

A Mixed Methods Study:
Examining the Relationship between Therapeutic Self-Care
and Adverse Events for Home Care Clients in Ontario,
Canada

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ABSTRACT**A Mixed Methods Study: Examining the Relationship between Therapeutic Self-Care and Adverse Events for Home Care Clients in Ontario****Winnie Wai Ling Sun****Doctor of Philosophy in Nursing Science****Lawrence S. Bloomberg Faculty of Nursing, University of Toronto****2014**

The purpose of this mixed methods study was to examine the concept of therapeutic self-care in the context of home care, as well as its influence on the safety of home care clients and their informal caregivers. The quantitative approach used a retrospective cohort design and utilized secondary databases available for Ontario home care clients. Logistic regression analysis was used to examine the association between therapeutic self-care and adverse events. The qualitative approach utilized one-on-one interviews with the clients and their informal caregivers recruited from one home care agency in Ontario. Qualitative description was used to analyze data that generated themes about clients and their caregivers' perspectives of home care safety in relation to therapeutic self-care and informal caregiving.

The quantitative results indicated that low therapeutic self-care ability was associated with an increase in the odds of clients experiencing: (1) unplanned hospital visits; (2) decline in activities of daily living; (3) falls; (4) unintended weight loss, and (5) non-compliance with medication. Analyses of the qualitative interview data revealed four over-arching themes: (1) Struggling through multiple aspects of safety challenges; (2) Managing therapeutic self-care by developing knowledge, competency and self-confidence; (3) Coping with informal caregiving through problem-solving, stress management and caregiver relief; (4) Seeking education, support and collaboration from home care.

This mixed methods study advanced understanding of therapeutic self-care in the context of home care. The results provide a better understanding of the relationship between therapeutic self-care ability and the prevalence of adverse events experienced by home care clients. The qualitative findings provide insight into the safety problems related to therapeutic self-care and informal caregiving. This knowledge is vital to policy formulation related to the role of home care services in improving client's therapeutic self-care ability to reduce safety related risks and burden for home care recipients.

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Chapter One

Introduction and Problem Statement

1.1. Background

On August, 2007, the government of Ontario launched a \$1.1 billion initiative designed to increase services that help seniors to live in their homes (Ministry of Health and Long Term Care, 2010). The purpose of this initiative was to realign resources from acute to community care, and to better align home care services to provide seniors and their informal caregivers with care and support tailored to their needs. Home care is defined as the delivery of health care treatments and supports to clients remaining at home during the receipt of health care treatment, with the effect of preventing, delaying or substituting for care in the hospitals or other institutional settings (Canadian Home Care Association, 2013). In Ontario, clients may receive home care services through the Community Care Access Centres (CCACs). The CCACs are single-point entry agencies that determine eligibility for the community and institutional services. They also act as case management organizations contracting with the home care agencies to provide services including professional nursing, therapies and homemaking.

Over the past years, there has been an increasing amount of health resources devoted to home care settings for the management of disease conditions (Aging at Home Evaluation Project, 2010). Home care is now one of the fastest growing programs in the Ontario health care system. Home care in Canada grew by 55% between the year of 2008 and 2011 (Canadian Home Care Association, 2013). There were 1.4 million home care recipients and 5 million informal caregivers in Canada as of the year of 2011 (Health Council of Canada, 2012). In particular, it has been noted that the home care population is aging. In 2009, seniors made up just over 10%

of the population (The Change Foundation, 2011). By 2036, this number is expected to be more than double, and nearly one in four Ontarians (4.2 million of people) will be 65 or older (Ministry of Health and Long-Term Care, 2010). The oldest group will grow most quickly whereby the number of people 75 and older will be 2.5 times higher, while the number of people 90 and older will triple. Although home care services are available for clients of all ages, more than 75% of the home care clients in Canada are seniors (Health Council of Canada, 2012). Given the aging of the population, and the trend towards reduced use of institutionalized care settings, the number of clients being cared for at home will continue to increase in the future. It is therefore vital to ensure that adequate home care resources are available to support those who wish to remain at home.

