

Exploring long-stay seniors' transitions from home care services to self-management

by

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Author's Declaration

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

I understand that my thesis may be made electronically available to the public.

Abstract

As a result of longer life expectancies and below-replacement fertility rates, the Canadian population is aging. Approximately 14.8% of the Canadian population was aged 65 years or older in 2011. The senior population is faced with co-morbidities and polypharmacy. The result is a significantly higher usage of healthcare resources by seniors. Homecare services allow seniors to stay at home and manage their complexity by providing home support services and care coordination. However, limited resources for homecare have led to long waitlists and prioritization of short-stay, acute clients at the expense of long-stay seniors. As a result, long-stay seniors are often discharged faster, leading to transitions. Appropriate transitional care ensures the coordination and continuity of care and may help seniors avoid poor health outcomes.

This study used a qualitative approach, more specifically Grounded theory, to explore the transition from homecare to self-management and had 3 objectives: 1) to describe the preparation of long-stay seniors for self-management at discharge from home support services in the Waterloo-Wellington CCAC, through the perspectives of seniors and/or their caregivers, as well as care coordinators; 2) to assess the quality of transition from the perspectives of long-stay seniors and their caregivers, including successful actions and challenges, from homecare services to self-management; and 3) to examine the senior's and caregiver's experience of the transition and subsequent unmet needs for homecare services.

Three seniors, two dyads of seniors and caregivers, and one caregiver were interviewed, as well as six care coordinators from the Waterloo-Wellington Community Care Access Center (WW-CCAC) using a semi-structured interview guide. Interviews with

seniors and/or their caregivers were used to address all three objectives, while interviews with care coordinators helped address the first objective.

Results showed that the preparation for discharge lacked a discussion between care coordinators and seniors/caregivers on medication management and seniors and caregivers had limited knowledge of health conditions and health service. However, seniors and caregivers were aware of available community supports. Subsequently, the transitional care after discharge from homecare services lacked a mechanism to ensure follow-up with primary healthcare professionals as well as a formal process for medication review, though a large support network was available to the seniors. The seniors and caregivers reported a positive experience with managing their own care after discharge with limited perceived need of homecare or formal help and capability to manage and cope without homecare services. Overall, there was a poorly informed discharge and limited transitional care but a positive subjective experience and avoidance of adverse health issues. A theoretical framework for the perceived transition from homecare services to self-management after discharge from WW-CCAC was generated from the findings. The framework presents a disconnect between actual needs and perceived needs for transitional care. Seniors are hesitant in seeking out care or information while care coordinators expect seniors to take initiative if any issues or concerns need to be addressed. These findings suggest room for improvement when preparing seniors for discharge from homecare services to avoid poor health outcomes that may result. There seems to be an absence of many important elements of successful transitional care in this specific transition. Seniors' and/or their caregivers' lack of

proactively seeking information and resources may contribute to the lack of preparation by care coordinators.

This study provides an important first step in understanding the transition from homecare service to self-management after discharge. Further research should test the results of this study by implementing an intervention based on the theoretical framework presented in this study. The result also have the potential to contribute to discharge planning at WW-CCAC to improve the transition.

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“I have learned that success is to be measured not so much by the position that one has reached in life as by the obstacles which he has overcome while trying to succeed.”

-Booker T. Washington

Chapter 1: Introduction and Overview

The Canadian population is aging as a result of longer life expectancies and below-replacement fertility rates (Canadian Institute for Health Information [CIHI], 2011). In 2011, the senior population represented a record 14.8% of the Canadian population (Statistics Canada, 2012). Aging can be accompanied by a combination of chronic health conditions and disabilities. Consequently, complexity in seniors and usage of multiple medications (polypharmacy) can lead to complications that require more healthcare resources than other age groups (CIHI, 2011). The per capita health expenditure on Canadian seniors was \$11,196 in 2009. This was 4.5 times greater than per-capita spending on 20-64 years old adults (CIHI, 2011).

In order to manage complex conditions at home, seniors and their caregivers may turn to homecare services. Homecare services provide support and case management for seniors who would otherwise require institutionalization as a result of difficulty with self-management (CHA, 2008). With the desire to remain at home, the popularity of publicly funded homecare services has been rising in frail seniors (Canadian Healthcare Association [CHA], 2009; Health Council of Canada [HCC], 2012). However, limited availability of funds in Ontario has led to long waitlists to access services and prioritization of short-stay and highly complex, high-needs, and high acuity seniors at the expense of long-stay seniors with less acute conditions. Long-stay seniors consist of at-risk homecare recipients with chronic conditions/disabilities with predictable and stable care needs in Ontario that receive continuous service for at least 60 days (CHA, 2009; Auditor General of Ontario[AGO],

2010; Community Care Access Center [CCAC], 2012). Long-stay seniors are often discharged early or placed in long-term care homes prematurely due to difficulties in managing complex health without homecare services (Heckman, McKinnon-Wilson, Hillier & Manderson, 2011).

Discharge from healthcare services constitutes a transition in care. Transitional care involves a series of steps to ensure the coordination and continuity of care during transition between healthcare settings (Parry, Coleman, Smith, Frank & Kramer, 2003). A poor transition can lead to poor health outcomes in frail seniors, including rehospitalisation, re-referral to homecare and admission to long-term care homes (Dedhia *et al.*, 2009; Heckman *et al.*, 2011; Legrain *et al.*, 2011; Watkins, Hall & Kring, 2012). Poor transitions may lead to poor medication management and reviews, lack of knowledge on necessary tests and appointments, follow-up on tests and appointments, red flags, and worsening health conditions (Coleman, 2003; Moore, Wisnivesky, Williams & McGinn, 2003; Parry *et al.*, 2003). Successful transitions are important to avoid poor health outcomes and discontinuity in healthcare.

The purpose of this study to explore the transition after discharge from homecare service to self-management. The preparation of seniors and/or caregivers by care coordinators will be examined as well as the subsequent transitional care after discharge. Experience of seniors and/or caregivers is also examined. A theoretical framework of the overall transition from homecare services to self-management after discharge will be presented based on the findings of this study.

Chapter 2 : Literature Review

The following literature review was conducted to examine home care service delivery and healthcare transitions in addressing the complexity of care needs for the senior population in Canada. The search strategy is described in **Appendix G** and **Appendix H**. Challenges that arise from insufficient supply of homecare services in response to increasing demand were examined, as well as the effect of insufficient amounts of service and premature discharge on the seniors' health outcomes and their ability to reside independently within the community. Furthermore, the quality of the resulting transition after discharge from one care setting to another setting was explored. The effects of a successful versus a poor transition on the health of seniors and ability to live within the community were also examined. Elements of successful and unsuccessful transitions were reviewed to help inform the methods of this study.

2.1 Population Aging in Canada

Canada has an aging population (CIHI, 2011). Between 2006 and 2011, the growth rate for seniors was higher than any other age group (Statistics Canada, 2012). This trend is expected to continue with life expectancies predicted to reach 75.8 years for men and 81.4 years for women in 2041 (CIHI, 2011). The senior population is projected to reach 9.9-10.9 million in 2036 (Statistics Canada, 2010).

Old age can be associated with an increased prevalence for chronic health conditions. In 2008, 24% of Canadian seniors reported being diagnosed with at least 3 chronic health conditions and using an average of 6 medications daily (CIHI, 2011). Usage of multiple medications resulted in greater risks for side effects and medical attention. Furthermore, 59%

of seniors who reported 3 or more chronic conditions in 2009 also reported having at least one disability (Health resources and Skills Development Canada [HRSDC], 2011).

As a result, seniors are more frail than other age groups. Frailty is described as an increased vulnerability to adverse outcomes due to the accumulation of impairments across the physiological systems (Bergman *et al.*, 2007). A greater sum of multiple symptoms and signs results in a greater vulnerability (Bergman *et al.*, 2007).

In order to manage frailty, seniors have been turning to publicly funded homecare services. Homecare services help seniors and their caregivers manage conditions and perform everyday tasks at home that would otherwise be very challenging.

2.2 Homecare Services

Most seniors prefer to stay at home instead of being admitted to long-term care homes (CHA, 2009; HCC, 2012). Investment in publicly funded homecare in Canada has progressively increased to substitute for care in long-term homes, acute care and Alternate Level of Care (ALC) beds and avoid relatively higher costs (Hollander, Chappell, Havens, McWilliam & Miller, 2002; Cohen, Murphy, Nutland & Ostry, 2005; Jacobs *et al.*, 2007). In the 2004 Health Accord, a 10-year plan was drawn up by all levels of government to strengthen homecare and federal funding was guaranteed for two weeks of short-term home care after discharge from acute care; two weeks of short-term community mental health home care; and end-of-life care (HCC, 2012). In 2007, the government provided \$1.1 billion over three years for the Aging at Home strategy (Canadian Home Care Association [CHCA], 2008). Other initiatives have also been developed to strengthen homecare in Canada, including the Canada Health and Social Transfer Act (1996), Health Transition Fund (1999-

2003) and Primary Health Care Transition Fund (2000-2006), and the Compassionate Care Benefit Plan (Health Canada [HC], 1999; CHA, 2009). However, the full amount of funding may not flow to these initiatives and much of it may be used up in administrative costs; for example, the Auditor General of Ontario (2010) found that only a portion of the funding has flowed for the “aging at home” strategy and more steps are required to meet its goals. Direct funding for the provision of homecare services may still be insufficient to keep up with the increasing demand by the aging population.

2.2.1 Homecare in Ontario

Fourteen Local Health Integrated Networks (LHINs) are responsible for coordinating and delivering homecare services in Ontario (AGO, 2010). They provide funding to 14 Community Care Access Centers (CCAC’s). CCAC’s are local, community-based non-profit agencies in Ontario that provide access to home and community care, arrange for provision of services, inform Ontarians and provide referrals on community-related services, and authorize admission to long-term care homes (Ministry Of Health and Long-Term Care [MOHLTC], 2012). Case managers assess long-stay clients using the Resident Assessment Instrument – Home Care (RAI-HC) to determine eligibility for services and consequently develop a care plan to coordinate services (MOHLTC, 2012).

Services provided by CCAC’s include nursing, personal support/homemaking, physiotherapy, occupational therapy, speech language pathology, social work, nutrition/dietetics and case management (CHA, 2008). Case management includes communication with health professionals and coordination of services such as transportation,

appointments, information on available resources and admission to long-term care homes (MOHLTC, 2012).

Homecare services can provide active treatment for conditions that would otherwise require inpatient care, as well as supervision, psychosocial support, personal assistance, basic nursing, case management, and help with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (Richardson, 1990; Woodward, 2004; Jacobs *et al.*, 2007; CHA, 2008; Markle-Reid *et al.*, 2008; HCC, 2012). ADL's include activities necessary for self-care such as bathing, feeding, grooming, toileting, and eating while IADL's include activities that support self-care such as shopping, cleaning, and medication management (Hollander & Tessaro, 2001; Cohen *et al.*, 2006 as cited in Markle-Reid *et al.*, 2008). These services help seniors and their caregivers manage complex conditions at home.

Although homecare services help seniors manage their health at home and avoid acute care episodes and institutionalization, funding for homecare in Ontario has not kept up with the increasing demand (CHA, 2009; AGO, 2010). Between 2003 and 2010, homecare clients increased 66% while funding only increased 40% (CHA, 2009). In 2002/03, per capita funding for homecare services was \$3,846 but in 2008/09, this funding decreased to \$3,003 per capita (CHA, 2009). The lack of funding increase in response to higher demand has led to a shift in focus towards 'high-needs' and short-stay seniors, and a reduction in long-stay seniors. In 2010/11, 18% of all Community Care Access Center (CCAC) clients receiving homecare services were considered 'high-need', compared to only 4% in 2008/09 (CCAC, 2012). 'High-need' clients are defined as those with very complex conditions who are at a high risk for hospitalization, ALC, or institutionalization while short-stay clients are defined

those who receive acute care or rehabilitation after an acute episode for a limited period of time to transition into self-care (CCAC, 2012). Short-stay clients are predictable and stable and very likely to return to complete independence. In general, long-stay seniors receive low levels of personal support and therapy to help with ADL's and IADL's while short-stay and 'high needs' seniors receive nursing and other homecare services targeted at managing acute or very complex conditions. The number of clients receiving personal support care decreased from 174/ 1,000 people to 160/ 1000 people between 2008/09 to 2010/11 (CCAC, 2012). In one CCAC, services were prioritized so only 'high-needs' individuals were eligible for personal support services (AGO, 2010). In another instance, one client waited 134 days on the waitlist before finally receiving homecare services (AGO, 2010). With greater emphasis being placed on short-stay and very complex clients, long-stay seniors with lower needs are facing cuts in service and facing earlier discharge.

2.2.2 Discharge from Homecare services

Limited resources for homecare leads to faster discharge of long-stay seniors. Some discharged seniors are able to cope without homecare services and receive help from informal caregivers (HCC, 2012). Others are able to purchase homecare services privately. However, some frail seniors and their caregivers may not yet be ready for discharge and struggle with self-management at home. They may experience a decline in health and poor outcomes such as unnecessary hospitalization as a result of poor preparation and planning for the transition after discharge from homecare services and difficulty with self-management (Heckman *et al.*, 2011). Regional health authorities could potentially experience significant increases in rehospitalisation rates when seniors are prematurely discharged in their

respective regions (Hollander *et al.*, 2001; Jacobs *et al.*, 2007). In British Columbia, health units that discharged seniors as a result of funding cuts subsequently experienced a significant increase in use of hospital beds, homemaker services and rates of admission to long-term care homes in their respective regions (Hollander *et al.*, 2001). Premature cuts in homecare service can also lead to an increase in ALC days by up to 65% and significant emergency room overflows (Cohen *et al.*, 2005). Hospital-based agencies providing acute care may also experience a higher demand for services because seniors who experience adverse outcomes after premature discharge from homecare services may require more active treatment at home (Mccall, Petersons, Moore & Korb, 2003; Kilgore *et al.*, 2009). Hospice payments for regional health authorities can increase by up to 70% (Kilgore *et al.*, 2009).

Furthermore, restricting existing homecare services may not be enough to support independent living (ADL's, IADL's) at home. Inadequate amount of services can lead to greater costs and hospital days in seniors and premature movement to long-term care homes (LaPlante, Kaye, Kang & Harrington, 2004; Markle-Reid, 2008; Byrne, Sims-Gould, Frazee & Martin-Mathews, 2011; Heckman *et al.*, 2011) . In focus groups conducted with healthcare providers for the local Waterloo-Wellington LHIN, participants pointed to the importance of appropriate and sufficient care plans and revealed that even low levels of home support services such as medication management could help avoid admissions to long-term care homes (Heckman *et al.*, 2011). Participants suggested that withdrawal of home support services often leads to a decline in health and re-referral to homecare, an acute episode, or institutionalization (Heckman *et al.*, 2011).

Limited resources for homecare services seem to precipitate early discharge and impose restrictions on homecare services. Therefore, enabling seniors and their caregivers to manage care at home without homecare services has the potential to avoid decline in health, acute care episodes, hospitalization, and/or institutionalization in frail seniors. Preparing seniors and their caregivers for self-management for transitional care after discharge can be very important to maintain their health.

2.3 Caregivers

Caregivers often play a large role in managing care for seniors. They manage seniors' medications, monitor their health, coordinate and communicate with healthcare professionals, organize appointments, and provide other supportive care to allow seniors to live independently at home (HCC, 2012). When seniors are discharged from homecare services, the burden of care may increase for informal caregivers such as family members. In 2007, approximately 3.1 million Canadians provided 1.5 billion hours of informal care to seniors across Canada (Hermus, Stonebridge, Theriault & Bounajm, 2012).

In a study with caregivers, participants wanted more information about pain management, system navigation, practical details for providing care, knowledge of disease progression, dealing with care teams, and legal/financial information (Dunbrack, 2005 as cited in HCC, 2012). Support for caregivers is crucial to maintaining the health of seniors. In many cases, caregivers themselves are seniors with their own health problems and caregiver stress can increase their risk of injury and aggravation of health issues (Jull, 2010 as cited in HCC, 2012). The lack of access to resources and services can also increase caregiver stress. When caregivers are unable to manage health of seniors, seniors may be admitted to long-

term care homes or experience adverse outcomes (Jull, 2010 as cited in HCC, 2012). Thus, support and a significant role for caregivers during a transition are important to ensure successful transitions for seniors.

2.4 Care Coordinators

Care coordinators at CCAC are responsible for assessing and reviewing requirements for homecare, determining eligibility, developing and evaluating the plans of service for homecare, and authorizing expenditures for funding of services and admissions to long-term care homes (MOHLTC, 2006). Care coordinators ensure coordination and communication with clients to ensure the appropriate delivery of services and to allow clients to live independently. They assess clients and work with them to develop a service plan that is appropriate and sufficient. Furthermore, they also coordinate service delivery with contracted providers and link clients to community resources and volunteer services as necessary. Care coordinators work with clients to address any needs and issues and to provide information on resources that help manage chronic conditions at home.

2.5 Preparing Clients for Discharge

As outlined in the CCAC client services policy manual (Ministry Of Health & Long-term Care, 2006), the client and/or caregiver must be trained to carry out necessary care independently without homecare support. As a result, the senior and/or their caregiver must be prepared to adequately self-manage care independently after discharge. Appropriate preparation can allow this transition to achieve all pillars of successful transitional care (Coleman, 2003). In order to prevent any adverse outcomes during self-management, the care

coordinators must play an important role at discharge to ensure logistical arrangements, education of clients and their families, and coordination among health professionals involved. Preparation must include discussion of medication self-management, use of a dynamic patient-centered record, primary care and specialist follow-up, knowledge of red flags (Parry *et al*, 2003), communication between healthcare professionals, reconciling medication before transfer and current regimen, follow-up plan for understanding tests and follow-up appointments, and education on signs and symptoms that indicate a worsening condition and who to contact (Coleman, 2003). Care coordinators must also help seniors and/or caregivers find community resources or private care to ensure independent living and raise awareness of available resources.

2.6 Healthcare Transitions

When seniors are discharged from homecare services, they undergo a transition to self-management of care. During this transitional care, they coordination and continuity of health care must be maintained. Transitional care can include logistical arrangements, education of clients and their families, and coordination among health professionals involved (Parry *et al.*, 2003). Seniors can be at risk for medical errors, duplication of service, inappropriate care or care plan falling through the cracks at any given transition (Parry *et al*, 2003). Therefore, it is important to ensure a successful transition.

Discontinuity of healthcare during a transition may potentially lead to medical errors. These errors include medication continuity errors, test follow-up errors and work-up errors (Moore *et al.*, 2003). In a sample of 86 patients who had transitioned from hospital to home, Moore *et al.* (2003) found 49% of patients experienced at least 1 of the three errors. Work-up

errors (inpatient provided suggested/scheduled outpatient test/procedure but outpatient provider failed to follow up) were significantly related to increased rehospitalisation rates. This means that seniors must ensure follow-up with healthcare providers after discharge or they may experience acute issues and rehospitalisation. A discussion around appointment management, including information about following up with healthcare professionals, during preparation for discharge may be important to improve self-management of care.

