and sharing your experience.

To prompt patients and/or encourage them to expand, questions such as:

- Could you tell me more about...?
- Could you give me an example of?
- Do you remember anything else about...?
- How important wasto you?

APPENDIX E – DALHOUSIE REB APPROUVAL

Health Sciences Research Ethics Board Letter of Approval

April 02, 2014

Ms Martine Trudelle
Health Professions\Occupational Therapy

Dear Martine,

REB #: 2014-3197

Project Title: Patients' Experience of Occupational Therapy Discharge Preparation

Effective Date: April 02, 2014 Expiry Date: April 02, 2015

The Health Sciences Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*. This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Catherine Connors, Director

Post REB Approval: On-going Responsibilities of Researchers

After receiving ethical approval for the conduct of research involving humans, there are several ongoing responsibilities that researchers must meet to remain in compliance with University and Tri-Council policies.

1. Additional Research Ethics approval

Prior to conducting any research, researchers must ensure that all required research ethics approvals are secured (in addition to this one). This includes, but is not limited to, securing appropriate research ethics approvals from: other institutions with whom the PI is affiliated; the research institutions of research team members; the institution at which participants may be recruited or from which data may be collected; organizations or groups (e.g. school boards, Aboriginal communities, correctional services, long-term care facilities, service agencies and community groups) and from any other responsible review body or bodies at the research site.

2. Reporting adverse events

Any significant adverse events experienced by research participants must be reported in writing to Research Ethics within 24 hours of their occurrence. Examples of what might be considered "significant" include: an emotional breakdown of a participant during an interview, a negative physical reaction by a participant (e.g. fainting, nausea, unexpected pain, allergic reaction), report by a participant of some sort of negative repercussion from their participation (e.g. reaction of spouse or employer) or complaint by a participant with respect to their participation. The above list is indicative but not all-inclusive. The written report must include details of the adverse event and actions taken by the researcher in response to the incident.

3. Seeking approval for protocol / consent form changes

Prior to implementing any changes to your research plan, whether to the protocol or consent form, researchers must submit them to the Research Ethics Board for review and approval. This is done by completing a Request for Ethics Approval of Amendment to an Approved Project form (available on the website) and submitting three copies of the form and any documents related to the change. Please note that no reviews are conducted in August.

4. Submitting annual reports

Ethics approvals are valid for up to 12 months. Prior to the end of the project's approval deadline, the researcher must complete an Annual Report (available on the website) and return it to Research Ethics for review and approval before the approval end date in order to prevent a lapse of ethics approval for the research. Researchers should note that no research involving humans may be conducted in the absence of a valid ethical approval and that allowing REB approval to lapse is a violation of University policy, inconsistent with the TCPS (article 6.14) and may result in suspension of research and research funding, as required by the funding agency.

5. Submitting final reports

When the researcher is confident that no further data collection or analysis will be required, a Final Report (available on the website) must be submitted to Research Ethics. This often happens at the time when a manuscript is submitted for publication or a thesis is submitted for defence. After review and approval of the Final Report, the Research Ethics file will be closed.

6. Retaining records in a secure manner

Researchers must ensure that both during and after the research project, data is securely retained and/or disposed of in such a manner as to comply with confidentiality provisions specified in the protocol and consent forms. This may involve destruction of the data, or continued arrangements for secure storage. Casual storage of old data is not acceptable.

It is the Principal Investigator's responsibility to keep a copy of the REB approval letters. This can be important to demonstrate that research was undertaken with Board approval, which can be a requirement to publish (and is required by the Faculty of Graduate Studies if you are using this research for your thesis).

Please note that the University will securely store your REB project file for 5 years after the study closure date at which point the file records may be permanently destroyed.

7. Current contact information and university affiliation

The Principal Investigator must inform the Research Ethics office of any changes to contact information for the PI (and supervisor, if appropriate), especially the electronic mail address, for the duration of the REB approval. The PI must inform Research Ethics if there is a termination or interruption of his or her affiliation with Dalhousie University.

8. Legal Counsel

The Principal Investigator agrees to comply with all legislative and regulatory requirements that apply to the project. The Principal Investigator agrees to notify the University Legal Counsel office in the event that he or she receives a notice of non-compliance, complaint or other proceeding relating to such requirements.

9. Supervision of students

Faculty must ensure that students conducting research under their supervision are aware of their responsibilities as described above, and have adequate support to conduct their research in a safe and ethical manner.