In addition to the aging population, Canada faces an epidemic of chronic diseases. More than one third of home care recipients have multiple long-term health problems (Public Health Agency of Canada, 2011). In particular, chronic conditions are more common among older home care clients with 77 percent of people over the age of 65 experiencing at least one chronic condition (Canadian Home Care Association, 2013). The World Health Organization has identified that chronic conditions will be the leading cause of disability by 2020, and such conditions will become the most expensive problem for the health care systems if not successfully managed (World Health Organization, 2005). Living with a chronic disease has a significant impact on client's quality of life and on their families. As age advances, older adults may require help from their informal caregivers for personal care or tasks around the home due to physical or mental decline. Current research suggests that very few seniors receiving home care are managing the care by themselves. Of 131,000 home care clients 65 and older, 98 % are receiving help from an informal caregiver (CIHI, 2010). Therefore, the support from informal

caregiver is vital to facilitating home care client's ability to maintain independence and continue successfully living in their own homes (Health Care in Canada, 2011).

Home care forms an important bridge between acute care received in hospital and a patient's ultimate recovery or ability to return to a more independent level of functioning (Hollander, 2008). A study by Hollander and Tessaro (2001) indicated that home care service is of critical importance in the management of chronic diseases by avoiding unnecessary visits to emergency room and unnecessary hospitalizations, as well as delaying admissions to long-term care homes. Therefore, supportive care from hospital to home is vital to the successful management of client's chronic conditions (Ontario Association of Community Care Access Centres (OACCAC), 2009). Frequent health care transitions, shorter hospital lengths of stay, and lower health conditions on discharge are some examples of why the need for quality care planning from acute care to the home is more important than ever (Health Council of Canada, 2012). Home care potentially plays a critical role in maintaining the independent function of the growing older populations, as well as restoring and encouraging self-care in clients with chronic conditions (Suter et al., 2008). McCormack (2003) suggests that the issue of self-care is especially important for those with chronic diseases because the client and their informal caregivers are responsible for his/her day-to-day care over the length of the illness.

Self-care encompasses the ability to take medications as prescribed, to recognize and manage symptoms that may be experienced such as pain, to perform and adjust regular activities of daily living, and to manage changes in condition (Sidani, 2003). Self-care relates to the client's ability to manage their disease conditions at home, such as after discharge from the hospital. Dai, Chang, Hsieh & Tai (2003) described how the discharge of a client with a chronic disease is not only a medical problem, but it is also a condition with social implications because

both clients and their family members face challenges related to self-care. Often, clients and their family caregivers have to cope with psychosocial problems generated by the chronic diseases, and must manage daily living within the constraints of their financial and social conditions (Lorig, & Holman, 2003). Barlow, Wright, Sheasby, Turner and Hainsworth (2002) propose that successful self-care of chronic conditions requires sufficient knowledge of the condition and its treatment, performance of management activities and application of the necessary skills to maintain adequate psychosocial functioning.

Despite the increasing demand for home care services to support the management of chronic diseases, there is a growing body of evidence that suggests at least one-third of all home care clients and their informal caregivers are unprepared for self-care in the home care settings (Coleman, 2006). Coleman, Mahoney & Parry (2005) assessed hospital discharge planning, and found that 20% of clients were not told about important side effects; 39% were not told what signs and symptoms to watch for at home; 32% were not told when they could resume normal activities; and 29% were not told what activities they could or could not do at home. This study suggests that hospitals often discharge clients with insufficient planning for self-care skills, poor instruction and inadequate information about the management of self-care. Naylor et al. (2003) reviewed 94 studies, and found that the transition of older adults from hospital to home is associated with high rates of preventable poor post-discharge outcomes. In Ontario, a study by Forster et al. (2004) found that an estimated 23% of patients discharged from the hospital to home experienced at least 1 adverse event. Among these adverse events, 12% were preventable; 12% lead to hospital readmissions; and 72% were due to medication errors. In particular, home care clients who were older adults coping with multiple chronic conditions and complex health

care regimens were significantly more vulnerable during the transition from acute care to home (Naylor et al., 2004).