When seniors are discharged from homecare services, they may face difficulties in performing simple tasks related to ADLs and IADLs (Hollander *et al.*, 2001; Byrne *et al.*, 2011). They may also face financial hardships, emotional distress and decline in health (Hollander *et al.*, 2001). Deficits in homecare services or discharge may lead to adverse outcomes such as weight loss, dehydration, falls and burns (Laplante *et al.*, 2004). Such adverse outcomes can lead to an acute event, hospitalization and/or rehospitalisation. Seniors and their caregivers must be prepared adequately for the transition from discharge to self-management to enable management of their care and prevent adverse outcomes.

Successful transitions are important for seniors to avoid rapid decline in health. Support and strategies for seniors and their caregivers need to be considered in achieving successful transitions. Preparing seniors and caregivers to self-manage their care while they are receiving homecare services may be beneficial to help them ensure a successful transition and be ready to live independently without homecare support. Preparation and planning while seniors receive the services is relatively much easier because they can be eased into performing self-management tasks instead of providing them with support and strategies at discharge and leaving them to manage their health without any previous experience.

Interventions that help seniors and their caregivers prepare for the transition after discharge from one healthcare setting to the next can be very important. The Care Transition Intervention (CTI) was designed to provide tools and support to help seniors and their caregivers during their transition from acute care to home (Coleman *et al.*, 2004). Seniors who received this intervention had increased confidence in self-management and understanding/recognizing red flags; the ability to obtain necessary information during follow-up visits with physicians; the ability to report reasoning behind their medication; the ability to administer medication; and understanding of associated side effects (Coleman *et al.*, 2004). They also had lower hospitalization rates compared to seniors who did not receive the intervention (Coleman *et al.*, 2004).

The Care Transition Measure (CTM) was developed to assess the quality of transitional care using 15 items arranged on a 4-point scale (Coleman *et al.*, 2002). A higher score is associated with better quality of transitional care. Coleman, Mahoney & Parry (2005) showed the measure to be reliable in predicting emergency visits and rehospitalisation after discharge from hospital. However, the measure is used *at* discharge from acute care to predict the quality of transition as determined by the patients' preparation and planning; it is important to examine the transition *after* it has occurred to better understand its quality. Furthermore, the measure may not include important aspects of transitional care present after discharge from homecare services that have yet to be examined (McLeod, Stolee, Walker & Heckman, 2010)

Preparing seniors and their caregivers before or at discharge could be important in ensuring a smooth transition and avoiding adverse outcomes. Interventions at discharge from

acute care that are designed to identify barriers to discharge, perform medication reconciliation, plan appointments pre-discharge, and provide communication with primary care providers can reduce emergency department visits and lower the rate of readmission within 30 days (Dedhia *et al.*, 2009). Comprehensive review of medications, educating seniors and caregivers on self-management of conditions and detailed communication with health professionals during transitional care after discharge from acute care may also reduce readmissions to hospital, emergency department visits and reduce adverse events in seniors (Legrain *et al.*, 2011). Similar interventions before discharge from homecare services can also be important.

2.6.1 Quality of Transitions

Several elements of a successful transition have been identified. Parry *et al.* (2003) conducted focus groups with seniors and caregivers who were hospitalized within the past 6 months and identified several key elements for a successful transition. These elements include medication self-management, use of a dynamic patient-centered record, primary care and specialist follow-up, and knowledge of red flags (Parry *et al.*, 2003). Coleman (2003) identified similar elements: communication between healthcare professionals; preparation during transition for next setting; reconciling medication before transfer and current regimen; follow-up plan for understanding tests and follow-up appointments; and education on signs and symptoms that indicate a worsening condition and who to contact. When these elements are present in a transition, the coordination and continuity of care is achieved and seniors and their caregivers can recognize red flags, contact and obtain necessary information from

healthcare professionals, administer and manage medication and plan and prepare for adverse outcomes.

Table 1: Elements of transitional care as identified by Parry *et al* (2003) and Coleman (2003).

Parry <i>et al</i> (2003)	Coleman (2003)
medication self-management	communication between healthcare professionals
use of a dynamic patient-centered record	preparation during transition for next setting
primary care and specialist follow-up	reconciling medication before transfer and current regimen
knowledge of red flags	follow-up plan for understanding tests and follow-up appointments
	education on signs and symptoms that indicate a worsening condition and who to contact

A number of key factors that influence the quality of a transition have also been identified. These include meanings, expectations, level of knowledge and skill, the environment, level of planning, and emotional and physical well-being (Shumacher & Meleis, 1994). It is important to examine the meaning attached to a transition by seniors and understand their subjective experience in order to determine whether the transition is successful. In some cases, a transition perceived as a negative experience by a researcher may be a positive one from the senior's perspective and vice versa (Shumacher & Meleis, 1994). Expectations during transitions may also influence the quality of a transition; unrealistic expectations could cause stress and present challenges. Expectations are

determined by previous experience and may not be applicable to new transitions (Shumacher & Meleis, 1994). In addition, a high level of knowledge and skill can prevent uncertainty and help seniors meet demands of a transition (Shumacher & Meleis, 1994).

The quality of a transition can also be determined retrospectively. Three main indicators of a successful transition are: subjective well-being, role mastery, well-being of relationships (Shumacher & Meleis, 1994). In successful transitions, subjective well-being replaces emotional distress and includes effective coping, role satisfaction, liberation, self-esteem, and empowerment (Shumacher & Meleis, 1994). Role mastery includes competence and self-confidence while well-being of relationships entails avoidance of disruption in relationships and establishing new relationships for enhanced coordination of care (Shumacher & Meleis, 1994).

2.7 Conclusion

Although homecare services are very beneficial and support seniors and their caregivers to live independently at home, limited resources due to increasing demand and an aging and complex Canadian population, have led to discharge of long-stay seniors in favor of 'high needs' and more acutely unwell seniors. Therefore, preparing seniors and their caregivers for self-management without homecare services is important. Effective preparation and planning before or at discharge is a necessity to ensure successful transitions and adequate self-management. Knowledge and information relevant to better self-management helps seniors and their caregivers cope without homecare services. Support and preparation will help seniors and their caregivers manage and understand their conditions and

seek help when needed. They will be able to communicate and collaborate with healthcare professionals and coordinate their own care. Successful transitions in seniors discharged from homecare services have the potential to alleviate system pressures as well and maintain quality of life. Most importantly, seniors and caregivers are able to manage their care in absence of homecare services and avoid unnecessary hospitalizations and institutionalization.

Chapter 3: **Study Purpose, Objectives and Rationale**

The overall purpose of this study was to explore transitional care for long-stay seniors after discharge from homecare services in Ontario. The strengths and weaknesses in preparation and planning for discharge and consequent experiences with self-management were examined.

The objectives of this study were to:

1. Describe the preparation of long-stay seniors for self-management at discharge from home support services in the Waterloo-Wellington CCAC, through the perspectives of seniors and/or their caregivers, as well as care coordinators.
2. Assess the quality of transition from the perspectives of long-stay seniors and their caregivers, including successful actions and challenges, from homecare services to self-management.
3. Examine the senior's and caregiver's experience of the transition and subsequent unmet needs for homecare services.

3.1 Study Rationale

With the aging Canadian population, the demand for homecare services continues to rise (HCC, 2012). The Auditor General of Ontario's report (2010) found long waitlists, difficulty accessing services, and decreasing per capita funding for homecare services in Ontario (AGO, 2010). A lack of funding to keep up with demand may precipitate early discharge of long-stay seniors from homecare and forces transitions within this population. If homecare services are prematurely cut leading to a poor transition, adverse outcomes might result and potentially lead to unnecessary and avoidable hospitalizations and admissions to

long-term care homes (Heckman *et al.*, 2011). Yet, the cost of hospitalization and institutionalization is much higher than the delivery of supportive homecare services (Cohen *et al.*, 2005; Jacobs *et al.*, 2007) .

Successful transitions after discharge from homecare services have the potential to prevent acute exacerbations of chronic issues, re-referrals to homecare, unnecessary acute care hospitalizations and institutionalization (Coleman *et al.*, 2004; Dedhia *et al.*, 2009 ; Legrain *et al.*, 2011). Successful transitions can contribute to more effective self-management and provide seniors and their caregivers with skills and resources related to better health management. In addition, successful transitions enable seniors and their caregivers to manage their own care after homecare services are no longer available. Adequate planning and preparation before discharge from homecare services is instrumental to avoid poor transitions (Coleman *et al.*, 2004; Dedhia *et al.*,2009; Legrain *et al.*, 2011). Therefore, exploring the planning and preparation of long-stay seniors and their caregivers before discharge as well as the quality of their transition is important to inform better ways of helping seniors experience a successful transition.

This study will contribute to the minimal existing literature regarding this specific transition. It focused on the preparation of long-stay seniors for discharge as well as the quality of transition after discharge. It enhanced an understanding of this specific transition for healthcare professionals and policy makers at the WW-CCAC to help improve preparation and avoid poor health outcomes in the future.

Chapter 4: **Methodology**

The following chapter summarizes the methods used to develop interview guides for seniors and/or their caregivers as well as care coordinators, and to collect and analyze data. The use of a qualitative approach and more specifically grounded theory is also justified.

4.1 Study Design

To address the research objectives of this study, grounded theory was used. This approach was selected because it helped to understand the process of transition and how seniors and their caregivers interpreted events that occur during the transition and their consequent responses (Creswell, 2012). Using the qualitative approach helped identify variables that were difficult to measure objectively, such as the subjective experience of seniors undergoing transitional care, and with little previous literature on the transition after discharge from homecare, the discovery of new information was important (Creswell, 2012). A qualitative approach helped explore *how* seniors and caregivers are led to poor health outcomes through specific actions and challenges during the process of transition from homecare services to self-management (Pope & Mays, 1995).

4.2 Interview Guide Design

The interview guides for seniors and/or their caregivers as well as care coordinators followed a semi-structured design. This approach used pre-determined questions but also allowed freedom to steer away from the guide and probe further on new themes and categories that were revealed during the interview process (Berg, 2001). In contrast, structured interviews have a defined set of questions that must be strictly followed while an

unstructured interview design does not have any pre-established set of questions (Berg, 2001). In this study, an unstructured interview was difficult to conduct because it is time consuming and seniors may be unable to address necessary topics without some direction.

With little previous literature on seniors' transition from homecare services to self-management in the community, the semi-structured interview guide allowed the researcher to probe for information revealed during interviews and discover information that has not been researched previously. For example, participants were asked about their ability to self-manage appointments and subsequently asked to elaborate further on any difficulties they revealed during the interview. Asking for elaboration encouraged participants to discuss and clarify any new information on topics that had not occurred to the researcher (Barriball & While, 1994), such as how relationships with care providers may have an effect on preparation for self-management.

Although this method can be time consuming, expensive and participants may provide answers they feel researchers want to hear or give them the wrong information (intentionally or unintentionally), it is a good method for gathering data on this transition and allows the researcher to explore and discover new knowledge that may not be present in previous literature (Barriball & While, 1994).

The interview guides in this study were not piloted due to time restrictions and difficulties with recruiting a large sample.

4.2.1 Seniors and/or their caregivers

The interview guide for seniors and their caregivers was divided into three sections corresponding to each study objective (refer to **Appendix B**). The first section was designed to ask participants about their preparation and planning for discharge from homecare services. The questions aimed to uncover how and by whom the participants were prepared for discharge and what tools and resources they were provided by the CCAC. The questions were designed based on previous interventions that aimed to improve transitions at discharge (Coleman *et al.*, 2004; Dedhia *et al.*, 2009; Legrain *et al.*, 2011). In this study, the researcher probed for elements of successful transitions that were identified in previous studies that focused on discharge from acute care. These elements of a successful transition include logistical arrangements, knowledge of medication management, links to resources and healthcare professionals, and ability to manage appointments (Coleman *et al.*, 2004; Dedhia *et al.*, 2009; Legrain *et al.*, 2011). Participants were asked whether the elements were covered during their preparation for discharge from homecare services. Participants were asked whether they were confident in managing their care after the preparation. They were also asked about any resources or contacts they were provided from their CCAC care coordinator for various needs.

The second section of the interview guide was designed to determine the quality of transitions and challenges experienced during transitions. The questions for the second objective were designed using literature that identified elements of a successful transition (Shumacher & Meleis, 1994; Coleman, 2003; Parry *et al.*, 2003). Participants were probed for elements that include medication management, patient-centered health record,

appointments and follow-ups, knowledge of red flags (signs of deteriorating health), expectations, level of knowledge and skill, emotional and physical well-being, role mastery, and system navigation. These factors have been identified as elements of successful transitions between other healthcare settings and this study questioned participants on these factors to determine whether seniors' transitional care was perceived as successful when moving from homecare to self-management.

The final section of the interview guide was designed to identify the participants' experience of the transition after discharge from homecare services. Schumacher & Meleis (1994) identified subjective well-being and well-being of relationships and role mastery in managing care as important components of a successful transition. Therefore, participants were asked about challenges that affected their ability to cope with self-management after discharge. Participants were also asked about how they perceived the transition and the challenges they faced during the transition. Participants were encouraged to describe how they were able to manage their health without homecare services and the effect it had on their ability to perform everyday tasks and live comfortably and independently at home. Emphasis was placed on the subjective experience of the seniors and their caregivers to determine overall subjective well-being during this transition.

4.2.2 Care Coordinators

The interview guide for care coordinators (**Appendix B**) explored how they prepared seniors and their caregivers for the transition after discharge. Care coordinators were asked whether they prepared seniors and/or their caregivers to achieve the elements of a successful

transition as identified by Coleman (2003) and Parry *et. al.* (2003). In addition, questions were designed to examine whether or not seniors and/or their caregivers were linked with community resources and additional supports. The interviews with care coordinators lasted approximately an hour. Questions were designed using the same literature used to develop questions for seniors and/or their caregivers for the first study objective; however, interviews with care coordinators aimed to understand the preparation from a care providers perspective.

4.3 Setting and Sample

The initial goal of this study was to conduct 12 interviews with seniors and/or caregivers. In a study involving interviews with relatives of people with Paget's disease about taking genetic testing, Francis *et al.* (2010) used an initial sample of 10 interviews with a stopping criterion of 3 and observed data saturation for all categories at interview 17. Guest *et al.* (2006) found data saturation after 12 interviews in data from a study with 60 in-depth interviews involving women in two West African countries. Therefore, an ideal sample size would be a minimum of twelve seniors and/or caregivers.

However, due to the voluntary nature of enrolment for participation in this study, the researcher was unable to recruit more than 6 seniors and/or their caregivers within the timeline of this study. Recruitment issues made it difficult because seniors and/or their caregivers declined to participate due to unknown reasons. Therefore, six care coordinators were also added to the sample in additions to 6 seniors and/or caregivers.

4.3.1 Seniors and/or Caregivers

This study used a convenience sample (Marshall, 1996). Convenience sampling occurs when participants are selected because they are easily accessible and close in proximity to the researcher. In contrast, theoretical sampling chooses subsequent participants to gather more information on themes revealed in interviews with previous participants (Marshall, 1996). Although theoretical sampling would have been beneficial because it allows for the development of emerging themes, difficulty recruiting seniors and/or their caregivers forced the researcher to select a convenience sample of seniors and/or their caregivers who were willing to participate and easily available.

Convenience sampling is limited because new cases may be very similar to previous cases; thus, it is difficult to generalize and make inferences about the entire population as it is not represented (Marshall, 1996). Participants who did not volunteer for an interview may be different from those who agreed to participate.

The inclusion criteria for participants in this study was seniors who were 65 years or older; residing in the community in Kitchener-Waterloo region; able to speak and understand English; had received >60 days of uninterrupted care by CCAC; had one or more chronic illnesses or disabilities; were at-risk due to conditions; were classified as ‘community independent’ or ‘chronic’ seniors with the Community Care Access Center (CCAC) (**Appendix F**); and were cognitively intact to participate or had a primary caregiver to answer on their behalf. In addition, the primary caregivers were primarily responsible for managing health of the senior and could speak and understand English. There was no exclusion criteria. Seniors and/or their caregivers who met the inclusion criteria were

identified by WW-CCAC between February 2013 and June 2013 using their client database and clients were contacted immediately after discharge to ask if they wanted to provide their contact information to the researcher for an interview.

The most recent Resident Assessment Instrument (RAI-HC) was used for each senior who participated in the study to characterize the final sample by including the diagnostic categories, age, gender, personal health profiles (PHP) scores. The RAI HC includes several validated scales including the following. The Cognitive Performance Scale (0-intact to 6-very severe impairment) measures memory impairment, level of consciousness, and executive functioning (Morris *et. al.*, 1994). The Depression Rating Scale (DRS) score measures level of depression (Burrows, Morris, Simon, Hirdes & Phillips, 2000) while the ADL self-performance scale screens for the stage of disablement process (Morris, Fries & Morris, 1999). The Changes in Health, End-stage disease, Signs and Symptoms scale (CHESS) identifies health stability and risk for serious decline (Hirdes, Frijters & Teare, 2003). The pain scale serves as a measure of pain (Fries, Simon, Morris, Flodstorm & Bookstein, 2001). Finally, the Method for Assigning Priority Levels (MAPLe) assigns clients one of five priority levels depending on their risk for adverse outcomes, including that of requiring a more supportive living arrangements (Hirdes, Poss & Curtin-Telegdi, 2008). WW-CCAC also provided client information such as services received by WW-CCAC and the timeframe of services received.

4.3.2 Care Coordinators

Care coordinators were employed by the WW-CCAC. The sample consisted of care coordinators (**Table 3**) who were assigned to work with long-stay seniors identified as “community independent” or “chronic” (**Appendix F**) and were able to speak fluent English. A convenient sample of 6 care coordinators who agreed to participate in the study were chosen.

A sample size of six care coordinators was chosen to match the number of interviews with seniors and/or their caregivers for an equal amount of data on each perspective. Furthermore, data analysis showed the interviews reached data saturation after five interviews so more than six interviews were not necessary for this study.

4.4 Data Collection

4.4.1 Seniors and/or their caregivers

Interviews were conducted with 3 seniors, 2 dyads of seniors and caregivers, and one primary caregiver (spouse) of a senior who fell ill on the day of the interview. Data collection by means of interviews allowed for privacy and sharing of sensitive information that participants may have otherwise felt uncomfortable sharing in other approaches such as focus groups (Fontana & James, 2000 as cited in Denzin & Lincoln, 2005; Berg, 2001). In this study, personal questions were explored such as managing medications and how ADL’s and IADL’s were performed. In a group setting, participants might not have been able to provide extensive amounts of detail on these topics and their discharge process. Also, all seniors had individualized care plans and issues and a group setting may not have allowed for the

individual aspects to be examined. Therefore, conducting private semi-structured interviews was appropriate to allow for a more comprehensive dialogue and comfort in sharing all necessary information.

Interviews were conducted between February 2013 and June 2013 within the seniors' place of residence. Times accommodate all seniors and/or caregivers. Seniors and caregivers were interviewed together using the same interview guide. The timing of the interviews was designed to help capture as many discharged seniors as possible and minimize attrition.

In a study of clients who were admitted to homecare after hospitalization, unplanned readmissions to hospital occurred after an average length of 18 days in homecare (Anderson, Helms, Hanson & DeVilder, 1999). Also, in a randomized controlled trial where patients discharged from hospital received either a comprehensive discharge plan or traditional discharge, 16% of those without the enhanced discharge plan in medical diagnostic-related groups were rehospitalized within 2 weeks of discharge (Naylor *et al.*, 1994). Readmission rates to hospitals after 15 days can be high and seniors who experience poor transitions may be lost (Naylor *et al.*, 1994; Anderson *et al.*, 1999). Although studies examining discharge of chronic seniors from homecare are lacking, literature focusing on acute care provides an indication of the time between discharge and adverse outcomes in seniors.