APPENDIX F – DALHOUSIE REB ANNUAL RENEWAL

Health Sciences Research Ethics Board Annual Renewal - Letter of Approval

March 12, 2015

Ms Martine Trudelle
Health Professions\Occupational Therapy

Dear Martine,

REB #: 2014-3197

Project Title: Patients' Experience of Occupational Therapy Discharge Preparation

Expiry Date: April 02, 2016

The Health Sciences Research Ethics Board has reviewed your annual report and has approved continuing approval of this project up to the expiry date (above).

REB approval is only effective for up to 12 months (as per TCPS article 6.14) after which the research requires additional review and approval for a subsequent period of up to 12 months. Prior to the expiry of this approval, you are responsible for submitting an annual report to further renew REB approval. Forms are available on the Research Ethics website.

I am also including a reminder (below) of your other on-going research ethics responsibilities with respect to this research.

Sincerely,

Catherine Connors, Director

Post REB Approval: On-going Responsibilities of Researchers

After receiving ethical approval for the conduct of research involving humans, there are several ongoing responsibilities that researchers must meet to remain in compliance with University and Tri-Council policies.

1. Reporting adverse events

Any significant adverse events experienced by research participants must be reported **in writing** to Research Ethics **within 24 hours** of their occurrence. Examples of what might be considered "significant" include: an emotional breakdown of a participant during an interview, a negative physical reaction by a participant (e.g. fainting, nausea, unexpected pain, allergic reaction), report by a participant of some sort of negative repercussion from their participation (e.g. reaction of spouse or employer) or complaint by a participant with respect to their participation. The above list is indicative but not all-inclusive. The written report must include details of the adverse event and actions taken by the researcher in response to the incident.

2. Seeking approval for protocol / consent form changes

Prior to implementing any changes to your research plan, whether to the protocol or consent form, researchers must submit them to the Research Ethics Board for review and approval. This is done by

completing a Request for Ethics Approval of Amendment to an Approved Project form (available on the website) and submitting three copies of the form and any documents related to the change. Please note that no reviews are conducted in August.

3. Submitting annual reports

Ethics approvals are valid for up to 12 months. Prior to the end of the project's approval deadline, the researcher must complete an Annual Report (available on the website) and return it to Research Ethics for review and approval before the approval end date in order to prevent a lapse of ethics approval for the research. Researchers should note that no research involving humans may be conducted in the absence of a valid ethical approval and that allowing REB approval to lapse is a violation of University policy, inconsistent with the TCPS (article 6.14) and may result in suspension of research and research funding, as required by the funding agency.

4. Submitting final reports

When the researcher is confident that no further data collection or analysis will be required, a Final Report (available on the website) must be submitted to Research Ethics. This often happens at the time when a manuscript is submitted for publication or a thesis is submitted for defence. After review and approval of the Final Report, the Research Ethics file will be closed.

5. Retaining records in a secure manner

Researchers must ensure that both during and after the research project, data is securely retained and/or disposed of in such a manner as to comply with confidentiality provisions specified in the protocol and consent forms. This may involve destruction of the data, or continued arrangements for secure storage. Casual storage of old data is not acceptable.

It is the Principal Investigator's responsibility to keep a copy of the REB approval letters. This can be important to demonstrate that research was undertaken with Board approval, which can be a requirement to publish (and is required by the Faculty of Graduate Studies if you are using this research for your thesis).

Please note that the University will securely store your REB project file for 5 years after the study closure date at which point the file records may be permanently destroyed.

6. Current contact information and university affiliation

The Principal Investigator must inform the Research Ethics office of any changes to contact information for the PI (and supervisor, if appropriate), especially the electronic mail address, for the duration of the REB approval. The PI must inform Research Ethics if there is a termination or interruption of his or her affiliation with Dalhousie University.

7. Legal Counsel

The Principal Investigator agrees to comply with all legislative and regulatory requirements that apply to the project. The Principal Investigator agrees to notify the University Legal Counsel office in the event that he or she receives a notice of non-compliance, complaint or other proceeding relating to such requirements.

8. Supervision of students

Faculty must ensure that students conducting research under their supervision are aware of their responsibilities as described above, and have adequate support to conduct their research in a safe and ethical manner.