As hospitals are discharging patients sooner and sicker, home care will play an important role in restoring and encouraging self-care in clients with chronic conditions. Self-care skills that are lost or not used as a result of health breakdown, must be regained (Pryor, 2009). However, the current trends in home care suggest that a greater proportion of home care resources have been directed towards post-hospitalized acute patients, with fewer resources available to support the long-stay clients with chronic health care needs (Williams et al., 2010). As a result, many home care clients, especially older adults are at increased risk of losing independence in self-care, and this situation may put clients in unsafe situations, leading to safety problems or adverse events (OACCAC, 2009). Underlying all of this is a recognized concern about the quality and safety of current home care services to support the self-care needs of home care clients. Also, the extent to which informal caregivers are able to safely support client's self-care needs is an important consideration. The current literature reveals gaps in care that raise concern about the safety of Canadian home care clients, and highlight the need for increased self-care support in home care.

While patient safety outcomes are well documented in acute care settings, only limited data exists about adverse events experienced by home care clients (Doran et al, 2009). In particular, there is a lack of research that explores the relationship between the client's self-care ability and safety problems in the home care settings. A recent Pan-Canadian Home Care Safety study determined that decline in activities of daily living or instrumental activities of daily living are important indicators of frailty and were found to be associated with increased odds of adverse events in home care (Blais et al., 2013; Doran et al., 2013). This finding raises the question to

what extent therapeutic self-care ability is associated with the occurrence of adverse events in home care. Therapeutic self-care is a concept developed by Sidani and Doran (2009) to expand our understanding of self-care practice. It is defined as the ability to manage medications and treatment; to recognize signs and symptoms; to carry out treatments as prescribed; as well as having the knowledge of what to do in case of an emergency (Sidani, 2001). To date, little is known about the concept of therapeutic self-care in the home care setting. My research addressed the existing gap by using an exploratory research approach to examine the role of therapeutic self-care ability in mitigating the risk of adverse events in home care. An exploratory research approach was chosen for this study because this research topic was relatively new and unstudied.

1.2. Problem Statement

The purpose of this research study was to expand the understanding of therapeutic self-care in the context of home care. I used a mixed methods approach to conduct both quantitative and qualitative analyses to investigate the multiple perspectives of the phenomenon of interest. The purpose of the quantitative method focused on examining the relationship between therapeutic self-care ability and the likelihood of adverse events experienced by the adult home care clients. In the qualitative method I used an exploratory approach to gain ideas and knowledge about the clients and their informal caregivers' perspectives of home care safety in relation to therapeutic self-care. The perspectives on the concept of therapeutic self-care could have implications for the design and delivery of home care services to promote safer client care.

1. Quantitative research question:

The following question was proposed: What is the relationship between home care clients' therapeutic self-care ability and the occurrence of adverse events? This question provided insight into whether therapeutic self-care explains variation in the frequency and types of adverse events experienced by the home care clients, such as client falls, emergency room visits and unplanned hospitalizations.

2. Qualitative research questions:

Through a qualitative method I investigated the following four questions:

1. What are the safety challenges and concerns home care clients report related to therapeutic self-care activities?
2. What are safety challenges and concerns informal caregivers report related to informal caregiving activities?
3. What supports do clients and their informal caregivers identify as needed to address their safety challenges and concerns?
4. What role do clients and their informal caregivers identify as important home care services in supporting therapeutic self-care?

The qualitative method focused on the geriatric home care client and informal caregiver dyad because they are the group of individuals who are more vulnerable of experiencing challenges in therapeutic self-care. Geriatric clients and their informal caregivers were invited to describe the safety problems related to therapeutic self-care, and the role of home care in supporting disease management to reduce the safety related risks and burden for the home care recipients.