The goal of this study was to interview participants approximately 15 days after discharge; however, scheduling conflicts and inconvenience to the participants made it difficult to follow a strict timeline. Consequently, interviews were conducted between 8 days and 30 days after discharge. Four interviews with the seniors and/or their caregivers were

conducted between 8 and 17 days, and 2 interviews were conducted as late as 29 and 30 days after discharge.

All interviews were audio-recorded using a voice recorder. The audio files were assigned a numeric value to protect the identity of participants. The interviews were transcribed verbatim by the primary researcher. Any identifying information was omitted from the transcripts.

4.4.2 Care Coordinators

Interviews were conducted with 6 care coordinators from the Waterloo-Wellington Community Care Access Center (WW-CCAC) when convenient, in private rooms at their respective CCAC office. Care coordinators were being interviewed to explore the preparation of seniors and/or their caregivers for discharge from WW-CCAC.

Private interviews were also used to collect data from care coordinators because it allowed for privacy and sharing of sensitive information as opposed to focus groups (Fontana & James, 2000 as cited in Denzin & Lincoln, 2005; Berg, 2001). Care coordinators may hesitate sharing detailed information in group settings because they were being asked to comment on their own work in preparing seniors for discharge.

All interviews were audio-recorded using a voice recorder. The audio files were assigned a numeric values to protect the identity of participants. The interviews were transcribed verbatim by the primary researcher and any identifying information was omitted.

4.5 Participant Recruitment

4.5.1 Seniors and/or caregivers

The researcher worked in collaboration with the Waterloo-Wellington Community Care Access Center (WW-CCAC) to recruit 6 long-stay seniors (low- to high- risk) and/or caregivers of seniors who were discharged from homecare services. Clients who were identified as “community independent clients” and “chronic clients” (**Appendix F**) based on WW-CCAC’s client care model (CCAC, 2012) were eligible to participate in the study. The researcher contacted a designated WW-CCAC contact to explain the study. The designated contact used the eligibility criteria for this study to identify potential participants discharged between February 2013 to June 2013. Following receipt of University of Waterloo Research Ethics Clearance, the designated contact and a research assistant at WW-CCAC identified and contacted each potential client via phone, provided information on the study, and obtained verbal consent to participate in the interview. If the client or their caregiver agreed, their contact information was forwarded to the researcher. Consequently, the researcher contacted the potential client to schedule an interview within a week of initial contact.

On the day of the scheduled interview, the researcher revisited the information letter (**Appendix C**) previously provided to participants, explained the study, answered any questions and obtained signatures for their consent (**Appendix D**) to participate in the study before conducting the interview. The information letter provided participants with details on who was conducting the study, the researcher’s contact information, purpose of the study, benefits and risks of participation, benefits to others from their participation, how much time was required, any remuneration, confidentiality, researcher affiliation, and independence

from CCAC or other care providers. The information letter also contained information on how their most recent Resident Instrument Assessment (RAI-HC) conducted by WW-CCAC would be used in the study.

The consent forms included agreement to participate in the study as well as permission to use the RAI-HC, audio-record interviews and quotations anonymously and confidentially. Once written consent to participate was obtained, the researcher used the semi-structured interview guide to conduct the interview.

4.5.2 Care Coordinators

Concurrently, the designated contact at WW-CCAC sent out a call to participate in this study via e-mail to all care coordinators at the Waterloo, Guelph and Cambridge head offices. Care coordinators who worked with community independent clients or chronic clients were eligible to participate in the study. Six care coordinators agreed to participate and their contact information was sent to the researcher. The researcher contacted the care coordinators to schedule an interview at their CCAC head office at a time that was convenient. Care coordinators were electronically provided with information letters and consent forms by the designated contact prior to the interviews. On the day of interview, the researcher revisited the information letter (**Appendix C**), answered any questions care coordinators had, and obtained signatures for consent (**Appendix D**) to participate in the study.

4.6 Ethics, Confidentiality, Security

This project received approval from the Office of Research Ethics at the University of Waterloo as well as Homewood's Research Ethics Board on behalf of WW-CCAC. All private information was kept confidential and stored electronically in a safe, password-protected USB drive that was only accessible by researchers involved directly with the study. The data will be stored for 5 years and destroyed after this period of time. Participation in the study was entirely voluntary and there were no known anticipated benefits or risks. Participants could withdraw from the study at any time without negative consequences.

4.7 Data Analysis

4.7.1 Grounded Theory

A grounded theory approach was used to analyze the data (Charmaz, 2000; Creswell, 2012). Grounded theory helps generate an explanation for a process or action and focuses on *understanding* the process (Creswell, 2012). Using grounded theory, a theoretical explanation can be produced for observed data (Adolph *et al.*, 2011). This method allowed the generation of themes and categories that explained behavior during the transition (Glaser, 1978 as cited in Adolph *et al.*, 2011). Grounded theory is useful for studies in areas of research that have not been studied previously or areas that might benefit from a new perspective (Adolph *et al.*, 2011). With little previous literature of the seniors' transition being examined, it was important to discover information and help explain how seniors and their caregivers transitioned from homecare services to self-management. Previous literature

(Parry *et al.*, 2003; Coleman, 2003) examined transitions through other healthcare settings such as hospital to home and found critical elements of transitional care which, when present, indicate a successful transition that is associated with reduced rates of adverse events, hospitalization and/or institutionalization. In this study, elements of transitional care from existing literature were used as a guide to look for themes and categories that are present in this specific transition (Coleman, 2003; Parry *et al.*, 2003; Coleman, 2004).

Using grounded theory, the researcher explored the process of transition and self-management for seniors and their caregivers after discharge from homecare services. The researcher identified common themes and categories across interviews to understand how seniors and their caregivers manage care and the challenges and strengths associated with self-management, as well as how care coordinators prepare clients for discharge (Charmaz, 2000; Creswell, 2012). Grounded theory is important to examine how people manage their lives during a problematic situation and the process of understanding and dealing with this situation (Schreiber & Stern, 2001 as cited in Adolph *et al.*, 2011). This study explored challenges seniors and caregivers may face after discharge and how they were prepared by care coordinators to deal with these challenges before discharge. Although grounded theory methodology can be time consuming and concept definition can be challenging, it can make analysis easy to refine, uses a rigorous process to increase reliability and validity, makes data more generalizable than other qualitative methods, creates a theoretical framework that fits data and enables new insight into the topic being studied (Adolph *et al.*, 2011; Creswell, 2012).

In this study, interview transcripts were analyzed for common themes on the transition from homecare services to self-management. Next, a theoretical framework describing this specific transition was generated. Major themes for preparation for this transition by the care coordinators were identified.

Analysis of the data was conducted by using a constant comparative analysis approach (Charmaz, 2000; Creswell, 2012). In this approach, interview data is collected and analyzed concurrently. New data were compared with already analyzed and coded data to identify common themes and categories which could be further probed in subsequent interviews.

Analysis of the transcripts using grounded theory involved three steps of hierarchical coding (Charmaz, 2000; Creswell, 2012). All analysis was conducted manually in Microsoft Word by using 'comment' boxes to label data on the transcripts. Initially, transcripts were read multiple times by the researcher for immersion in the data as it was being collected. Then, three levels of coding were used. First, *open coding* was used to assign codes to sections of data identifying, naming, and describing a specific phenomenon. These codes were named using words that came directly from the text. Second, *axial coding* was conducted to group codes into specific themes that described the relationship between codes using inductive and deductive reasoning. For example, 'no medication review' and 'poor knowledge of medications' were grouped together under the theme of 'lack of appropriate medication management.' At this stage, two coding manuals were created, one for the data collected from seniors and/or their caregivers, and one from the data collected from care coordinators. These coding manuals listed all of the codes and themes that were found during

data analysis. Each transcript was coded and compared to earlier transcripts to either support existing concepts or form new themes (Charmaz, 2000; Adolph *et al.*, 2011; Creswell, 2012). Last, *selective coding* linked all major themes and categories to a core category that explained the data and formed a theoretical framework for this transition from perspectives of seniors and/or their caregivers, and care coordinators.

Codes were operationalized using information revealed during the interviews. The patterns of behavior revealed within the codes were used to generate definitions for the themes and categories (Adolph *et al.*, 2011). For example, ‘medication management’ was defined as having a discussion on medications with care coordinators, and frequently reviewing medications with care providers.

The interviews with seniors and/or their caregivers were analyzed separately from the interviews with care coordinators. The data analysis of seniors and/or their caregivers aimed to address all 3 research objectives while the interviews with care coordinators aimed to address the first research objective only. This method allowed the researcher to examine both the perspectives of seniors and/or caregivers, as well as the care coordinators to come to an overall perspective of the transition from homecare services to self-management after discharge.

4.7.2 Memo Writing

Memo writing was used to help explain the formation of themes and categories by providing the reasoning behind each decision. Memo writing is a crucial component of grounded theory and helps increase credibility (Creswell, 2012). Through the use of memos, the researcher wrote down ideas about themes and their relationships to increase the

trustworthiness and defensibility of the study (Adolph *et al.*, 2011). Use of memo assisted in data analysis by identifying how themes and categories related to each other.

4.7.3 Intercoder Reliability

In addition to coding by the primary researcher, the transcripts were also independently coded by a research assistant who had experience in qualitative methodology and coding interviews. The research assistant was also familiar with knowledge of seniors undergoing healthcare transitions.

Once coding manuals were created independently by both researchers, main themes were compared and consensus was reached for all of the final themes in results. This process ensured peer examination to reduce researcher bias and enhanced validity and reliability (Krefting, 1991). Memos kept track of the reasoning behind all themes in the final results.

4.8 Data Saturation

Data saturation occurs when no new information or theme is observed in subsequent interviews and analysis (Guest, Bunce & Johnson, 2006). A stopping criterion of 3 (no new themes are observed during analysis of three successive interviews) is used to determine data saturation (Francis *et al.*, 2010). The goal of this study was to reach data saturation with a stopping criterion of 3 during analysis of interviews with seniors and/or caregivers, as well as care coordinators.

4.9 Member Check

After analysis was completed, feedback letters with the findings were sent to the seniors and/or their caregivers as well as care coordinators (**Appendix E**). Feedback to participants ensures that data has been presented fairly and in a way that depicts their experience. Seniors and their caregivers as well as care coordinators were given one week to contact the researcher if there were any concerns. Their concerns were discussed over the phone and detailed notes were taken. Results of the member check are presented under **Participant Feedback** in the **Findings** chapter.

4.10 Trustworthiness

The methods of this study and the data analysis were designed to help ensure trustworthiness. Trustworthiness in qualitative research is determined by credibility, transferability, dependability and confirmability of qualitative studies (Shenton, 2004). Credibility refers to the internal validity of a study, which explains how well the study findings reflect the reality of participants. The use of established qualitative methods helps enhance credibility. Transferability refers to external validity, which explains how generalisable the study is to the rest of the population. The dependability of a qualitative study refers to reliability, which explains how well the results can be replicated using the similar methods. Confirmability refers to objectivity of a study, which aims to eliminate bias (Shenton, 2004).

Memos were kept to help describe formation of themes and categories and ensure transferability and dependability. A second coder allowed for greater rigor and increased

credibility and confirmability of the results to ensure minimal researcher bias and eliminate as much subjectivity as possible in deciding themes that were relevant. In addition, the results were sent back to participants as a 'member check' and they were allowed to address any concerns regarding the accuracy of results and confirm the findings. These steps ensured a rigorous process for data analysis that increased the overall trustworthiness of the findings and minimized researcher bias.

Chapter 5: Findings

The following chapter presents the findings of this study. Characteristics of seniors and/or their caregivers and care coordinators are presented, followed by the results of the analysis. Major themes are discussed.

5.1 Sample Characteristics

5.1.1 Seniors and/or Caregivers

In total, 3 seniors were interviewed with their caregivers, 2 seniors were interviewed without a caregiver, and one caregiver was interviewed without the senior. All primary caregivers were spouses who cared for their partner on a full-time basis (24/7). Each seniors' RAI-HC, scores are presented in **Table 2**. One senior was cognitively impaired and required supervision with ADL's (ADL self-performance score) but all other seniors were cognitively intact and rated as independently able to perform ADL's. Two seniors showed signs of mild depression (DRS score) but no indication of a major depressive disorders. One senior showed low health instability and another showed moderate health instability (CHESS scores) while all other seniors showed minimal health instability. Four seniors had mild or moderate daily pain, one had less than daily mild pain and one senior had no pain. Finally, one senior with cognitive impairment had a very high need (MAPLe scores) for care, two seniors had mild need, two seniors had a moderate need, and one had low need.

Overall, the seniors interviewed were on average 81.7 years old and 5 out of 6 seniors were female (**Table 3**). Three of the six seniors had spouses as primary caregivers.

Table 2: The age, gender, cognitive performance scale (CPS) score, depression rating scale (DRS) score, ADL self-performance score, CHESS score, Pain scale score and MAPle for all senior participants in the study.

Senior	Primary Caregiver?	Age	Gender	CPS score (out of 6)	DRS score (out of 14)	ADL self-performance score (out of 6)	CHESS score (out of 5)	Pain scale score (out of 3)	MAPle
1	Yes	75	Male	2 (mild impairment)	2	1 (supervision required)	2	2 (moderate)	Very high
2	Yes	93	Female	0 (intact)	0	0 (independent)	1	2 (moderate)	Mild
3	No	82	Female	0 (intact)	0	0 (independent)	1	2 (moderate)	Low
4	No	86	Female	0 (intact)	0	0 (independent)	1	2 (moderate)	Mild
5	Yes	74	Female	0 (intact)	2	0 (independent)	3	1 (mild pain)	Moderate
6	No	80	Female	0 (intact)	0	0 (independent)	1	0 (no pain)	Low

Furthermore, all seniors suffered co-morbidities. Three seniors were identified by WW-CCAC as ‘community independent’ while three were ‘chronic’ seniors (**Appendix F**). Most seniors received occupational therapy and personal support services while two seniors also required physical therapy.

Table 3: The health conditions, caregiver status (and age), homecare services received, reason for enrolment into homecare and length of homecare services for all senior participants in the study.

Senior/Dyad?	Health conditions of senior at initial enrolment with CCAC	Caregiver Status (age)	Identification of senior by CCAC at initial enrolment	Services received while on service	Reason for homecare services	Length of homecare services
Dyad 1 (Senior 1 + Caregiver 1)	Irregularly irregular pulse, dementia, arthritis	Able to manage ADL's/IADL's (unavailable, 65+)	Chronic	OT	Help with ADLs	84 days
Dyad 2 (Senior 2 + Caregiver 2)	Coronary artery disease, hypertension, arthritis	Mobility issues, receiving support – hearing/eyes/housework (91)	Community independent	PT and personal support	Help with ADLs; suffered from a fractured pelvis	108 days
Senior 3	Coronary artery disease, hypertension, arthritis, diabetes, COPD, legally blind	N/A	Community independent	OT and personal support	Help with ADLs; showers	320 days
Senior 4	Coronary artery disease, hypertension, osteoporosis, thyroid disease	N/A	Community independent	OT and personal support	Help with ADLs; suffered from a fractured humerus	131 days
Dyad 5 (Senior 5 + Caregiver 5)	Congestive heart failure, hypertension, diabetes, renal failure, thyroid disease, legally blind	Memory issues, able to manage ADL's/IADL's (unavailable, 65+)	Community independent	OT, PT and personal support	Wound care	126 days
Senior 6	Irregularly irregular pulse, arthritis, COPD	N/A	Community independent	OT	Help with ADLs; bathing	88 days

Seniors and/or caregivers were interviewed at their homes. The interviews were audio-recorded and lasted approximately an hour.

5.1.1.1 Dyad 1

Senior 1 was a 75 year old man, who was cognitively impaired and required supervision for ADL's and IADL's. He had an irregularly irregular pulse, dementia, arthritis, and was at risk for falls. He had received occupational therapy from CCAC for bathing/dressing and was identified as 'chronic' (moderate case management/help seniors prevent further deterioration). His wife, caregiver 1, was able to drive and perform all ADL's and IADL's for herself and her husband. They lived alone in their own house. Senior 1 and Caregiver 1 were interviewed 9 days after discharge from WW-CCAC.

5.1.1.2 Dyad 2

Senior 2 was a 93 year old woman who had coronary artery disease, hypertension and arthritis at the time of enrolment with CCAC. She did not have any cognitive limitations. She had received physiotherapy (help with ADL's) and personal support (help with cooking/cleaning/IADL's) from WW-CCAC and was identified as 'community independent' (moderate-to-low case management/supported independence). She lived with her spouse, caregiver 2. He was able to drive and could manage ADL's and IADL's of senior 2. They resided at their son's house.

Both senior 2 and caregiver 2 were able to help each other manage ADL's and IADL's, along with the help of their son. Senior 2 and Caregiver 2 were interviewed 8 days after her discharge.

5.1.1.3 Senior 3

Senior 3 was an 82 year old woman who suffered from coronary artery disease, hypertension, arthritis, diabetes and COPD. She was also legally blind. She lived alone in an apartment building. She was involved with the Canadian National Institute for the Blind. She received help from her neighbor, who was a nurse. She also had volunteers help her with IADL's and she was able to perform ADL's on her own. She marked everything in Braille. She had received occupational therapy and personal support services from CCAC and was identified as 'community independent'. She was interviewed 30 days after her discharge.

5.1.1.4 Senior 4

Senior 4 was an 86 year old woman, who suffered from coronary artery disease, hypertension, osteoporosis and thyroid disease. She had received occupational therapy and personal support from WW-CCAC and was identified as 'community independent'. She lived in an apartment building for seniors. She received physiotherapy in the building. Her son and his family lived down the street and her daughter-in-law was very helpful in supporting her to perform ADL's and IADL's as well as attend appointments. She also had friends within the building who could help her with transportation. Senior 4 was interviewed 29 days after her discharge.

5.1.1.5 Dyad 5

Senior 5 was a 74 year old woman who suffered from congestive heart failure, hypertension, diabetes, renal failure, and thyroid disease. She was legally blind. She had received occupational therapy, physiotherapy and nursing from WW-CCAC and was identified as 'community independent.' She was experiencing an exacerbation of a previously treated stomach

ulcer during the time of this interview and did not participate due to poor health condition.

Instead, the researcher interviewed only caregiver 5.

Caregiver 5 was the husband of senior 5 and managed her care full-time by performing ADL's and IADL's and administering her medications. He was still able to drive and able to perform all ADL's and IADL's. Caregiver 5 suffered from memory issues and had to manage his own health conditions as well. Dyad 5 lived at their own home and were interviewed 17 days after discharge from WW-CCAC.

5.1.1.6 Senior 6

Senior 6 was an 80 year old woman who had an irregularly irregular pulse, arthritis, COPD, thyroid disease and had suffered from a stroke. She had received occupational therapy from WW-CCAC and was identified as 'community independent.' She lived alone but had a daughter and other family members residing on the same floor of her apartment building. She was able to manage her care and perform ADL's and IADL's with help from family and friends. Senior 6 was interviewed 16 days after her discharge.

5.1.2 Care Coordinators

Six care coordinators were interviewed. Gender, experience, background and the type of senior population the care coordinators are assigned to are presented in **Table 4**. Three care coordinators worked with 'chronic' (**Appendix F**) seniors and three worked with 'community independent' seniors (**Appendix F**).