APPENDIX G - TOH REB APPROVAL







Ottawa Health Science Network Research Ethics Board/Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa

Civic Box 411 725 Parkdale Avenue, Ottawa, Ontano K1Y 4E9 613-798-5555 ext 14902 Fax 613-761-4311 http://www.chrr.ca/ohsn-reb

July 20, 2015

Ms. Martine Trudelle
The Ottawa Hospital - General Campus
Division of Physical Medicine & Rehabilitation
501 Smyth Road
Ottawa, Ontario
K1H 8L6

Dear Ms. Trudelle:

Re: Protocol # 20150254-

01H

Occupational Therapist's perspective of their contribution to discharge

in acute care

Protocol approval valid until -

September 20, 2015

Thank you for your e-mail dated July 16, 2015. I am pleased to inform you that this protocol underwent expedited review by the Ottawa Health Science Network Research Ethics Board (OHSN-REB) and is CONDITIONALLY approved for two months to start recruiting English-speaking participants. No changes, amendments or addenda may be made to the protocol or the consent form without the OHSN-REB's review and approval.

Approval is conditional upon the following:

- 1. Receipt and acknowledgement of the University of Ottawa Research Ethics Board approval letter.
- 2. A FULLY-SIGNED STUDY CONTRACT/AGREEMENT BETWEEN THE OTTAWA HOSPITAL RESEARCH INSTITUTE, THE PRINCIPAL INVESTIGATOR AND THE SPONSOR (OR AS OTHERWISE REQUIRED). YOU CANNOT START THE STUDY, OR BEGIN TO RECRUIT RESEARCH PARTICIPANTS INTO THE STUDY UNTIL THE STUDY CONTRACT/AGREEMENT HAS BEEN SIGNED BY ALL PARTIES, AND HAS BEEN RECEIVED BY THE OTTAWA HOSPITAL RESEARCH INSTITUTE'S CONTRACTS OFFICE. FOR FURTHER DETAILS, PLEASE CONTACT CHRISTINE LAFONTAINE, CONTRACTS ADMINISTRATOR AT CHRILAFONTAINE@OHRI.CA OR AT 613-798-5555 EXT. 19690.

Approval is for the following documents:

- Protocol dated July 16, 2015
- Interview Guide for occupational therapist participants dated March 31, 2015
- English recruitment e-mail, version 1, dated June 9, 2015
- English participant informed consent form, version 1, dated July 16, 2015

The REB no longer requires a 'valid until' date at the bottom of all approved informed consent forms. The consent form currently approved for use by the REB is listed above.

Upon receipt and review of the French recruitment e-mail and consent form, the protocol may be extended to July 19, 2016 (one year from the initial approval date) and the recruitment of French-speaking participants may begin.

When submitting the French documentation to the OHSN-REB, please be sure to indicate how the document was translated. Refer to SOP # 1000 for the translation options when submitting your French documents to the

.../2

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REB for approval. The SOP can be found in the Translation section of the OHSN-REB website (www.ohri.ca/OHSN-REB). The OHSN-REB does offer a fee for service translator, Mr. Eric Lépine (elepine@ohri.ca).

OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline; the provisions of the Personal Health Information Protection Act 2004.

Yours sincerely,

Francine F-A. Sarazin, Ph.D., C.Psych. Vice-Chairperson Ottawa Health Science Network Research Ethics Board

/cb

APPENDIX H – TOH REB ANNUAL RENEWAL







Ottawa Health Science Network Research Ethics Board/ Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa

Civic Box 411 725 Parkdale Avenue, Ottava, Ontario Kty 4E9 613-798-5555 ext. 14902 Fax: 613-761-4311 http://www.ohir.ca/ohsn-reb

November 18, 2015

Ms. Martine Trudelle
The Ottawa Hospital - General Campus
Division of Physical Medicine & Rehabilitation
501 Smyth Road
Ottawa, Ontario
K1H 8L6

Dear Ms. Trudelle:

RE: Protocol# - 20140329- Patients' experience of Occupational Therapy Discharge Preparation 01H

Renewal Expiry Date - November 17, 2016

Thank you for your e-mail dated November 17, 2015, requesting the projected date of study completion be extended to May 2016. This is approved.

I am pleased to inform you that your Annual Renewal Request was reviewed by the Ottawa Health Science Network Research Ethics Board (OHSN-REB) and is approved. No changes, amendments or addenda may be made in the protocol without the OHSN-REB's review and approval.

It is noted that there was a lapse in ethical approval from August 12, 2015 to November 17, 2015, but that no new data was collected.

Renewal is valid for a period of one year. Approximately one month prior to that time, a single renewal form should be sent to the REB office.

OHSN-REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline; and the provisions of the Personal Health Information Protection Act 2004.

Raphael Saginur, M.D. Chairperson Ottawa Health Science Network Research Ethics Board

/cb