1.3 Summary

One of the best ways to reduce the impact of chronic conditions on people's lives and on their need for expensive health care services is to support clients in the development of self-care skills. Providing self-care support to help clients manage their diseases is an important focus of home care services in the context of chronic disease management. A review of current research evidence suggested that breakdowns in care from hospital to home could lead to increased utilization of health care resources, and negatively affect the quality of life and safety of clients and their informal caregivers (Parry, Mahoney, Chalmers & Coleman, 2008). The care and safety of home care clients cannot be addressed without considering the informal caregivers because home care is intended to be a complement to their support (Stajduhar, 2003). It is important to examine the relationship between clients' therapeutic self-care ability and their experiences of adverse events while receiving home care services. It is also imperative to explore what supports the informal caregivers need to take care of their loved ones and maintain their own health.

This research added a valuable contribution to the field of health services research by generating evidence about the role of therapeutic self-care in explaining variation in adverse events for home care clients. The knowledge gained from this study provided insight about how to support risk mitigation and promote effective disease management for clients and their informal caregivers. In an era of a rapidly increasing number of older people who require home care services, clients must possess or develop therapeutic self-care ability in order to manage safety in their homes. This research is both timely and important as Ontario embarks on a number of policy initiatives related to "Aging-at-Home-Strategy" with the goal to increase services that help seniors with chronic conditions to live independently in their homes (Ontario Ministry of Health and Long-Term Care, 2010).

Chapter Two

Review of the Literature

2.1. Introduction

The purpose of this chapter is to provide a literature review on what is already known about the concept of therapeutic self-care and adverse events in home care. In the first section, the literature review begins with an overview of the conceptualization of therapeutic self-care in home care. The second section of the literature review includes a critique of the self-care movement in home care. In the last section of the literature review, the empirical evidence on therapeutic self-care in home care is reviewed and summarized in relation to the following five related concepts: (1) Self-care; (2) Patient activation; (3) Therapeutic self-care in acute care setting; (4) Self-management in chronic disease management; and (5) Adverse events in the context of home care. The definitions of key concepts to be discussed in the literature review are presented below:

2.1.1. Concept Definitions

Self-Care:

Self-care is viewed as encompassing a broad set of practices that individuals perform on their own behalf for the purposes of maintaining quality of life and well-being (Jenerette & Murdaugh, 2008). Self-care refers to the ability to care for oneself and the performance of activities necessary to achieve, maintain, or promote optimal health, including activities specific to acute and chronic health conditions (Richard & Shea, 2011). According to Orem (2001), self-care practice is defined in relation to the universal, developmental, and health-deviation

requisites. Universal requisites are concerned with basic life processes, such as maintaining an adequate intake of air and food, and a balance between activity and rest (Sidani, 2011).

Developmental requisites focus on continued developmental growth and healthy functioning.

Health-deviation requisites are related to changes in health condition that demand actions to manage, control, and prevent them (Kumar, 2007; Orem, 2001).

Self-Management:

Self-management is conceptualized as a subset of self-care that focuses on managing the actual or potential impact of disease, and it is often seen in the chronic disease literature (Barlow et al., 2002; Wilkinson & Whitehead, 2009). Lorig (1993) defines self-management as “learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition” (p13) and involves working actively with health care providers to develop at home strategies which will control or reduce the impact of the disease on health status. To distinguish the difference between self-care and self-management, Richard & Shea (2011) describe that self-care is a broad concept subsuming self-management. Adams, Grenier and Corrigan (2004) explain that self-management focuses on the day-to-day tasks a client must undertake to control or reduce the impact of disease on physical health status while these self-management tasks may include medical management, role management, and emotional management of disease conditions.