Table 4: Demographic information of care coordinators who participated in the study, including gender, experience, background and type of population they deal with.

	Gender	Experience as a care coordinator with WW-CCAC	Professional Background	Population
CC1	Female	7 years	Social Work	Community Independent seniors
CC2	Female	20 years	Nursing	Chronic seniors
CC3	Female	8 years	Social Work	Chronic seniors
CC4	Female	13 years	Nursing	Chronic seniors
CC5	Female	21 years	Nursing	Community Independent seniors
CC6	Female	3 years	Nursing	Community Independent seniors

Care coordinators were interviewed at their office. The interviews were audio-recorded and lasted approximately an hour.

5.2 Intercoder Reliability

Once transcripts were coded independently by the primary researcher and a research assistant, there was disagreement for two of the themes. After further discussion, ‘no expectations’ was removed and ‘network of informal support’ was added to the *second* objective. Consensus was reached by further discussion of the second objective. The two coders felt that ‘no expectations’ was not necessary because it was not relevant to the specific objective while

‘network of informal support’ would be added because it was considered important to the objective upon further discussion. There were no other disagreements.

5.3 Data Saturation

This study included 6 interviews with seniors and/or caregivers and 6 interviews with care coordinators. Due to a small sample size, data saturation was not observed in analysis of data from interviews with seniors and/or their caregivers. However, data saturation was observed in interviews with care coordinators. Analysis of the interviews with care coordinators did not yield any new themes after 5 interviews.

In analysis of interview transcripts of seniors and/or caregivers, the absence of new themes was not observed in three straight interviews. On the other hand, new themes were absent in three consecutive interviews during analysis of interview transcripts of care coordinators.

5.4 Objective 1: Preparation for self-management after discharge from WW-CCAC

5.4.1 Discharge process (as described by care coordinators)

After seniors were referred to WW-CCAC (by the hospital, community, or self-referral), a care coordinator visited the senior at their home to conduct an extensive intake assessment (RAI-HC) and determine the required level of care as determined by the RAI scores (**Appendix F**). Care coordinators then set up a care plan at the intake visit and assigned nurses, PSW’s, and/or therapists to work with the client according to care level. The nurses, PSW’s and/or therapists assessed care progress through observation and the achievement of goals (after the allocated time of hours is completed) and informed their employers via a progress report, which

was then forwarded to care coordinators. Next, care coordinators called seniors via phone to discharge clients who were deemed ready. Due to the care coordinator's heavy workload, a final visit or reassessment was rare.

5.4.2 Interview Analysis

Objective 1: Describe the preparation of long-stay seniors for self-management at discharge from home support services in the Waterloo-Wellington CCAC, through the perspectives of seniors and/or their caregivers, as well as care coordinators.

To address the first objective, we analyzed interview data from both the care coordinators' and the seniors' and/or their caregivers' perspectives. Initially, data was analyzed separately for both groups and major themes were discovered but analysis found similar themes between interviews with care coordinators and interviews with seniors and/or caregivers so results were combined and major themes were presented together. The themes may have been similar due to the use of a similar interview guide for both groups which yielded similar data from both perspectives. Four major themes were identified during interviews with both seniors and/or their caregivers, and care coordinators to describe the preparation of long-stay seniors for self-management at discharge from home support services in the Waterloo-Wellington CCAC. These themes are discussed in detail below: 1) Focus on medication management; 2) Links to Community Supports; 3) Information on health service providers and appointment management; and 4) Knowledge provided on health conditions.

5.4.2.1 Medication management

For this study, the theme ‘medication management’ encompasses all quotes describing medication management, discussion on understanding medications and their side effects and encouragement to visit a pharmacist for medication review.

At the time of discharge planning, none of the senior and caregiver participants had a discussion with the care coordinator regarding medications and their side effects. They did not receive help in understanding the medications they were taking and no information regarding any side effects of these medications or complications that could result from drug interaction was provided. Only one of the 3 spouses was able to describe the reason for taking medications and dosage and only 3 of the five seniors could describe the reason for taking their medications or behind the dosage of each medication and relied on family and friends for help with care.

“Not really. the doctors, you know, put prescription in at the pharmacy, at the hospital. The nurses come down, they give you the pills or give her the pills but I don’t know what the pills are or what they’re supposed to do.” (**Caregiver 5, lines 199-201**)

The only discussion regarding medication management took place at initial assessment or at reassessments. Medication management was part of the overall discussion about care plan and was only discussed specifically as part of the RAI-HC section on medications. Further discussion took place at the intake assessment if medication issues were identified through CAPS as part of the RAI assessment. . However, medication management was not revisited after the initial intake assessment or at the time of discharge.

One care coordinator acknowledged that issues with medication compliance may be an important reason for why seniors experience acute issues after discharge. Another care coordinator also stressed that a discussion on medication management is not a part of the discharge process.

In addition, four seniors and/or their caregivers had not discussed polypharmacy with their pharmacists or even contacted them, and were not encouraged to do so by their care coordinator. Yet, care coordinators stressed that the responsibility for medication reviews lies with seniors and their families and that medications would not be discussed, even at intake, if they were not identified as a concern during the initial RAI-HC assessment. Care coordinators also mentioned that they did not review medications of all seniors prior to discharge, only seniors with medication issues identified at intake assessment . This was described by one of the care coordinators:

“No I don’t revisit the medications prior to discharge, unless polypharmacy was a significantly identified issue. So this couple that...he’s taking blood thinners for his headache, and yes I’d pulled in family to help. And again, it’s not my responsibility to get their medications settled. It still rests with themselves. So I talk to them about who do you want in your family to help with this?” (CC3, lines 360-363).

In conclusion, there was no discussion around medication management after the initial intake assessment and especially absent near or at the time of discharge. Care coordinators felt the onus was on seniors and/or their caregivers to discuss any issues with medications.

5.4.2.2 Community Supports

The second theme in the overall topic of preparation for self-management after discharge was related to links to community supports. This theme included referrals to the seniors' center, other community supports and retirement homes and discussions around private pay options for supports after discharge. Community supports were subsidized programs in partnership with the local CCAC that provided services to help seniors with activities of daily living (ADL's) and instrumental activities of daily living (IADL's).

A seniors' center hosts a day program for seniors where they attend a few days per week for 4 to 8 hours daily and receive meals as well as partake in social activities with other seniors. All seniors and/or their caregivers mentioned being referred to a seniors' center by their care coordinator and 3 of the participating seniors were enrolled in one. Seniors described this as a pleasant experience and one caregiver described it as an opportunity for respite.

Care coordinators described linking seniors with formal community supports at discharge. The most often linkage provided was the seniors' day program.

“They just came and looked to see whether he was able to deal with the bath and such. But beyond that, nothing. Nothing, other than suggesting that he go to the senior's center there one day a week.” (Caregiver 1, lines 12-13)

If necessary, care coordinators also provided seniors with information of retirement homes and what to expect when moving. Care coordinators described leaving a brochure with all options for formal community support with seniors and/or their caregivers during the initial visit;

however, they mentioned only supports that were needed at the initial visit (but not at discharge) and the rest were in the brochure left with clients. The care coordinators did not repeat discussion on *all* available community supports at discharge. One of the care coordinators describes this as follows:

“Oh yes lots of times. We often...so we have a brochure of all the community supports and we’re linking to those for housework, getting to appointments, shopping...all those needs that a person can manage independently. Travel, how to get around the city. All the options. And we link to those we have a process for getting them linked so that they don’t have to make the call, I can set it up so the person comes to their homes and talks to them more about each of these things that helps them.” (CC 1, lines 216-220)

At discharge, seniors were also provided with information on the private pay options for community supports where they could continue with community supports by paying privately. Once discharged, seniors had to pay a subsidized fee for community supports if eligible and care coordinators mentioned informing seniors of this process before discharge.

“Yeah but the community supports are kind of pseudo-private. They don’t cost as much as private supports. The person could choose to go private but it’s just an option to use the community support. Its reasonable, very reasonably priced...” (CC1, lines 227-229)

In conclusion, seniors were well informed of community supports and their options for private care after discharge. The linkage to seniors’ center was well received as some seniors attended this service and enjoyed it while care coordinators had a chance for respite.

5.4.2.3 Information of health service providers

The third theme describes information provided to the seniors and/or caregivers on health service providers and appointment management in preparation for self-management of care. This theme is defined as seniors and/or caregivers receiving contact information of all healthcare providers/professionals, scheduling follow-up appointments with healthcare providers/professionals and discussion on making arrangements for appointments and visits.

Seniors were provided contact information for their local CCAC and told to call when needed. However, seniors and/or their caregivers were not encouraged to contact their existing physicians or pharmacists to schedule a follow-up appointment upon discharge from WW-CCAC. There were linked to formal community supports if needed but not physicians or pharmacists.

Furthermore, the seniors reported they were not given any tips or suggestions by the care coordinators on managing appointments with healthcare professionals, such as scheduling and logistical arrangements for any appointments.

“Researcher: Have they given you any help or tips on managing appointments with doctors?”

Senior 3: No, no.

Researcher: CCAC hasn't?

Senior 3: No I just do it myself.” (Senior 3, lines 114- 117)

Care coordinators confirmed findings from interviews with seniors and/or their caregivers and mentioned that they did not discuss appointments with healthcare providers as part of the discharge process. Care coordinators only inquired about ‘major’ appointments specifically related to the care plan such as physician follow-ups for ulcer being treated by WW-CCAC, but only while seniors were receiving homecare, not at or near discharge. One of the care coordinators describes that a discussion about appointments with care professionals does not fall in her job domain:

“I don’t help establish that. I rely on families for that. I do encourage: ‘how often do you see your physician? is it every 3 months?’ I specifically prod people with appointments around eye doctors as well. Many of our diabetic clients don’t know that they need to have routine follow-up with an eye doctor because of the complications of diabetes to eyes.” (CC3, lines 394-397)

In conclusion, a discussion on appointment management after discharge between care coordinators and seniors and/or their caregivers was lacking and only contact information for CCAC was provided. Care coordinators inquired about care plan-related appointments but this inquiry was only carried out at the initial assessment, not at discharge.

5.4.2.4 Knowledge of health conditions

The fourth and last theme during analysis of interviews with care coordinators and seniors and/or their caregivers is related to knowledge on health conditions was defined as discussions between seniors and/or their caregivers and care coordinators on health conditions,

including information on existing health conditions and any signs and symptoms that could lead to a deterioration in health. These signs and symptoms were defined as “red flags.”

In the interviews, seniors and/or their caregivers indicated there was no discussion at discharge regarding red flags related to health conditions. Similarly, care coordinators did not report discussing red flags in preparation for this transition.

“For me, I can’t say that I really do a red flag.” (CC1, line 321)

In one case, a senior experienced an exacerbation of the ulcer previously treated by nursing care from CCAC. The caregiver mentioned a discussion around ulcer management and what to do when things went wrong would have been preferable.

“No [discussion on managing ulcer]. And of course I didn’t think to ask questions like that because I didn’t know they would even have an idea of what they’re talking about.” (Caregiver 5, lines 292-293)

In conclusion, the preparation for self-management after discharge lacked a discussion on knowledge of existing health conditions. Seniors and/or caregivers reported receiving, if any, knowledge of health conditions from sources other than care coordinators in preparation for discharge.

5.4.2.5 Conclusion

In conclusion, analysis of the interview transcripts with seniors and/or caregivers and care coordinators showed a poorly informed discharge for this transition. This transition was lacking preparation to achieve successful transitional care as studied in previous literature (Coleman, 2003; Parry *et al*, 2003). Seniors and/or caregivers had limited knowledge of health

conditions, information on health service providers and medication management. However, there was knowledge awareness of community supports.

5.5 Objective 2: Transitioning from homecare services to self-management

Objective 2: Assess the quality of transition from the perspectives of long-stay seniors and their caregivers, including successful actions and challenges, from homecare services to self-management.

Since care coordinators were not present after discharge from WW-CCAC and only contributed to preparation for the transition before discharge, data was analyzed through the perspective of seniors and/or their caregiver only for this objective. Three major themes were identified to assess the quality of the transition from homecare services to self-management after discharge. These themes are discussed in detail below: 1) Formal process for medication review; 2) follow-up with healthcare professionals; and 3) network of informal support.

5.5.1.1 Formal process for medication review

In this analysis, a formal process for medication review was defined as discussing medications with a healthcare professional to review and reconcile all drugs in order to avoid potentially harmful drug interactions and adjust dosage.

None of the seniors interviewed had visited with a healthcare professional for a formal medication review after discharge. In one case, a senior had relied on her granddaughter, a pharmacist in Saskatchewan, to conduct an informal medication review and check all

medications. Another senior described using a drug book to understand the prescribed medications. This senior had experienced problems with medications and side effects in the past.

In one case, a caregiver did not understand what to do when the medication was finished; he was unsure whether the course of medication was completed or whether he needed to visit the physician for a refill. One of the caregivers described this:

“It might help if they can answer the questions like, say the doctor in the hospital says he’s got refills for say 300 pills and at the end of that, do I need to go back to the doctor in the hospital? Because the doctor in the hospital hasn’t said that [senior] needs more or that’s the...when we’re finished with that, that’s the end of it, she won’t need anymore?”

(Caregiver 5, lines 188-191)

In conclusion, lack of a formal process to ensure medication review may hinder the quality of a transition and successful transitional care because of potential complications and adverse outcomes. Seniors did not visit their pharmacists after discharge and did not get their medications reviewed. Some seniors reported having family and friends look at medications.

5.5.1.2 Follow-up with healthcare professionals

The second theme within analysis for the second objective is related to the lack of follow-up with healthcare professionals, defined as having a follow-up visit or call with CCAC after discharge and a follow-up with a family physician or a specialist.

Participants described a lack of follow-up from CCAC, and in one case where the ulcer had returned after being previously treated by CCAC, the care coordinator was unaware because the caregiver had not informed him.

“No, [CCAC] don’t even know about it, I don’t think. The doctor said that if [senior]- with the medication [doctor] gave [senior]- doesn’t do any better by Friday, [doctor] is going to refer [senior] to a skin specialist- dermatologist.” (Caregiver 5, lines 21-23)

In addition, CCAC or care coordinators did not inform seniors to make follow-up appointment with healthcare professionals upon discharge from homecare services. Seniors did not see physicians/specialists outside of regular appointments and did not schedule any check-ups or visits. One senior had not seen his doctor in 3 months and only attended regular blood tests every two weeks.

In conclusion, seniors were told by the care coordinators to contact CCAC when needed and see a doctor when needed but no specific appointments for a follow-up with a doctor were scheduled after discharge. Seniors were expected to take initiative and follow-up with their physicians or specialists as well as contact a pharmacist to review their medications with pharmacists themselves.

5.5.1.3 Network of informal support

The third and last theme for assessing the quality of transition was ‘network of informal support.’ This theme was defined as having support for the senior which included spousal support, friends and family (other than spouse) and neighbors and volunteers. Informal support includes any unpaid supports received by volunteers, family members and friends.

Participants indicated spousal support as most crucial. Spouses were full-time caregivers which allowed significantly impaired, physically and/or cognitively seniors to stay at home. Spouses managed all tasks related to ADLs and IADLs, including dressing, cooking, and

bathing. Spouses also helped cope with loneliness and isolation for seniors and supported the seniors to attend social events or activities by driving seniors when necessary. Spouses described being able to manage care for their partner as long as they were physically capable and the seniors were not too compromised in terms of health.

“And I said well I’m able to look after the house and make sure [senior] gets food and dressed and cleaned up and run him to the doctor when he has to go, run him to the lab when he needs to go. He gets to the bowling alley, he gets to the seniors place. A few other places if and when we feel like...” (Caregiver 1, lines 510-513)

There was also a great deal of support provided by other informal caregivers, such as family or friends in managing tasks related to ADL’s, IADL’s and health of seniors to maintain independence and avoid institutionalization. Seniors described neighbors and volunteers from the community as very helpful in managing IADL’s, including shopping and snow removal. Friends helped seniors manage medications and helped with shopping. Family members helped manage tasks related to ADL’s and IADL’s, and also helped manage finances. Family and friends were relied on to help organize medications and ensure orders were being followed according to the physicians. One of the seniors described this as followed.

“Well she’s a nurse and she’s a friend of mine. When I get my medication, [nurse friend] takes the bottles and she – because you have to keep the new bottles, you can’t use the old ones – so she gives me those and then I mark them down. So I have all this done until...now this will do me for about two months and then we start over.” (Senior 3, lines 96-99)

In conclusion, all seniors received help from informal supports which allowed them to manage their care.

5.5.1.4 Conclusion

In conclusion, analysis of interviews in this study showed limited transitional care as many elements of successful transitional care as identified in previous literature (Coleman, 2003; Parry *et al*, 2003) were lacking. During this transition, there was a lack of follow-up with healthcare professionals and a formal process for medication review. However, there was a large network of informal support available to seniors.

5.6 Objective 3: Examine the senior's and caregiver's experience of the transition and subsequent unmet needs for homecare services.

Objective 3: Examine the senior's and caregiver's experience of the transition and subsequent unmet needs for homecare services.

Data was analyzed for the experience of seniors and/or their caregivers undergoing the transition after discharge from WW-CCAC and unmet needs, in any, for homecare support. During interviews with seniors and/or their caregivers, two major themes were identified to explain their perspectives on managing on their own. These two themes are discussed in detail below: 1) perceived **capacity to manage/cope**; and 2) limited perceived needs of homecare or formal help.

5.6.1.1 Perceived capacity to manage/cope

In this analysis, perceived capacity to manage/cope with one's own care was defined as a reported confidence and capability to independently perform tasks without formal, paid support.

Overall, seniors and/or their caregivers felt fairly independent in managing their own care. They felt fortunate to avoid any major health issues and remain capable and independent.

“Well I can. I'm fine. I get up in the morning and do everything. Make my own breakfast and cook and like I say, I'm involved in quite a few things so I'm busy busy...” (Senior 3, lines 202-203)

In addition, seniors and/or their caregivers felt confident in their ability to manage the care and did not want to ‘bother’ with seeking formal help. In one case, a caregiver felt he was able to do the necessary tasks to care for his spouse even when her condition deteriorated.

“Yes. I wouldn't bother them unless [senior] went back in the hospital and came back and needed it. Because like I said, right now I'm doing all of this stuff...” (Caregiver 5, lines 55-56)

In conclusion, seniors and/or their caregivers expressed capability manage their care.. They did not want to seek help until absolutely necessary.

5.6.1.2 Limited perceived needs of homecare and formal help

The last theme to examine the experience of seniors and/or their caregivers and unmet needs for support was a limited perceived need for homecare and formal help. This was defined as seniors and/or their caregivers perceiving themselves as able to managing independently on

their own without any further homecare service and formal, private care, other than community supports, after discharge from homecare services.

In general, seniors and/or their caregivers did not perceive themselves as needing homecare or any formal support after discharge. In one case, even after the senior had experienced a return of her ulcer, the caregiver felt it was not necessary to seek help because he could manage. Seniors and/or caregivers did not want to be a ‘burden’ and felt other seniors in the community could use homecare more.

“So at this stage of the game it’s still...as long as I can look after [senior], I will do it. If anything happened to me, yes we would have to have somebody come in to look after the 2 of them.” (Caregiver 5, 365-366)

The absence of perceived need for help may also be due to the high level of informal support that allowed seniors to stay home. There was a great deal of support or help provided by informal caregivers, such as family or friends, or community supports in managing tasks related to ADL’s, IADL’s and health of seniors to maintain independence and avoid institutionalization.

5.6.1.3 Conclusion

In conclusion, analysis of the interviews for objective three showed a positive subjective experience as seniors and caregivers felt capable of managing their own care and received informal help from family, friends and neighbors. There was a limited perceived need for any kind of support after discharge and seniors and/or caregivers felt independent caring for themselves without homecare services or formal help.

5.7 Conclusion

This chapter presented the results of the qualitative analysis of this study. Results showed that the preparation for discharge lacked a discussion between care coordinators and seniors/caregivers on medication management, limited knowledge of health conditions and limited information of health service providers of seniors and caregivers. However, seniors and caregivers were aware of available community supports. Subsequently, the transitional care after discharge from homecare services lacked a follow-up/check-up with healthcare professionals as well as a formal process for medication but a large network was available to the seniors. The seniors and caregivers reported a positive experience with managing their own care after discharge with limited perceived need of homecare or formal help and capability to manage and cope without homecare services. Overall, there was a poorly informed discharge and limited transitional care but a positive subjective experience and avoidance of adverse health issues. The findings of this study are used to generate a theoretical framework of the perceived transition from homecare services to self-management after discharge by long-stay seniors at WW-CCAC. This theoretical framework is presented and discussed in the following chapter.

Chapter 6: Discussion

6.1 Introduction

The following chapter presents an interpretation of the findings, framed in the context of existing literature on other care transitions. In addition, a theoretical framework of the perceived transition from homecare services to self-management by long-stay seniors after discharge from WW-CCAC. Finally, the implications of the findings on the health of seniors are provided. Furthermore, strengths and limitations of this study are discussed as are directions for future research.

6.2 Discussion of the findings

This study set out to explore the quality of the transition of long-stay seniors after discharge from homecare services to self-management. Participants in this study, including care coordinators, described the lack of preparation for this transition and missing elements of transitional care. Although this specific transition is understudied in existing literature, studies examining other care transitions found similar results as this study. Parry *et. al.* (2003) conducted focus groups to understand challenges faced by older adults during care transitions (after hospital discharge) and discovered poor communication among providers and between providers and seniors, patient confusion about questions to ask their providers at discharge, what medications to take and inaccessibility of providers to have questions answered. In addition, seniors did not feel prepared or supported by their healthcare providers. In the present study, similar issues of

unpreparedness and lack of support were found as there was a lack of preparation for this transition at discharge due to a lack of a comprehensive discussion or final visit. There was also a lack of follow-up by care coordinators.

Another study by Halasayamani *et. al.* (2006) reviewed literature to explore challenges during care transitions (discharge from hospital) and identified medication management as a concern. They also identified follow-up appointments within 2 weeks of discharge as an important step for successful transitional care. Boling (2009) studied transitional care and discovered issues with absent or limited clinical information and content of care plan as well as medication related errors. Foust *et. al.* (2013) examined transitional care from hospital to home and found issues such as poor discharge instructions and inadequate preparation. In addition, informal caregivers were not involved in the process. Other studies found poor communication between seniors and providers, lack of follow-up by providers and need for adequate training of healthcare providers to provide necessary transitional care who are being limited by the system and lack of resources (Davis *et. al.* 2012; Dossa *et. al.*, 2012). These results are echoed by findings in the present study such as the lack of follow-up and discussion on medication management.

There was a lack of final visit or discussion for transitional care after discharge between seniors and their care coordinators in this transition which led to a poorly informed discharge and limited transitional care. Care coordinators mentioned a heavy workload as part of the reason for a lack of final visit or even reassessments. Communication between care coordinators and the clients' family physicians was also lacking as seniors and/or their caregivers were expected to take initiative and manage appointments on their own.

Care coordinators reported the onus was on seniors and/or caregivers to discuss any concerns or pose questions related to the preparation. However, seniors and/or their caregivers, even in the presence of issues, expressed desire to, and satisfaction in, independently managing their care and living at home. This may be in part due to the fact that seniors and/or their caregivers are unaware of what constitutes truly successful transitional care and discharge planning due to the lack of a discussion with care coordinators. The timing of interviews (less than a month after discharge) may have also played a part in a lack of perceived needs because the length of time after discharge may not be enough to observe any challenges with care or a deterioration in health. Therefore, the realization that certain transition needs may not have been met might not have occurred due to the short time frame.

6.2.1 Informed discharge and transitional care

Informed discharge prepares seniors and their caregivers to identify barriers to discharge, perform medication reconciliation, plan appointments pre-discharge, and provide communication with primary care providers. This can reduce emergency department visits and lower the rate of readmission within 30 days (Dedhia *et al.*, 2009). Successful preparation for a transition includes comprehensive review of medications, educating seniors and caregivers on self-management of conditions and detailed communication with health professionals (Legrain *et al.*, 2011).

Seniors may be at-risk for a medication error due to polypharmacy (Ellenbecker, Frazier & Verney, 2004). Medication mismanagement may result from seniors being discharged without understanding medications, unclear, ambiguous or conflicting medical orders, medication orders in record not updated and medication being prescribed by more than one provider (Ellenbecker,

Frazier & Verney, 2004). In this study, results showed a lack of discussion on medication management.

Absence of assistance with medication administration can lead to an increased risk for hospitalization and/or mortality in older adults in the community (Ernst & Grizzle, 2001; Juurlink, 2003; Simonson, 2005; Vik *et. al.*, 2006; Budnitz, 2007). Drug interactions can include drug-drug, drug-disease, drug-food, drug-alcohol, drug-herbal and drug-nutritional interactions (Mallet, Spinewine & Huang, 2007). It is important to discuss medication management with seniors and/or their caregiver during preparation for self-management to help avoid any unsafe drug interactions. Medication mismanagement can be very costly to the healthcare system (Simonson & Feinberg, 2005). Medication related problems include a medical condition that requires new or additional drug therapy; patient taking unnecessary drug given present condition; incorrect drug for current medical condition' correct drug, dose too high/too low; adverse drug reaction; drug interaction; and patient not administering medication correctly (Simonson & Feinberg, 2005). Although medication issues may be identified by RAI-HC Clinical Assessment Protocols (CAPS), the RAI-HC is only carried out during intake. The CAPS help identify significant health issues from the RAI-HC assessment that should be the focus of a care plan. Medications were not discussed at discharge even if they were previously identified as a concern. This suggests that these specific RAI HC functionalities were not fully implemented.

In this study, seniors had not formally reviewed their medications after discharge with a healthcare professional which could lead to adverse outcomes and hospitalization (Krska *et. al.*, 2001; Zermansky *et. al.*, 2006; Vinks *et. al.*, 2009). Medication reviews can be useful in solving

pharmaceutical care issues and also lead to increased contact with healthcare professionals which can serve as a preventive measure and lead to fewer hospital admissions (Krska *et. al.*, 2001).

Visiting the pharmacist also increases the likelihood of having changes made to repeat prescriptions, updating the correct administering of medications and avoiding any medication interactions (Zermansky *et. al.*, 2001). As a result, changes in the drug regimen could also reduce the likelihood of a fall by avoiding drowsiness and associated risks of unsafe drug interactions (Zermansky *et. al.*, 2006). In this study, there was a lack of a referral to the pharmacist in preparation for this transition as well as during the transition itself.

While the care coordinators at the CCAC may not have the skill set or knowledge to conduct a medication review and it may not be a part of their role, they can take active measures to encourage seniors to have one conducted by a qualified professional and ensure seniors follow up with the qualified professional.

In addition, an absence of a discussion at discharge regarding healthcare providers, including appointments and follow-ups, after discharge can also lead to health issues and adverse events (Foust *et. al.*, 2013). Physician follow-ups within 90 days of hospital discharge can reduce readmissions (Lin, Barnato & Degenholtz, 2011). Follow-up visits with physicians, by reducing readmission, can also lower annual health expenditures in seniors (Lin, Barnato & Degenholtz, 2011). A study involving seniors who had experienced heart failure found that seniors who had a physician follow-up within 7 days of discharge were less likely to be readmitted within the next 30 days than seniors who did not have a follow-up (Hernandez *et. al.*, 2010). In this study, there was a lack of information on health service providers in preparation for discharge after homecare

services as well as a lack of follow-up with healthcare professionals during the transition after discharge.

Furthermore, both seniors (and/or caregivers) and care coordinators mentioned a lack of discussion around health conditions, most notably red flags. Co-morbidity was a major issue for the seniors and made them more vulnerable to complications. A discussion around red flags can be important in helping seniors recognize signs of deteriorating health conditions and seek help to prevent further decline or adverse outcomes. Seniors with low levels of health literacy are more likely to be hospitalized and have worse health outcomes (Mark, 2009). Also, seniors have difficulty in effectively communicating with a healthcare provider because of their lack of knowledge related to their health conditions. A discussion on chronic illness self-management can reduce inpatient hospital days and hospitalizations, and improve health behavior (Leveille *et. al.*, 1998; Lorig *et. al.*, 1999).

The lack of contact between care coordinators and seniors (and/or their caregivers) at discharge could lead to a poor relationship with the care coordinator and lack of communication during the discharge process. In a study with heart failure patients (McCauley, Bixby & Naylor, 2006), results showed that healthcare providers may be more effective in preparing seniors for self-management by knowing them as individuals, understand how seniors' own goals will provide motivation to learn to care for themselves and persist in effective self-management over time, and also improve communication between the patients and provider.

Although the preparation was very limited, most seniors were enrolled in community supports, such as the adult day program. The adult day program provided seniors with the

opportunity to receive therapy, physical activity, and partake in social activities with other seniors such as playing cards. The seniors center also provided meals to the seniors. Seniors paid a subsidized fee to attend the seniors center. Seniors center can reduce caregiver stress and improve their well-being, allowing them to better take care of seniors (Gitlin *et. al.*, 2006; Zarit *et. al.*, 1998). Care coordinators also provided seniors with information and links with other community supports such as meals on wheels. These community supports provided meals at a subsidized cost, or help with transportation and other useful services to manage their ADL's and IADL's.

There was a large network of informal support which made it possible for seniors to manage at home. Seniors received help for ADL's and IADL's from their spouses, families, friends and neighbors which made it much easier for seniors to live independently at home. Consistent with this study, Keating *et. al.* (2003) also found that care networks were very important and allowed seniors to stay at home independently. These care networks included family and friends who helped with tasks related to care. Seniors with larger care networks were able to manage more effectively. Graham, Ivey & Neuhauser (2009) also found that seniors relied heavily on informal support during the transition from hospital to home. Chen & Wilkins (1998) also confirmed seniors living in private household relied on informal sources of support to manage their care. In this study, a large network of informal support may have been helpful in ensuring seniors and caregivers are able to manage their own care and perform ADLs and IADLs without homecare services.

This network of informal support was independent of care coordination or services provided by CCAC and existed through social connections between seniors and their family

members and communities. Care coordinators did not play a role in creating the informal network.

6.2.2 Perceived needs and experience

Overall, results for objective 3 showed that seniors and/or informal caregivers interviewed felt ‘fine’ with managing their own care and did not feel as though they needed formal help. Seniors and/or caregivers expressed satisfaction in managing their own care. Seniors and/or their caregivers expressed satisfaction in managing independently without homecare services. They were able to perform ADL’s and IADL’s with help from informal support.

However, some seniors and/or caregivers, as shown by the results and other studies (Brown, McWilliam & Mai, 1997; Howse, Ebrahim & Goberman-Hill; 2004), may not seek out formal help until their deterioration becomes relatively advanced or they experience an adverse event. Furthermore, their perception of health may not match up with the medically-defined definition and they may underestimate the amount of deterioration. Lack of knowledge about their health conditions and available help may act as a barrier to access. In some cases, seniors may be in denial because they want to remain independent, as reported by care coordinators, or they may be afraid of institutionalization. Therefore, it is difficult to determine need for care based on perceived needs and seniors should be well prepared with knowledge to recognize signs and seek help proactively.

Furthermore, seniors’ and/or their caregivers’ refusal to acknowledge need for help or wanting to manage on their own may act as a barrier to appropriate preparation for this transition and potential adverse outcomes in the future. Although seniors and/or caregivers reported they were ‘fine’ managing themselves, they also reported no expectations for how to manage during

this transition because they had not experienced it before. They had not thoroughly discussed the transition and what to expect with care coordinators at discharge.

Discussing expectations with care coordinators in preparation for discharge may be important as seniors can avoid challenges by anticipating any issues or difficulties and manage them accordingly. Furthermore, both seniors and care coordinators can raise awareness of potential challenges to help avoid them.

6.3 Theoretical framework of the perceived transition from homecare services to self-management after discharge from WW-CCAC by long-stay seniors

Throughout the analysis, it was clear that there was a lack of preparation and steps taken to ensure a successful transition based on elements of successful transitional care as previously identified (Coleman, 2003; Parry *et al*, 2003).

Figure 2 illustrates a theoretical explanation of what this transition entails, between the preparation before discharge to self-management after discharge from WW-CCAC. The core concept in this theoretical explanation is the *need for adequate preparation and appropriate transitional care versus experience during this transition*. The categories connected by the core concept are *informed discharge*, *limited transitional care* and *subjective experience*.

6.3.1 Informed Discharge

As shown by the major themes detailed above, there was limited preparation at discharge. The lack of a visit or a *purposeful* phone call at discharge resulted in a missed opportunity for care coordinators to have a discussion with seniors and/or their caregivers. Care coordinators only called clients to inform them their service had been terminated and they would be

discharged immediately. Further, seniors and/or their caregivers were expected to take initiative and reach out to care coordinators for information; however, they were very reluctant in seeking help from others because they may not know how to do this.

6.3.2 Limited Transitional Care

There was limited transitional care after discharge. Seniors did not receive information on medication review or scheduled follow-up visits with their family physicians. The major reason seniors did cope at home was the large network of informal support. Since seniors and/or their caregivers were expected to take initiative by care coordinators and they did not do so, elements of successful transitional care as identified in previous literature were lacking.

These elements include medication self-management, use of a dynamic patient-centered record, primary care and specialist follow-up, communication between healthcare professionals; preparation during transition for next setting; and education on signs and symptoms that indicate a worsening condition and who to contact (Coleman, 2003; Parry *et al*, 2003).

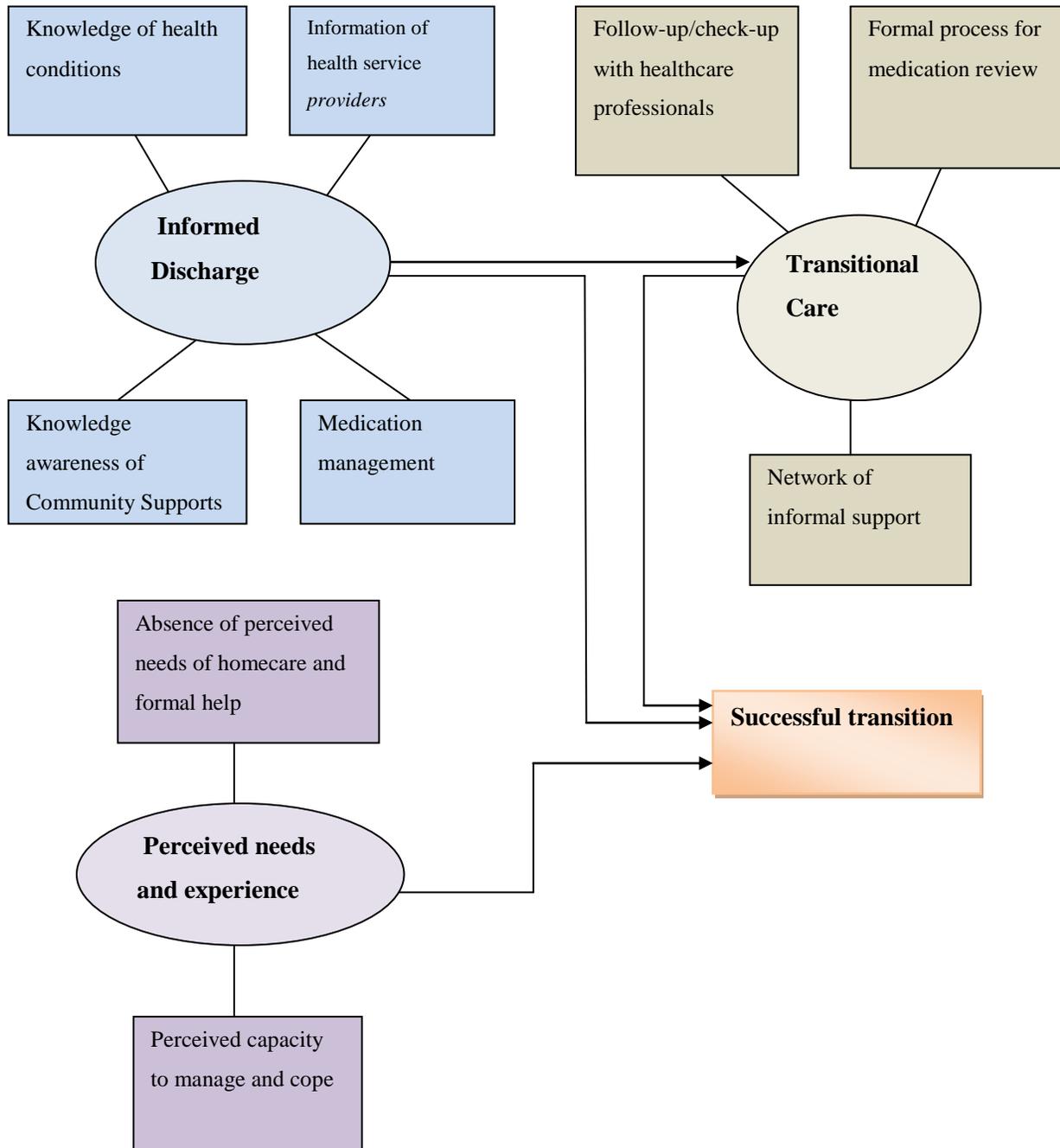
6.3.3 Subjective Experience

Seniors and/or their caregivers reported a positive experience with self-management and expressed satisfaction managing their care after discharge. They also reported a perceived absence of need for formal help or additional support. Due to their large network of informal support, seniors felt comfortable staying at home.

Although the preparation for transitional care was lacking, seniors did not perceive this as such because they were able to carry out physical tasks and feel capable in the short-term.

Using the information above, the following theoretical explanation for this specific transition was produced.

Figure 1: Theoretical framework of the perceived transition from homecare services to self-management after discharge by long-stay seniors from WW-CCAC.



6.3.4 Disconnect between perceived needs and actual transitory needs

The theoretical explanation of the perceived transitional care shows that this transition is missing many elements of transitional care as identified by Parry *et. al* (2003) and Coleman (2003). Results showed that seniors and/or their caregivers and care coordinators did not discuss medication reconciliation, plan for follow-up appointments with healthcare professionals, education on health conditions and knowledge on worsening conditions. In addition, there was limited preparation for the next setting (self-management) and care coordinators mentioned a lack of communication with healthcare providers administering services to determine readiness for discharge, with late or no reports by personal support workers or PTs/OTs. The communication between care providers and care coordinators was lacking as care coordinators communicated with the supervisors of agencies that employed care providers, instead of directly working with care providers themselves. Furthermore, care coordinators did not work with physicians or pharmacists to follow-up with seniors before or after discharge and relied on seniors themselves or their families to look after their care.