Therapeutic Self-Care:

Therapeutic self-care is viewed as a sub-concept of self-care, and it entails the level of knowledge and skill needed to support self-care practice. Therapeutic self-care focuses on health deviation requisites where changes in health condition demand actions to manage, control, and prevent them. Examples of managing health deviation requisites are self-monitoring and symptom management, including monitoring of specific physiologic parameters or symptoms of a health condition; adjustment to activities of daily living, seeking care as needed, and participating in treatment (Kumar, 2007). This conceptualization of therapeutic self-care is consistent with Sidani and Doran (2010)'s definition where they define therapeutic self-care as the clients' knowledge and ability to manage their health condition, manage symptoms, and follow the prescribed treatments. The domains of therapeutic self-care activities include the following areas: client's knowledge of the prescribed medications and treatment; ability to recognize signs and symptoms; skills to carry out treatments as prescribed, and knowledge of what to do in case of an emergency (Sidani, 2011).

Both self-management and therapeutic self-care are sub-concepts of self-care with a focus on disease management. Although both concepts incorporate self-monitoring and symptom management, self-management is broader in that it addresses medical management, role management, and emotional management of disease conditions (Richard & Shea, 2011). On the other hand, therapeutic self-care is viewed as the knowledge and skill that facilitate self-care practice in relation to the management of health deviation. Therapeutic self-care enables clients to make informed choices regarding their self-management tasks and behaviors.

Patient Activation:

Patient activation is the process that clients go through in becoming engaged in therapeutic self-care activities. This process is delineated by the following stages of patient activation: (1) Believes active role important; (2) Confidence and knowledge to take action; (3) Taking action; and (4) Staying the course under stress (Hibbard, Mahoney, Stockhard & Tusler, 2005). Although the stages of patient activation were not measured in this study, this concept was useful to help understand the different levels of client engagement in therapeutic self-care.

Adverse Events:

The World Health Organization (WHO) (2008) defines adverse events as the incidents that result in harm to a client. WHO considers healthcare-associated harm as “harm associated with plans or actions taken during the provision of health care rather than an underlying disease or injury” (WHO, 2008, p. 8). The WHO definition of adverse events is useful for studying safety in home care context because it recognizes that health care is not limited to medical care provided by health professionals, and it includes self-care (Doran et al., 2009). In the literature adverse events are usually in reference to a breakdown in the process of care by the health care system. However, Lang et al. (2009) proposed that the safety of the home care client, informal caregiver, and health care providers are closely linked. This recognition is consistent with the context of home care, where much of care is provided by clients and informal caregivers. As a result, this study examined the adverse events that were expected to be sensitive to the client’s therapeutic self-care ability.

Specifically, I focused on clients and their informal caregivers as the care system in home care, and examined the occurrence of two types of outcomes that were most likely sensitive to

therapeutic self-care ability: (1) use of health care resources, including new emergency room visits and unplanned hospital admissions; and (2) adverse events, including client falls; unintended weight loss; new urinary tract infection; activity of daily living (ADL) decline; compliance/adherence with medications; new pressure ulcer or ulcer deterioration; and new caregiver distress. The two types of outcomes were chosen because these were the most prevalent adverse events identified by Doran et al. (2009) and Doran et al. (2013), including client fall, emergency room visits, new hospital visits, unintended weight loss, new urinary tract infection, ADL decline, medication related incidents and new caregiver distress. The following section provides the operational definition and empirical evidence for each outcome of interest (Refer to appendix A for a detailed description of the conceptual definitions). All the definitions for each outcome concept were derived from previous literature and/or from the interRAI assessment tool which has been shown to have both construct and content validity (Hirdes et al., 2008).