Seniors and/or their caregivers as well as care coordinators perceived that the preparation for this transition was adequate and that seniors were expected to take initiative and seek out information before discharge if they felt there were any issues. However, seniors and/or their caregivers felt they were capable and ready to manage on their own. The perceived needs by care coordinators as well as seniors and/or their caregivers were met by the preparation for discharge and transitional care. However, the actual needs based on previous literature (Coleman, 2003; Parry *et al*, 2003) required during this transition remained unmet.

6.4 Participant Feedback

The researcher developed and provided the theoretical framework (presented below in **Discussion**) to all six seniors and/or their caregivers and briefly discussed all of the major themes and categories with participants at their home. The seniors and/or their caregivers were asked to look over the theoretical framework carefully after the visit and contact the researcher within one week if there were any concerns.

One senior followed-up with the researcher and was ‘impressed’ with the results. The senior felt she had nothing to add to the framework and agreed with the information. She felt it represented her experience and was very ‘happy’ with the feedback.

Furthermore, the researcher provided all six participating care coordinators with the feedback letter and theoretical framework via e-mail. The care coordinators were given one week to reply with any comments/concerns.

One care coordinator responded to the researcher and the theoretical framework was discussed via phone. The care coordinator had comments related to the appearance of **Figure 1** but no comments/concerns on the content of the framework or results. She was satisfied with the framework and felt it was a fair representation of the data. In terms of appearance, the care coordinator felt that it would be easier to place positive/negative signs beside each theme instead of the categories only. Also, she felt that using terms such as ‘lack of’ or ‘limited’ beside each major theme would also make it more clear for the reader. However, the researcher explained the

reason for a lack of descriptors and positive/negative signs was to avoid making the framework seem biased and after further discussion, the care coordinator agreed it should be left unchanged.

6.5 Re-referrals/death

The findings showed a poorly informed discharge and limited transitional care. Although a follow-up was not a part of the study plan, the researcher was unable to contact one senior for the member check. When the researcher contacted WW-CCAC to inquire about this senior, it was discovered that the senior had passed away. Two other seniors who were contacted for a member check also reported they were re-enrolled for homecare services with WW-CCAC. One senior returned to homecare services after 150 days (hip fracture) while the other returned after 78 days (exacerbation of skin ulcer) of initial discharge from homecare services before the interview was conducted.

Although a causal link between poor transitional care and re-referrals/death cannot be inferred from this study, these observations reinforce the findings from this study that care Transitions following discharge from homecare services may be suboptimal and further work is required to understand how these might be improved.

6.6 Limitations

The biggest limitation of this study is the small sample size of seniors and/or their caregivers. Only 6 seniors and/or their caregivers were interviewed in this study. Initially, twelve or more were expected to be interviewed but recruitment was a major hurdle. Many seniors declined to participate due to inconvenience or illness and some eligible seniors who were

contacted had died. A small sample size resulted in failure to achieve data saturation for interviews with seniors and/or their caregivers. Recruitment took place over 5 months (February – June) but only six seniors volunteered to participate in this study.

The sample may not be representative of all seniors who undergo this transition. Seniors who had challenges during this transition may not have volunteered and more research needs to be conducted. The findings may not be generalizable to all seniors who experience this transition. Nonetheless, the findings were able to identify how seniors are prepared and elements of successful transitions that are missing for all seniors. There were similarities with previous literature on transitional care.

In addition to seniors, only 6 care coordinators agreed to participate in the study. Although data saturation for major themes was observed across all 6 interviews with care coordinators, 3 of the care coordinators dealt with ‘chronic seniors’ while 3 dealt with ‘community independent’ seniors. Therefore, more interviews with care coordinators would have helped ensure data saturation for both types of care coordinators.

Furthermore, due to the qualitative nature of this study, interviewer bias may be unavoidable. The researcher is a part of the data and co-constructs it with the participants through personal, rather than detached, engagement. Interviewer bias may be introduced during interviews in the way questions are framed, as well as during analysis where the researcher must form a theoretical explanation using the co-constructed data. Therefore, the researcher is a part of the data and must actively ensure as little bias as possible. In this study, the questions were designed using previous literature from other transition settings and the researcher had little knowledge of this transition to eliminate any pre-existing bias. Also, a second coder ensured the

themes were constructed from the data by confirming the findings and member check also ensured accuracy of themes to eliminate as much bias as possible. Memo's were also kept to keep track of theme formation and how the theoretical explanation was created from the data.

6.7 Strengths

This study contributed to the little existing literature with respect to this specific transition. Although there exists an extensive amount of literature on transitions between other healthcare settings, research on the transition after discharge from CCAC is lacking. This study was able to identify how seniors are prepared, the quality of transition and the subjective experience of seniors and/or their caregivers.

The theoretical framework for this transition formed in this study helps to show the disconnect between actual transitory needs and perceived needs of seniors and/or their caregivers. These findings have the potential to inform appropriate discharge of this specific senior population from WW-CCAC and enhance preparation of clients for this transition.

6.8 Implications for Future Research

The findings were an important initial contribution to the understanding of this specific transition, since there is little previous literature. Future research will test the theoretical framework of this perceived transition by examining health outcomes after discharge.

Further studies regarding this transition should select a randomized sample to try to capture all seniors, including ones who may have experienced a health issue and declined participation in this study. This will ensure greater validity and generalizability. Future research may also follow-up with seniors after interviews to examine if they faced any issues and require

hospitalization, institutionalization or re-referral to homecare services. This will help link the lack of preparation and poor quality of transitions to any adverse outcomes in the future.

In addition, future research needs to examine the extent to which seniors' perceived experience of managing helps contribute to the lack of preparation by care coordinators, who may be led to believe that seniors do not require a final visit because they are reporting ability to manage independently. Many seniors and/or their caregivers in this study were hesitant to seek help and follow-up because they reported being confident in their abilities to manage. As a result, care coordinators may have chosen to forego preparation, if any, and may have been falsely led to believe seniors do not require any more care coordination, which could contribute to future issues.

6.9 Chapter Summary

The developed theoretical explanation for transition after discharge from homecare services to self-management for long-stay seniors is valuable in describing the preparation for self-management and experience of seniors and/or their caregivers undergoing transitional care. It helps explain the disconnect between how care coordinators, and seniors and/or their caregivers, perceive their lack of need for information or knowledge to ensure necessary steps for a successful transition and their actual transitory needs. This results in a lack of preparation and poor transitional care, which places seniors at a greater risk for experience preventable adverse health outcomes which could lead to rehospitalisation, re-referral to homecare services and/or institutionalization.

The developed theoretical framework for this transition addressed the three objectives of this study: 1) describe the preparation of long-stay seniors for self-management at discharge from home support services in the Waterloo-Wellington CCAC, through the perspectives of seniors and/or their caregivers, as well as care coordinators; 2) assess the quality of transition from the perspectives of long-stay seniors and their caregivers, including successful actions and challenges, from homecare services to self-management; and 3) examine the senior's and caregiver's experience of the transition and subsequent unmet needs for homecare services.

First, results showed there was a poorly informed discharge from homecare services as there was a lack of final visit or thorough discussion at discharge. Seniors were only informed of their imminent discharge from care coordinators without any further discussion. Second, there was limited transitional care during this transition as elements of successful transitional care were missing. Third, seniors and/or their caregivers reported a positive subjective experience, as they expressed satisfaction in self-managing their care and an absence of perceived needs for formal care.

6.10 Conclusion

The purpose of this study was to explore the transition to self-management after discharge from WW-CCAC homecare services for long-stay seniors and their caregivers. Using previous literature on successful transitional care (Coleman, 2003; Parry *et al*, 2003), this study sought out to explore whether the specific transition after discharge from homecare services contained elements identified as important to successful transitional care.

The preparation of seniors and/or their caregivers by the care coordinators was examined as well as the quality of transitional care and the subjective experience of seniors and/or their

caregivers. Results showed a lacking transition overall but a positive subjective experience. A theoretical framework of this specific transition was presented.

This study is an important first step in improving discharge planning from CCAC to allow discharged clients to experience a successful transition and avoid potential adverse outcomes and hospitalization and/or institutionalization due to avoidable deterioration of health.

Further research is important to explore this transition in more detail using the presented theoretical framework and improve transitional care from WW-CCAC homecare services to self-management of care for seniors residing in the community.

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Appendix A: Script for Designated Contact (WW-CCAC)

6.11 Seniors:

Hello [Senior's name] and [Caregiver's name],

I have been informed of a study being conducted by a researcher at the University of Waterloo. The researcher would like to interview seniors and their caregivers for an hour, approximately 15 days after discharge from homecare services. The study aims to understand the experience of seniors and their caregivers with self-management of health, after discharge from homecare services. Participation in the study involves an interview with the researcher which would take about one hour.

Please take a look at the provided information letter. Let me know if you would be interested in participating and I can forward your contact information to the researcher.

Your participation will be greatly appreciated. The researcher is not affiliated with CCAC and your participation will not have any effect on any homecare services you may receive in the future. All information will be strictly confidential and stored in a secure location.

Thank you!

6.12 Care Coordinators:

Hello [Care Coordinator's name],

I have been informed of a study being conducted by a researcher at the University of Waterloo. The researcher would like to interview care coordinators for approximately an hour. The study aims to understand the preparation for self-management after discharge for long-stay seniors.

Please take a look at the provided information letter. Let me know if you would be interested in participating and I can forward your contact information to the researcher.

Your participation will be greatly appreciated. The researcher is not affiliated with CCAC and your participation will not have any effect on any homecare services you may receive in the future. All information will be strictly confidential and stored in a secure location.

Thank you!

Appendix B: Interview Guide

6.13 Seniors + Caregivers

A. Introduction

- Explain researcher role
- Researcher background and Affiliation with University of Waterloo
- Assure them of privacy and confidentiality

B. Purpose of Study

C. Audio-tape

D. Consent form

- Obtain Signatures from both seniors and caregivers
Procedure
 - Explain meeting agenda for the day

Identify the quality of preparation of chronically ill seniors for self-management at discharge from home support services in the Waterloo-Wellington CCAC.

- What services were being provided by the CCAC? How long were you receiving home care services?
- How were you prepared for discharge? *Describe
- Did you plan for discharge and how to manage your medications, appointments, etc.? *Describe
- Do you feel like you were prepared to manage on your own?
- What kind of help or arrangements did you make for yourself after discharge? Were you informed of any resources you could use to help with the transition? Did they help with linking you up to the services? (i.e. phone number, or phone call on your behalf, appt. made on your behalf)
- Do you feel like you were adequately prepared for discharge from home support services? *Explain
- Will it be very difficult to continue to live independently without the home support services? *Elaborate
- What were your expectations at discharge?

Assess quality of transition, including successful set of actions and challenges, from homecare services to self-management.

- a. Do you feel as though you are better off or worse off without home support services now that it has been some time? Or about the same?
- b. How well have you managed your own during the last 15 days?
- c. What challenges did you face? What went well?
- d. Were you able to manage appointments? Did you feel as though you had to repeat information at every visit with each healthcare provider?
- e. Did you review your medications the last 15 days? Can you describe the reasoning behind your medications to me? Do you understand why you take the amount of dosage for each medication? (an assessment of the quality of transition—helps determine whether they have learnt to manage their own medications during this transition (good) or whether they are struggling with this transition to self-management after discharge from homecare services)
- f. Do you know who to contact for appointments with healthcare professionals regarding health-related issues? Do you know how to set up appointments? Have you been unable to make any appointments?
- g. In retrospect, were you prepared for managing your own health without homecare services or did you require home support services?
- h. Were there any particular challenges you faced managing your own health without homecare services?
- i. Overall, what were some of the successful ways you were able to manage your own health? What were some of the hardships faced in the transition that could have been avoided with better preparation/planning or continuation of home support services?

Explore/examine the client's experience of the transition and unmet needs for homecare services.

- Were there any consequences as a result of not having help through home care?
 - Did you have any health issues during the last 15 days? How were you able to deal with them? OR How were you able to avoid any issues?
 - Did your quality of life or independence suffer as a result of no longer receiving home support services? *Did you have trouble performing everyday tasks?
 - Would a continuation of low levels of home support services be important? *Did you absolutely require those services or were you able to manage without such services?
 - What is the minimum amount of home support services that you believe would be helpful?
 - What was the impact on your caregivers/family members?
 - Have any of your relationships been affected after losing homecare?
 - Have you been limited by your environment? Your house? *Could changes be made to your house layout or bedroom to help you better manage your health?
 - Did you explore other options after discharge?
 - What do you think could have been done differently or better to make receiving help a better experience?
 - Any other suggestions or comments?
- a. Questions/Comments?
 - b. Conclusion
 - Explain how results will be used

- Re-assure them of independence from CCAC or other care providers and that their identities will be kept confidential
- c. Thank-you letter

6.14 Care Coordinators

A. Introduction

- Explain researcher role
- Researcher background and Affiliation with University of Waterloo
- Assure them of privacy and confidentiality

B. Purpose of Study

C. Audio-tape

D. Consent form

- Obtain Signatures from case managers

Procedure

- Explain meeting agenda for the day

Identify the quality of preparation of chronically ill seniors for self-management at discharge from home support services in the Waterloo-Wellington CCAC.

- How were the clients prepared for discharge? *Describe
- Were they given tips on how to manage their medications and appointments?
- Were they trained to manage their self-care independently? How?
- Were they satisfied with being discharged? Did they still want to be on service?
- Were they evaluated on whether or not they could take care of themselves independently?
- Were they given any tips and links to community resources? *Describe
- What arrangements were made for independence in care after discharge?
- What were the seniors and their caregivers expecting after discharge?
- Were they linked up with private care and other healthcare providers?
- Were there any modifications made to the home or any changes to their lifestyle to manage independently?
- Were they provided with information and knowledge on recognizing red flags and where to seek help?
- Were they given any resources to help locate appropriate providers?
- What are your expectations for seniors and their caregivers who were discharged? DO you feel they are adequately prepared for this transition? *Elaborate
- What challenges do you think they will face during the transition?
- Do you feel as though they would be better off being admitted to LTC or other healthcare services?
- Were seniors and their caregivers compliant and easy to deal with during preparation for discharge?
- Do you think seniors and their caregivers refused or exaggerated their ability to manage care at home to avoid institutionalization or extra help?
- Would you like to add anything else?
-

- a. Questions/Comments?
- b. Conclusion
 - Explain how results will be used
 - Re-assure them of independence from CCAC or other care providers and that their identities will be kept confidential

Appendix C: Information Letter

6.15 Seniors/Caregivers



School Of Public Health
and Health Systems

a42malik@uwaterloo.ca

University of Waterloo
200 University Avenue West
Waterloo, Ontario, Canada
N2L 3G1

This letter is an invitation to seniors who have received homecare services and their caregivers to participate in an exploratory research study. My name is Ali Malik, and I am a full-time M.Sc. student at the School of Public Health and Health Systems, at the University of Waterloo, currently conducting research under the supervision of Professor George Heckman on self-management after discharge from CCAC services.

Study Overview

A successful switch (transition) from receiving homecare services to managing one's own health after discharge from CCAC is important to avoid adverse outcomes and illness. The purpose of this study is to examine this switch after discharge from home support services and understand the strengths and challenges in preparation for discharge, the quality of transition, as well as the overall experience of seniors and their caregivers.

The research involves one interview to explore self-management of care in seniors without homecare services. The interview will be conducted 15 days after discharge from receiving homecare services. Overall, the study will explore your experience with the transition. Seniors and their caregivers will be interviewed for approximately one hour.

Your Involvement

You (senior AND caregiver) will be asked exploratory questions regarding your experience after discharge from CCAC and your input or feedback will be greatly appreciated. Participation in this study will allow both of you the opportunity to identify strengths and challenges during this transition and to raise any concerns you may have in order to help ensure successful transitions.

The interview will last approximately one hour and would be arranged at a time and place most convenient for both of you. To ensure the accuracy of your input, I would ask your permission to audio record the interview.

Participation in the interview is entirely voluntary and there are no known or anticipated risks to participation in this study. You may decline to answer any of the questions you do not wish to answer. Further, you may decide to withdraw from this study at any time, without any negative consequences, by advising the student researcher who will be conducting the interview. In addition, participation in this study will have **no effect** on any homecare services you may receive in the future.

Also, your most recent RAI-HC on file at the WW-CCAC will be anonymously used for demographic and background information.

Confidentiality/Security

Any personal information you provide will be kept confidential and stored in a secure location. No details pertaining to your identification, such as your name, will be disclosed.

All interview information will be kept for 5 years in a safe, password-protected USB drive that will only be accessible by the primary researcher. After 5 years, all information will be destroyed. With your permission, anonymous quotations may be included in the thesis and publications.

Contact Information

If you have any questions regarding this study, or would like additional information about participation, please contact me at **647-860-6281** or by email (a42malik@uwaterloo.ca). You can also contact my supervisor Professor **George Heckman** by telephone at 1-519-888-4567 ext. 31028 or by email at gheckman@uwaterloo.ca

This study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

This research project has also been reviewed by Homewood's Research Ethics Board on behalf of WW-CCAC. Please contact Steve Abdool, chair of the REB at 519-824-1010 ext 2118, should you have any questions as a research participant.

Thank you in advance for participation with this research study.

Yours very truly,

Ali Malik

M.Sc. Candidate

6.16 Care Coordinators



School Of Public Health
and Health Systems

a42malik@uwaterloo.ca

University of Waterloo
200 University Avenue West
Waterloo, Ontario, Canada
N2L 3G1

This letter is an invitation to case managers who work/have worked with seniors who have received homecare services and their caregivers, to participate in an exploratory research study. My name is Ali Malik, and I am a full-time M.Sc. student at the School of Public Health and Health Systems, at the University of Waterloo, currently conducting research under the supervision of Professor George Heckman on self-management after discharge from CCAC services.

Study Overview

A successful switch (transition) from receiving homecare services to managing one's own health after discharge from CCAC is important to avoid adverse outcomes and illness. The purpose of this study is to examine this switch after discharge from home support services and understand the strengths and challenges in preparation for discharge, the quality of transition, as well as the overall experience of seniors and their caregivers.

The research involves interviews with case managers to explore preparation for self-management of care in seniors after discharge from homecare services. Case managers will be interviewed for approximately one hour.

Your Involvement

You will be asked exploratory questions regarding your experience with preparation of seniors and their caregivers for discharge from CCAC and your input or feedback will be greatly

appreciated. Participation in this study will allow you the opportunity to identify strengths and challenges during this preparation and to raise any concerns you may have in order to help ensure successful transitions.

The interview will last approximately one hour and would be arranged at a time and place most convenient for both of you. To ensure the accuracy of your input, I would ask your permission to audio record the interview.

Participation in the interview is entirely voluntary and there are no known or anticipated risks to participation in this study. You may decline to answer any of the questions you do not wish to answer. Further, you may decide to withdraw from this study at any time, without any negative consequences, by advising the student researcher who will be conducting the interview.

Confidentiality/Security

Any personal information you provide will be kept confidential and stored in a secure location. No details pertaining to your identification, such as your name, will be disclosed.

All interview information will be kept for 5 years in a safe, password-protected USB drive that will only be accessible by the primary researcher. After 5 years, all information will be destroyed. With your permission, anonymous quotations may be included in the thesis and publications.

Contact Information

If you have any questions regarding this study, or would like additional information about participation, please contact me at **647-860-6281** or by email (a42malik@uwaterloo.ca). You can also contact my supervisor Professor **George Heckman** by telephone at 1-519-888-4567 ext. 31028 or by email at ggheckman@uwaterloo.ca

This study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

This research project has also been reviewed by Homewood's Research Ethics Board on behalf of WW-CCAC. Please contact Steve Abdool, chair of the REB at 519-824-1010 ext 2118, should you have any questions as a research participant.

Thank you in advance for participation with this research study.

Yours very truly,

Ali Malik
M.Sc. Candidate

Appendix D: Consent Form

6.17 Seniors/Caregivers

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by *Ali Malik* of the School of Public Health and Health Systems at the University of Waterloo, under the supervision of Professor *George Heckman*. I have had an opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts interviews may be included in the thesis and/or publications to come from the research, with the understanding that quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Yes No

I agree to have the in-person interview audio-recorded.

Yes No

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

Yes No

I agree to the use of my most recent RAI-HC on file at WW-CCAC, anonymously.

Yes No

Participant Name (Senior) : _____(Please print)

Participant Signature: _____

Participant Name (Caregiver) : _____(Please print)

Participant Signature: _____

Witness Name: _____(Please print)

Witness Signature: _____

Date: _____

6.18 Care Coordinators

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by *Ali Malik* of the School of Public Health and Health Systems at the University of Waterloo, under the supervision of Professor *George Heckman*. I have had an opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts interviews may be included in the thesis and/or publications to come from the research, with the understanding that quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Yes No

I agree to have the in-person interview audio-recorded.

Yes No

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

Yes No

Participant Name (Case Managers) : _____(Please print)

Participant Signature: _____

Witness Name: _____(Please print)

Witness Signature: _____

Date: _____

Appendix E: Feedback Letter



School Of Public Health
and Health Systems

a42malik@uwaterloo.ca

University of Waterloo
200 University Avenue West
Waterloo, Ontario, Canada
N2L 3G1

Dear (*Name*);

Enclosed is a draft copy of the theoretical framework based on my analysis of all interview transcripts that will form part of my thesis which has the full title *Exploring long-stay seniors' transitions from home care services to self-management*.

I hope you like the analysis, and in particular I hope you will find that I have been faithful to the information you gave me and to the general circumstances of the transition as you described them. If you feel that I have misrepresented you in any way, or if my presentation of events with which you were connected is not as you remember them, I invite you to send me your comments and I shall take them into consideration as I revise this draft. And of course, you may, as always, contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca if my draft chapter raises any concerns. This project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo.

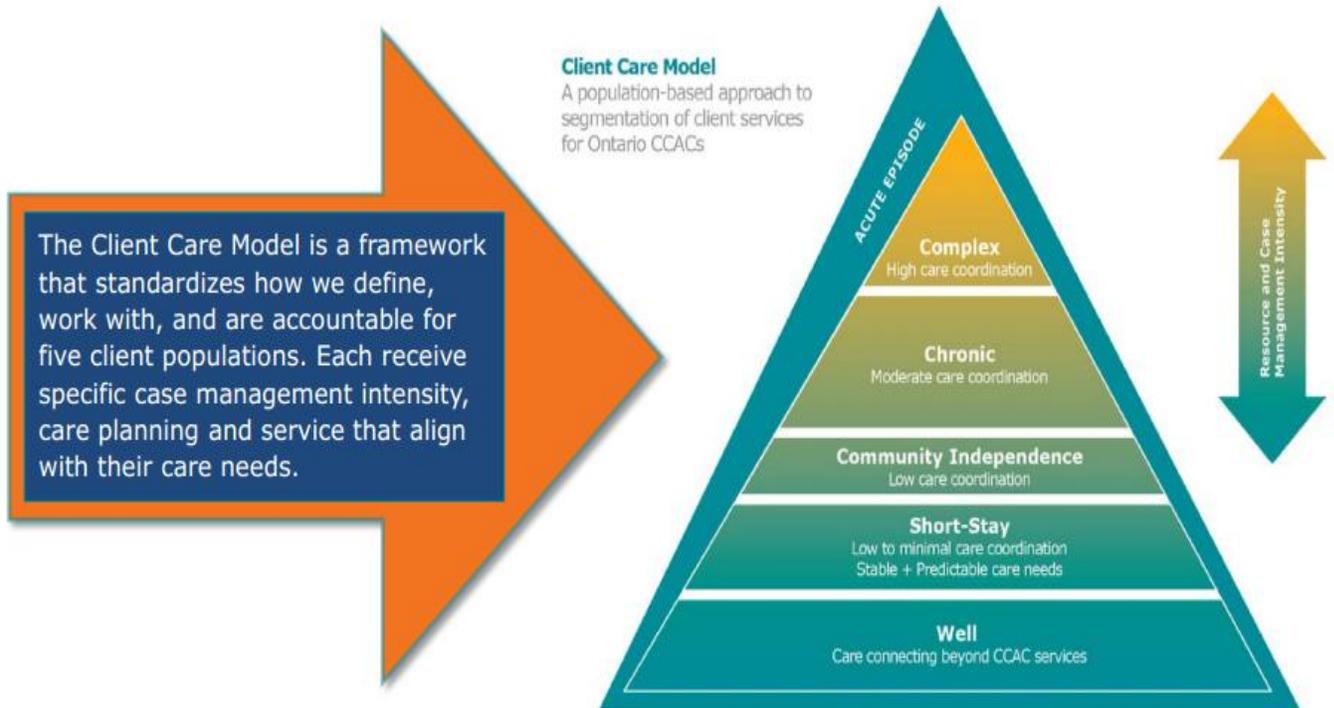
This research project has also been reviewed by Homewood's Research Ethics Board on behalf of WW-CCAC. Please contact Steve Abdool, chair of the REB at 519-824-1010 ext 2118, should you have any questions as a research participant.

I look forward to receiving your critique within the next two weeks. If you do not have time to write things down, feel free to give me a call at 647-860-6281.

Sincerely,

Ali Malik
M.Sc. Candidate

Appendix F: CCAC Client Care Model



Obtained from <http://www.ccac-ont.ca/Upload/ww/General/BoardMeetings/2012/Presentations%20at%20Board%20Mtg/2012-Apr-25%20CCM%20presentation%20Final.pdf>

Client Population, Sub-populations & Characteristics	Anticipated Outcomes	Case Management Intensity
<p>Complex – RAI aggregate 17+</p> <ul style="list-style-type: none"> •Complex medical, physical, cognitive and social conditions at risk for hospitalization, ALC or premature institutionalization. <p>Sub-populations</p>	<ul style="list-style-type: none"> • To support clients to maintain their health and well being so they can age at home and in their communities • Support clients and their families in managing the client's complex medical and support needs to enable the client to achieve some degree of stability in their preferred care destination. 	<ul style="list-style-type: none"> • High case management intensity required to manage complex array of services and care requirements • Significant role in coordination for effective system navigation – intensity of engagement with care partners within and beyond health sector • Outcomes oriented monitoring
<p>Chronic – RAI aggregate 11-16</p> <ul style="list-style-type: none"> •One or more health/chronic conditions with complicating factors. •Direct care needs are stable and predictable. •Can achieve stability with the right support network, but at risk due to chronic conditions •See CM Algorithm for further details <p>Sub-populations</p>	<ul style="list-style-type: none"> • To support clients to maintain their health and well being so they can age at home and in their communities. • To help clients maintain stability at home or in preferred care destination, • Provide a support structure that promote self-reliance (e.g. Helping with ADLs and IADLs) to keep clients in their home 	<ul style="list-style-type: none"> • Moderate case management intensity focused on helping client manage their health condition(s) and prevent further decline; creation of support networks to address functional needs • System Navigation • Outcomes oriented monitoring
<p>Community Independence - RAI aggregate 1-10</p> <ul style="list-style-type: none"> •May have one or more chronic illnesses/disabilities with some activity limitation •Is capable of independent living with connection to community resources •Has a stable support network •Anticipated time-limited CCAC contracted services (e.g., OT, PS supports) <p>Sub-population</p> <ul style="list-style-type: none"> •Supported Independence •Stable-at-risk (RAI aggregate 7-10) 	<ul style="list-style-type: none"> • To support clients to maintain their health and well being so they can manage at home and in their communities by fostering a self management approach and linkages to community-based resources. 	<ul style="list-style-type: none"> • Moderate to low case management intensity with a focus towards enablement of increased independence via effective pathways and system navigation • Opportunities for prevention of further disability should be considered for this client population to prevent avoidable escalation of care needs
<p>Short Stay</p> <p>Short term acute need</p> <p>Typically predictable and stable care trajectory Typically high likelihood of return to complete independence</p> <p>Sub-populations</p> <ul style="list-style-type: none"> •Acute •Wound 	<ul style="list-style-type: none"> • To support clients with acute or rehabilitation needs to transition to self-care by providing the required CCAC supports with a range of home and community based services. • Proactively identify clients to transition to long stay (where appropriate) 	<ul style="list-style-type: none"> • Overall, low case management intensity – with a focus upon clients with exceptions to the pathway / expected outcomes • Focused outcome monitoring and system navigation for clients with exceptions and additional needs off the pathway

Obtained from Barbara McKay (personal communication, October 26, 2012)

Appendix G: Search Strategy for Literature Review on Home Care and Seniors

Search 1:

"Home Care Agencies"[Mesh] OR "Home Health Aides"[Mesh] OR "Home Nursing"[Mesh]
OR "Homebound Persons"[Mesh] OR "Homemaker Services"[Mesh] OR "Home Care Services"
[Mesh] OR "Home Care Services, Hospital-Based" [Mesh] OR "Home Health Care"

Search 2:

"Community Health Services" [Mesh] OR "Community Medicine" [Mesh] OR "Long-Term
Care" [Mesh]

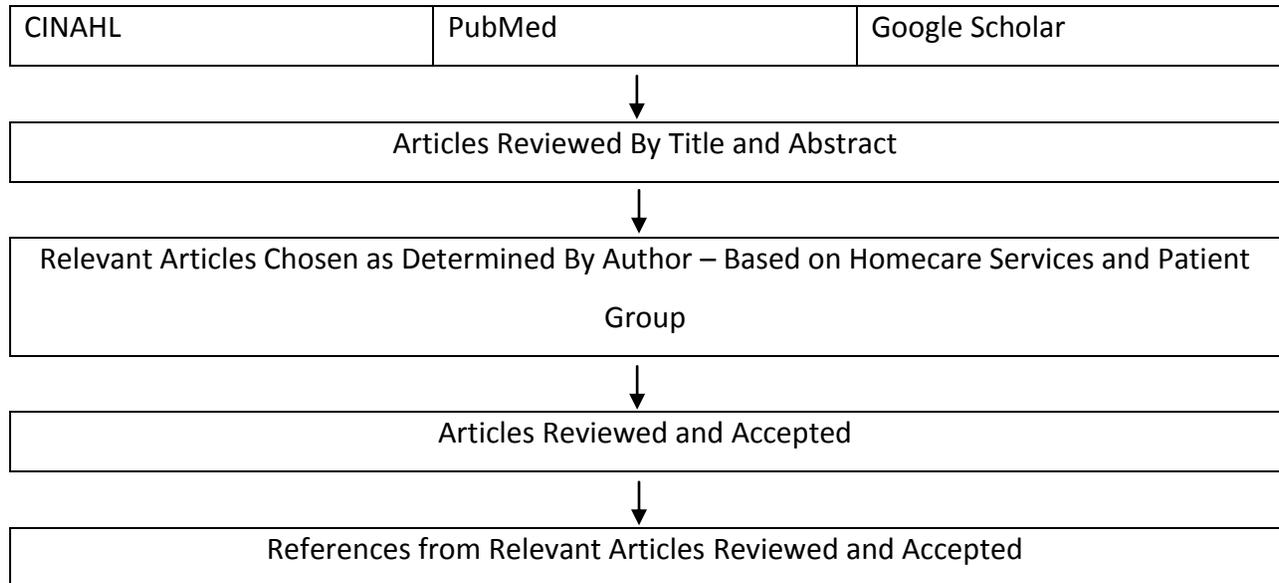
Search 3:

"Aged"[Mesh] OR "Aged, 80 and over"[Mesh]

Search 4:

(Search 1 + Search 2)*Search 3

Appendix H: Search Flow



Appendix I: Care Coordinator coding manual

1. Initial visit at intake
 - 1.1. Care Coordinators not hands-on with service
 - 1.2. Preparation starts at initial assessment
 - 1.3. begin with end in mind
 - 1.4. Usually see client once at intake
 - 1.4.1.1. may do additional visit depending on length of service
 - 1.5. Intake Assessment
 - 1.5.1. RAI
 - 1.5.2. provide brochure for CCAC and range of services
 - 1.6. depends on population of seniors
 - 1.1.1. chronic often discharged to retirement home/nursing home
 - 1.1.2. chronic need ongoing support
 - 1.1.3. community independent to achieve independence
 - 1.4. Ensure person meeting medications
 - 1.5. Ensure senior meeting investigations/tests
 - 1.6. Any dietary follow-up
 - 1.7. All done in discussion
 - 1.7.1. not in writing
 2. Avoid fostering independence
 - 2.4.1. don't provide unnecessary services
 3. Discussion via final phone call/visit
 - 3.4.1. Care is ending
 - 3.4.2. why its ending
 - 3.4.2.1. goal is met
 - 3.4.3. what are your options
 - 3.4.4. hiring privately
 - 3.5. Reduce services appropriately
 - 3.5.1. give extension if needed
 - 3.5.2. not giving therapists an extension
 - 3.6. RAI not conducted at discharge
 - 3.6.1.1. RAI at intake to establish goals
 - 3.6.1.2. false positive in RAI
 - 3.7. Don't do a global assessment at discharge
 - 3.7.1.1. only the 2 or 3 areas worked on during service
 - 3.8. Pre-discharge RAI
 - 3.8.1.1. never conducted because of large workload
4. choosing retirement home
 - 4.4. review retirement home package

- 4.4.1. base price
- 4.4.2. add-ons
- 4.4.3. expectations
- 4.5. additional costs for retirement home
- 4.6. transfer care to retirement home
 - 4.6.1. may not need CCAC
 - 4.6.2. substitute care from retirement home
 - 4.6.3. wait 2 weeks after entry to discharge
- 4.7. role of PSW in retirement home
 - 4.7.1. amount of work they provide
 - 4.7.2. sponge bath
 - 4.7.3. getting dressed
- 4.8. Make sure seniors connect with retirement home coordinator
- 5. Suggestions at discharge
 - 5.4.1. continue with doctor
 - 5.4.2. strategies to cope with memory issues
- 5.5. seniors follow-up with doctors/specialist
- 5.6. Private pay option
 - 5.6.1. Nursing
 - 5.6.2. professional
 - 5.6.3. PSW
 - 5.6.4. information
 - 5.6.5. have sheets of private pay
- 5.7. Contact CCAC if needed
- 6. Service order plan
 - 6.4.1. seniors know they're being discharged
- 7. Day program
 - 7.4.1. coordinate
 - 7.4.2. isolation factor
 - 7.4.3. congregated meals
- 8. Seniors unaware of what's out there
 - 8.4.1. overwhelming
- 9. Medications
 - 9.4. Seniors don't realize vitamins are medications
 - 9.4.1.1. contraindications with newer medications
 - 9.5. Most wouldn't know what they're taking
 - 9.5.1.1. names?
 - 9.6. Medications part of RAI (section Q)
 - 9.7. Medication discrepancy form (RAI)
 - 9.8. Medications set at intake

- 9.8.1.1. blister pack
- 9.8.1.2. prepared dossette by pharmacy
- 9.8.1.3. Get medications done by pharmacy if forgetfulness
- 9.8.1.4. note if problems with medications
- 9.8.1.5. record on CC dashboard on monthly basis
- 9.8.1.6. responsibility rests with clients
- 9.8.1.7. educate about pharmacists
- 9.9. polypharmacy
- 9.10. Wouldn't do medications unless identified concern
 - 9.10.1.1. follow-up until issue resolved
 - 9.10.1.2. don't discuss at discharge
 - 9.10.1.3. not dizzy
- 9.11. Signs of concern
 - 9.11.1.1. Don't know where medications are
 - 9.11.1.2. in one spot
 - 9.11.1.3. not organized
 - 9.11.1.4. ability to tell what meds are for
 - 9.11.1.5. medications from hospital discharge don't match at home
- 9.12. Wouldn't go over each medication
- 9.13. May have family to help with meds
- 9.14. Easier with CC's of nursing background
- 9.15. Review medications at RAI
 - 9.15.1.1. intake
 - 9.15.1.2. reassessment
 - 9.15.1.3. Only do medications if identified as concern
- 10. Can't tell people what to do
 - 10.4.1. onus on seniors/caregivers
- 11. Reassessments
 - 11.4.1. go back if major issues
 - 11.4.2. very rare
 - 11.4.3. difficult to reassess meds over phone
- 12. Managing appointments
 - 12.4. tips
 - 12.5. only discuss if something outstanding
 - 12.6. Don't deal with appointment management
 - 12.7. Don't arrange appointments
 - 12.8. wouldn't talk about all appointments
 - 12.8.1. beyond expectations
 - 12.9. make sure they write on calendar
 - 12.10. ask to see what they've done

- 12.11. don't know about appointments after discharge
- 12.12. make sure they use calendars
- 12.13. rely on their family for managing appointments
- 12.14. prodding people
- 12.15. OT would work on strategies to deal with memory issues
- 12.16. No RAI question for last visit to physician
- 12.17. link to doctors during service to ask them to follow-up with seniors
- 12.18. Tell seniors to see healthcare professionals if needed
 - 12.18.1.1. orthopedic for post-fracture
 - 12.18.1.2. follow-up for cardiac bypass
- 12.19. Encourage dietitian
 - 12.19.1.1. if obese with cardiac or diabetic
- 12.20. Times when CC returns and seniors haven't followed through
- 12.21. Ask seniors about follow-ups during service
 - 12.21.1.1. heart specialist
 - 12.21.1.2. surgeon
 - 12.21.1.3. diabetic doctor
 - 12.21.1.4. wound care
- 13. Information on community supports
 - 13.4.1. referrals
 - 13.4.2. make sure they're connected if needed
 - 13.4.3. cleaning
 - 13.4.4. meals
 - 13.4.5. transportation
 - 13.4.6. friendly visiting
 - 13.4.7. lifeline
 - 13.4.8. discuss fees
- 14. CC advocate for subsidies
 - 14.4.1. continue when books closed
 - 14.4.2. conducted at beginning of service
 - 14.4.3. in place before discharge
 - 14.4.4. up to seniors to pursue community supports
 - 14.4.5. set up so seniors don't call
 - 14.4.6. provided at beginning
 - 14.4.7. pseudo-private supports
 - 14.4.8. only discuss what seniors need; not all options
 - 14.4.9. only do formal linking for community supports
- 15. Talk to Caregiver
 - 15.4.1. if cognition issue
- 16. Determine readiness for discharge