(1) Use of Health Care Resources:

- **New ER visit:** Derived from the National Ambulatory Care Repository System (NACRS). Any emergency room visit without an overnight stay within one year following HOBIC assessment. ER visit was found in previous research to be among the most prevalent adverse event for home care clients (7%) (Doran et al., 2009)
- **New hospital visit:** Derived from the Discharge Abstract Database (DAD).). Any admission to hospital with an overnight stay within one year following HOBIC assessment. New hospital visits were found in previous research to be among the most prevalent adverse event for home care clients (8%) (Doran et al., 2009). Specifically,

hospital discharge within the past 30 days was associated with significantly increased odds of a home care client experiencing an adverse event (Doran et al., 2013).

(2) Adverse Events:

- **Client falls:** The following definition for client falls was derived from the Resident Assessment Instrument-Home Care (RAI-HC) assessment tool: “. Number of times fell in last 90 days or since last assessment if less than 90 days” (Hirdes et al., 2004). Injurious falls and injuries from causes other than fall were the most frequent types of adverse events associated with hospitalization. Specifically, between 2% and 3% of home care clients had falls that resulted in injuries associated with hospitalization (Doran et al., 2013).
- **Unintended weight loss:** The following definition for unintended weight loss was derived from the RAI-HC assessment tool: “Unintended weight loss of 5% or more in the last 30 days (or 10% or more in the last 180 days” (Hirdes et al., 2004). Unintended weight loss was found in previous research to be among the most prevalent adverse outcomes for home care clients (9%) (Doran et al., 2009).
- **New urinary tract infection (UTI):** The following definition for urinary tract infection was derived from the RAI-HC assessment tool: “Urinary tract infection in last 30 days” (Dalby, Hirdes & Fries., 2005). Home care clients with an indwelling urethral catheter were found to be at risk for a catheter-associated UTI (8%) (Doran et al., 2013).
- **ADL decline:** The following definition for ADL decline was derived from the RAI-HC assessment tool: “ADL status has become worse (ie. now more impairment in self-performance) as compared to status 90 days ago (or since last assessment if less than 90

days” (Hirdes et al., 2008). ADL decline was found to be associated with increased odds of experiencing an adverse event (Doran et al, 2013). ADL decline was also found to be an adverse event most significantly ($p \leq 0.01$) associated with client self-care factors (Sears, 2008).

- **New pressure ulcer/deterioration:** The following definition for pressure ulcer was derived from the RAI-HC assessment tool: “Pressure ulcer appeared or stage increased at 2nd assessment compared with previous assessment” (Hirdes et al., 2004). Doran et al. (2006) found that therapeutic self-care at discharge in acute care was related to pressure ulcer prevention ($r = -0.18$). Therefore I reasoned in this study that therapeutic self-care would be associated with pressure ulcer outcome for home care clients.
- **Compliance/adherence with medications:** The definition for medication compliance was derived from the RAI-HC assessment tool: “Compliant all or most of time with medication prescribed by physician in last 7 days.” (Hirdes et al., 2004). Medication-related incidents were found to be the most frequent types of adverse events associated with hospitalization (2%) among a population of home care clients (Doran et al., 2013). A study of medication-related incidents associated with ER visits among community dwelling older patients reported a 12% rate (Zed et al., 2008), and another study reported a 4.7% rate (Hohl et al., 2010).
- **New caregiver distress:** The definition for new caregiver distress was derived from the RAI-HC assessment tool: “A caregiver is unable to continue in caring activities (e.g. decline in the health of the caregiver makes it difficult to continue); primary caregiver expresses feelings of distress, anger or depression.” (Hirdes et al., 2008). Lang and Edwards (2006) suggested that the safety of the client and family caregivers are

inextricably linked. Caregiver distress is a safety concern because caregivers need to make critical decisions regarding the care required by the client such as giving medications (Lang et al., 2009). Doran et al. (2013) found that the incidence of new caregiver distress ranged between 6% and 11%, and this rate was within the range of 6% rate reported by the Canadian Institute for Health Information (2004).

In the next section I discuss the conceptualization of therapeutic self-care in general and within the context of home care setting.