- 16.4.1. through conversation
- 16.4.2. Agency reports
 - 16.4.2.1. Evaluate through observation
- 16.4.3. Don't have a checklist
- 16.4.4. professional services discharge
- 16.4.5. recommendations from therapists
- 16.4.6. CC discharge personal support
- 16.4.7. goals are met and recommendation has been made
- 16.4.8. OTs observe for evaluation
- 16.4.9. wound healed
- 16.4.10. template in CC head based on other seniors
- 17. Don't always get PSW report in timely fashion
 - 17.4.1. Delays plan
 - 17.4.2. Don't require routine reporting
- 18. People unaware of CCAC
 - 18.4. how it exists
 - 18.5. what they do
- 19. Seniors expectations
 - 19.4. pleased to get back to self-management
 - 19.5. Feel ready because they're unaware of what to expect
 - 19.6. Overwhelming to self-manage
 - 19.7. Hard to absorb all the information CC provides
- 20. Some seniors return
 - 20.4. after fall
 - 20.5. accident
 - 20.6. health crisis
- 21. Sense of entitlement
- 22. Seniors Seeking Help
 - 22.1. Refuse help
 - 22.1.1. fear of being moved to nursing home
 - 22.1.2. pride
 - 22.1.3. culture
 - 22.2. Downplay need for help
 - 22.3. Reluctant to seek help
- 23. CC expectations
 - 23.1. know there will be issues when you leave house
 - 23.2. can't force anything on seniors
 - 23.3. expect seniors to do fine
- 24. OT's make modifications to home
 - 32.1. OT educate at intake for equipment

- 32.2. ramp
- 32.3. changes to bathroom
- 32.4. bridge if financial services available
- 32.5. OT work out finances
- 32.6. assess what equipment is needed
- 32.7. Clients assume rental after discharge
- 32.8. CC provide option to rent/purchase equipment
- 33. Little discussions around red flags
 - 33.1. blister pack
 - 33.2. stairwell fixed?
 - 33.3. light fixed?
 - 33.4. only discuss when it comes up
 - 33.5. discuss at intake
 - 33.6. scattered rugs
 - 33.7. discuss wound care
 - 33.7.1. info packages for ulcer/wound care
 - 33.8. Don't document red flags
 - 33.9. Discuss if condition deteriorates while on service
 - 33.9.1. need for higher level of care
- 34. Causes of potential issues after discharge
 - 34.1.1. poor support systems
 - 34.1.2. co morbidities
 - 34.1.3. poor education
 - 34.1.4. lack of ability to absorb information
 - 34.1.5. unforeseen issues
 - 34.1.6. recurrent problems
 - 34.1.7. old age

Appendix J: Seniors coding manual

Preparation

1. Evaluation for discharge
 - 1.1. Observe condition/ability
 - 1.1.1. manage in bathroom
 - 1.1.2. shower
 - 1.1.3. dressing
 - 1.1.4. workers observe without helping
 - 1.1.5. ulcer treated
 - 1.2. CCAC's belief senior can manage
 - 1.3. Only evaluated by observation
 - 1.3.1. goal-oriented observation conducted by service provider
2. Seniors unsure of evaluation process
3. Discharged over phone
 - 3.1. refused final visit
4. Physical Challenges
 - 4.1. trouble entering tub
 - 4.2. bad knee
 - 4.3. shower due to difficulty with bath
 - 4.4. knee replaced
 - 4.5. trouble opening jars
 - 4.6. trouble opening pill bottles
 - 4.7. soar arms
 - 4.8. ulcer
 - 4.9. prefer >1 shower
5. Homecare Services received
 - 5.1. help with baths
 - 5.2. help with laundry
 - 5.3. very little quantity of care time
 - 5.4. showering
 - 5.5. prepare meals
 - 5.6. CCAC fantastic when help needed
 - 5.7. no help with housework
 - 5.8. help with dressing
 - 5.9. treat ulcer on abdomen/chest area
6. Determine plan after end of care
 - 6.1. inform senior of imminent discharge
 - 6.2. provided exercises
 - 6.3. some helpful warnings on avoiding high risk tasks
 - 6.4. Seniors center/Adult Recreation Center
 - 6.4.1. CCAC coordinates with seniors center
 - 6.4.2. seniors center communicates with seniors

- 6.5. handrails in bathroom
- 6.6. raised toilet seat
- 6.7. instructions on getting up/sitting down
- 6.8. no referrals
- 6.9. help bracelet
- 7. Lack of discussion/Needs unmet/unaddressed
 - 7.1. Cooking
 - 7.1.1. no training with opening jars
 - 7.2. Medication management
 - 7.2.1. no guidance by CCAC
 - 7.2.2. lack of help understanding
 - 7.2.3. no understanding of complications resulting from medications
 - 7.2.4. pharmacist did not discuss polypharmacy
 - 7.2.5. lack of medication review
 - 7.2.6. vulnerable to complications
 - 7.2.6.1. previous complications from mismanaging medications
 - 7.2.6.2. possible risk of stroke due to warfarin
 - 7.2.6.3. cramps due to medications
 - 7.2.6.4. ulcer on abdomen/chest area
 - 7.2.6.5. bad reaction from morphine previously
 - 7.3. Appointments
 - 7.4. Health conditions
 - 7.4.1. vulnerable to exacerbations of chronic issues
 - 7.4.2. ulcer returned after discharge
 - 7.4.3. no training on preventing/managing ulcer
 - 7.4.4. no discussion on managing ADLs/IADLs
 - 7.4.4.1. only nursing received
 - 7.4.5. would prefer discussion on management
 - 7.5. Community resources
 - 7.5.1. not informed of all available options
 - 7.5.2. not informed of transportation options
 - 7.5.3. no link to housecleaning
 - 7.5.4. no link to anyone
 - 7.6. Healthcare providers
 - 7.6.1. only provided contact information for CCAC
 - 7.6.2. no discussion around private options/providers
 - 7.6.3. no contacts provided
 - 7.7. CCAC's role
 - 7.7.1. uninformed of all available services
 - 7.7.2. unaware of discharge process
 - 7.7.3. unsure of CCAC's plan for discharge
 - 7.7.4. no preparation
 - 7.7.5. poor communication with CCAC
 - 7.7.5.1. lack of communication with spouse
 - 7.7.6. unaware of CCACs services
 - 7.7.7. Unsure of how CCAC works

- 7.7.8. low confidence
 - 7.7.8.1. trouble enrolling with CCAC initially
- 7.7.9. satisfied while on service
- 8. Seniors don't know what to expect
 - 8.1. unaware of potential challenges
 - 8.2. unsure of what to expect
 - 8.3. things not thought of by seniors
 - 8.4. confident in self-managing
- 9. No arrangements for private care

Transition

- 10. Reliance on prior Experience
 - 10.1.1. Managed spouse's care
 - 10.1.2. Managing own care
- 11. Medication Management
 - 11.1.1. Help from spouse
 - 11.1.1.1.1. understand reasoning
 - 11.1.1.1.2. understand purpose
 - 11.1.1.1.3. ensure course followed
 - 11.1.2. Blister pack
 - 11.1.3. pill dispensers
 - 11.1.4. use drug book
 - 11.1.5. pick up from pharmacy
 - 11.1.6. Splitting pills into correct dosage
 - 11.1.7. lack of medication review
 - 11.1.8. hope to cut back medications
 - 11.1.9. Medications
 - 11.1.9.1.1. blood thinners
 - 11.1.9.1.2. warfarin
 - 11.1.9.1.3. 15 different pills
 - 11.1.9.1.4. excessive medications
 - 11.1.9.1.5. water pill
 - 11.1.9.1.6. heart medications
 - 11.1.9.1.7. stool softener
 - 11.1.9.2. Desire to learn about medications
 - 11.1.9.2.1. only understand few medications
 - 11.1.9.2.2. unfamiliarity with reasons for dosage
 - 11.1.9.3. understand blood pressure pills
 - 11.1.9.4. organize two weeks at a time
 - 11.1.9.5. sort out medications
 - 11.1.9.6. morning pills/night pills
 - 11.1.9.7. mark medication bottles
 - 11.1.9.8. no missed medications
 - 11.1.9.9. Help from Friends
 - 11.1.9.9.1. organize medications

- 11.1.9.10. help from family
 - 11.1.9.10.1. pharmacist granddaughter
 - 11.1.9.10.2. informally reviewed medications
 - 11.1.9.10.3. daughter checks medications
 - 11.1.9.10.4. daughter organizes
- 11.1.9.11. good pharmacist
- 11.1.9.12. not confident in pharmacist
- 11.1.9.13. managing prescription refills
 - 11.1.9.13.1. unsure when to get refills
- 11.1.9.14. caregiver uninformed of reasons for medications/dosage
- 11.1.9.15. taking medications without understanding
- 11.1.9.16. manage on own
- 11.1.9.17. understand reasons behind medication
- 11.1.9.18. understand dosage

12. Appointments

- 12.1.1. Contact Doctor when needed
- 12.1.2. regular doctor visits
- 12.1.3. regular blood tests
- 12.1.4. no missed appointments
- 12.1.5. write down on calendar
- 12.1.6. make lists
- 12.1.7. Transportation
 - 12.1.7.1.1. spouse drives
 - 12.1.7.1.2. private transportation
 - 12.1.7.1.3. take the bus
- 12.1.8. contact CCAC to set up appointments
- 12.1.9. unsure if CCAC helps with doctors visits
 - 12.1.9.1. blood work every 3 months
 - 12.1.9.2. heart specialist once a year
 - 12.1.9.3. pharmacist once a year
 - 12.1.9.4. bone specialist
 - 12.1.9.5. eye specialist
 - 12.1.9.6. chiropractor
 - 12.1.9.7. daily diary for appointments
 - 12.1.9.8. skin specialist/dermatologist

13. Communication

- 13.1.1. Doctor contacts if dosage changes
- 13.1.2. doctor phones directly
- 13.1.3. lack of follow-up from CCAC or anyone
 - 13.1.3.1.1. CCAC unaware of exacerbation of ulcer
- 13.1.4. pharmacist
- 13.1.5. skin specialist/dermatologist
- 13.1.6. would prefer if CCAC taught ulcer management
- 13.1.7. unsure of family doctors role after discharge

14. Reliance on senior/caregiver taking initiative

- 14.1.1. contact CCAC if needed

- 14.1.1.1.1. placed on inactive list until contact
- 14.1.1.1.2. kept on file
- 14.1.2. see doctor when needed
- 14.1.3. wife contacts patient transfer after fall
- 14.1.4. delaying housecleaning arrangement
- 14.1.5. maintain daily diary of tasks
- 14.1.6. contact pharmacist for concerns
- 14.1.7. delaying contact until hospitalization
- 14.1.8. Help Bracelet
- 15. Informal Support
 - 15.1.1. excellent neighbours
 - 15.1.2. snow removal
 - 15.1.3. driving
 - 15.1.4. Friends
 - 15.1.4.1.1. mark medications
 - 15.1.4.1.2. nurse
 - 15.1.4.1.3. volunteers help shopping
 - 15.1.4.1.4. driving
 - 15.1.4.1.5. IADLs
 - 15.1.5. Family
 - 15.1.5.1.1. Live with son
 - 15.1.5.1.2. cooking
 - 15.1.5.1.3. daughter-in-law
 - 15.1.5.1.4. sister-in-law
 - 15.1.5.1.5. pharmacist granddaughter
 - 15.1.5.1.6. manage finances
 - 15.1.5.1.7. live nearby
 - 15.1.6. Volunteers
- 16. Spouse
 - 16.1.1. full-time caregiver
 - 16.1.2. senior worries if spouse absent
 - 16.1.3. Challenges
 - 16.1.3.1.1. lack of sleep
 - 16.1.3.1.2. lack of respite
 - 16.1.3.1.3. spouse's own health
 - 16.1.3.1.4. forgetting own medications
 - 16.1.4. Limitations
 - 16.1.4.1.1. Unable to lift senior if fall occurs
 - 16.1.4.1.2. own health conditions
 - 16.1.4.1.3. senior with fetal alcohol syndrome/memory issues
 - 16.1.5. Role
 - 16.1.5.1.1. shopping
 - 16.1.5.1.2. cooking
 - 16.1.5.1.3. cleaning
 - 16.1.5.1.4. dressing
 - 16.1.5.1.5. driving

- 16.1.5.1.6. manage appointments
 - 16.1.5.1.7. discover senior after falls
 - 16.1.5.1.8. perform IADLs
 - 16.1.6. Able to manage if senior physically capable
 - 16.1.7. require respite for knee surgery
- 17. Performing non-health related tasks
 - 17.1.1. driveway repairs
 - 17.1.2. big driveway
- 18. Social activities
 - 18.1.1. bowling
 - 18.1.2. seniors center
 - 18.1.2.1.1. “nothing to lose”
 - 18.1.2.1.2. enjoy seniors center
 - 18.1.2.1.3. meals provided
 - 18.1.2.1.4. respite for spouse
 - 18.1.3. playing cards
- 19. Potential Issues from medical history
 - 19.1.1. prior hospitalization
 - 19.1.1.1.1. falls
 - 19.1.1.1.2. double bypass
 - 19.1.1.1.3. pneumonia
 - 19.1.1.1.4. heart operation
 - 19.1.1.1.5. broken arm
 - 19.1.1.1.6. blood clots
 - 19.1.1.1.7. intravenous
 - 19.1.1.1.8. minor heart attack
 - 19.1.2. prior complications from medications
 - 19.1.3. bad cramps due to medications
 - 19.1.4. problems with blood pressure
 - 19.1.5. prior treatment of ulcer
 - 19.1.5.1.1. ulcer returned after discharge
 - 19.1.5.1.2. Very horrible condition lately
 - 19.1.6. diabetic
 - 19.1.7. neuropathy in lower body
- 20. Physical condition of Senior
 - 20.1.1. Skin
 - 20.1.1.1.1. Husband has trouble handling senior
 - 20.1.2. steady on feet
 - 20.1.3. bath
 - 20.1.3.1.1. too nervous to bath
 - 20.1.4. bad knee
 - 20.1.4.1.1. prior knee replacement
 - 20.1.5. trouble entering tub
 - 20.1.6. nervous crossing street
 - 20.1.7. trouble opening jars
 - 20.1.7.1.1. unable to eat food until help opening jars

- 20.1.8. trouble opening pill bottles
 - 20.1.8.1. sore arms
 - 20.1.8.2. difficulty washing dishes
 - 20.1.8.3. numbness in leg
 - 20.1.8.4. bad shoulder
 - 20.1.8.5. use of wheelchair
 - 20.1.8.6. slowed by arthritis
 - 20.1.8.7. blindness
- 20.1.9. seniors lack of sleep
 - 20.1.9.1.1. lack of respite for wife
 - 20.1.9.1.2. feet burn/legs aching
- 20.1.10. Cognitive impairment
 - 20.1.10.1.1. wandering around house
 - 20.1.10.1.2. turning lights on at night
 - 20.1.10.1.3. disoriented
 - 20.1.10.2. Vulnerability to falls
 - 20.1.10.2.1. history
 - 20.1.10.2.2. cracked pelvis
 - 20.1.10.2.3. compression fracture
 - 20.1.10.3. unable to clean
 - 20.1.10.4. trouble opening jars
 - 20.1.10.5. trouble opening pill bottles
 - 20.1.10.6. soar arms
 - 20.1.10.7. unable to reach high with arm
 - 20.1.10.8. celiac
 - 20.1.10.9. problems with digestion
 - 20.1.10.10. unable to move heavy objects
- 21. Managing IADLs
 - 21.1.1. write down tasks
 - 21.1.2. cooking
 - 21.1.2.1.1. food poisoning
 - 21.1.2.1.2. volunteers
 - 21.1.2.1.3. frozen meals from family
 - 21.1.2.1.4. mini-meals community program
 - 21.1.2.1.5. unable to afford meals on wheels
 - 21.1.3. shopping
 - 21.1.3.1.1. help from friends
 - 21.1.3.1.2. shopping with volunteers
 - 21.1.4. unable to clean
 - 21.1.4.1.1. trouble vacuuming
 - 21.1.5. able to cook
 - 21.1.5.1.1. difficulty peeling vegetables
 - 21.1.6. laundry
 - 21.1.7. dressing
 - 21.1.8. help with dressing
 - 21.1.9. help with dishes

- 21.1.10. avoid tasks unable to perform
- 22. Financial support
 - 22.1.1. workers compensation
 - 22.1.2. retirement business
- 23. Transportation
 - 23.1.1. spouse able to drive
 - 23.1.2. friend
 - 23.1.3. taxi very expensive
 - 23.1.4. take bus
- 24. Services after discharge
 - 24.1.1. physiotherapist
 - 24.1.2. housecleaning
 - 24.1.3. volunteers
- 25. No adverse health issues
- 26. Exacerbation of acute condition
 - 26.1.1. Infection
 - 26.1.2. Ulcer
- 27. Staying Active
 - 27.1.1. walk twice a day
 - 27.1.2. stationary bike
 - 27.1.3. exercises suggested by physiotherapist/CCAC
 - 27.1.4. pulley on door
 - 27.1.4.1. slow improvement
- 28. Private formal care
 - 28.1.1. no arrangements
 - 28.1.2. procrastinating on housecleaning arrangement
- 29. Community support
 - 29.1.1. program for handicapped
 - 29.1.2. Wheel Transfer
 - 29.1.3. volunteers help
 - 29.1.3.1.1. cooking
 - 29.1.4. mobility plus
 - 29.1.5. CNIB for blind people
 - 29.1.6. Stay involved
 - 29.1.7. mini meals program

Experience

- 30. Feel fairly independent
- 31. Feel fortunate to avoid issues
 - 31.1.1. physically and mentally stable
- 32. Barriers
 - 32.1.1. long reassessment
 - 32.1.2. hesitant to seeking help
 - 32.1.2.1.1. feel like a burden
 - 32.1.2.1.2. don't want to utilize CCACs time
 - 32.1.2.1.3. refused follow-up
 - 32.1.2.1.4. avoid 'complaining'
 - 32.1.2.1.5. feel less needy than others
 - 32.1.2.1.6. avoid imposing on others
 - 32.1.3. seniors center too far
 - 32.1.3.1.1. long drive
 - 32.1.4. avoid bothering until hospitalization
 - 32.1.4.1.1. husband managing
- 33. Refuse formal help
 - 33.1.1. feel help not needed
 - 33.1.2. manage without considering it a challenge
- 34. Satisfied with discharge process
- 35. Good relationships
 - 35.1.1. family doctor
 - 35.1.2. care coordinators
 - 35.1.2.1.1. satisfied with CCAC
 - 35.1.2.1.2. contact CCAC anytime
 - 35.1.2.1.3. excellent staff
 - 35.1.2.1.4. CCAC fantastic when help needed
 - 35.1.3. family
 - 35.1.3.1.1. visit regularly
 - 35.1.3.1.2. activities with family members
 - 35.1.3.1.3. fishing
 - 35.1.3.1.4. call family more for help
 - 35.1.4. Friends
 - 35.1.4.1.1. activities
 - 35.1.4.1.2. hunting
 - 35.1.4.1.3. hang out
 - 35.1.5. Neighbours
 - 35.1.6. very good physiotherapist
 - 35.1.7. very good pharmacist
 - 35.1.8. volunteers
 - 35.1.8.1. poor experience with private provider
- 36. Anticipating future deterioration
 - 36.1.1. walker stored in garage
 - 36.1.2. wheelchair
 - 36.1.3. house ramp
- 37. Relationships in community

- 37.1.1. grocery store manager
- 37.1.2. butcher
- 37.1.3. confidence in Investment manager
- 38. Health Issues
 - 38.1.1. Absence of major issues
 - 38.1.2. Ulcer returned
 - 38.1.2.1.1. infection
- 39. Trust in family