2.1.2 Conceptualization of Therapeutic Self-Care in Home Care

Therapeutic self-care ability represents clients' readiness for self-care in relation to their disease and its treatment (Doran, 2011). It was proposed that this research could further advance the conceptualization of therapeutic self-care, as well as the understanding of its role in disease management and risk mitigation for adverse events in home care. More specifically I explored the relationship between home care clients' therapeutic self-care ability and the occurrence of adverse events. Currently, there is no conceptual model that explains the concept of therapeutic self-care in home care. Therefore, the literature on the concepts of self-care, self-management and patient activation were used to further expand the conceptualization of therapeutic self-care.

The concepts of self-care and self-management are often discussed interchangeably (Clark et al., 1991). Although the concepts of self-care and self-management are closely related to each other, there are differences that exist between these concepts that could be differentiated. Self-care is viewed as a broad concept subsuming self-management and therapeutic self-care. Self-care is concerned with basic life processes, continued developmental growth, healthy

functioning and managing health deviations (Orem, 2001). On the other hand, therapeutic self-care and self-management are sub-concepts of self-care that incorporate self-monitoring and symptom management (Richard & Shea, 2011). However, self-management is broader in that it addresses medical management, role management, and emotional management of disease conditions, while therapeutic self-care ability entails the level of knowledge and skill that facilitates self-care practice in relation to the management of health deviations.

In this study I focused on investigating the concept of therapeutic self-care ability, and examined whether therapeutic self-care ability influences the types and frequency of adverse outcomes experienced by home care clients. I proposed that therapeutic self-care ability entails the level of knowledge and skill that influence the processes and outcomes of disease management in home care. Specifically, the therapeutic self-care scale developed by Sidani and Doran (Doran et al., 2002) was used to assess clients' perception of their level of self-sufficiency in caring for themselves, and managing their therapeutic health care needs. Home care clients often must follow complex treatment regimens, monitor their conditions, make life-style changes, and make decisions about when they need to seek professional care and when they can handle a problem on their own (Hibbard, Mahoney, Stockard & Tusler, 2005). Therefore, the effective functioning in the role of disease management requires a high level of therapeutic self-care ability, such as self-care knowledge and skill.

I proposed that the level of individual's engagement in self-care practice may be influenced by patient activation. Although the Stages of Patient Activation developed by Hibbard and Tusler (2007) were not measured in this study, the concept of patient activation was useful for understanding the different levels of client engagement in therapeutic self-care. The Stages of Patient Activation is the process that clients go through in becoming fully competent

self-managers of their own health (Hibbard, Mahoney, Stockhard & Tusler, 2005). The first stage of activation involves beliefs about the importance of the client's role in self-care. The second stage involves confidence and knowledge necessary to take action. This includes knowledge of medications and lifestyle changes; confidence in talking to health care providers and following through on recommendations; knowing when to seek help, the nature and causes of the health condition, and different medical treatment options (Hibbard et al, 2005). The third stage involves actually taking action, including maintaining lifestyle changes, knowing how to prevent further problems, and handling symptoms on one's own. Finally, the fourth stage involves actually staying the course even when under stress. Clients at this stage are confident that they can maintain lifestyle changes when under stress, they can handle problems on their own at home, and they can keep their health problems from interfering with their life (Hibbard et al., 2004).

Patient activation theory informed the conceptualization of the mechanism by which therapeutic self-care is associated with adverse events in home care, although the underlying mechanisms were not measured. I propose that therapeutic self-care ability could predict the frequency and types of adverse events experienced by home care clients. Empirical evidence indicated that being an engaged and active participant in one's own care was associated with better health outcomes (Von Korff et al., 1997; Lorig et al., 1999 & Bodenheimer et al., 2002). Therefore, I propose that clients with higher measured therapeutic self-care would be more likely to become activated to engage in self-care practice. With high level of therapeutic self-care ability, clients may have the necessary knowledge to know how to manage their condition and prevent health declines, as well as having the skills and confidence needed to maintain their health functioning and access appropriate care. On the other hand, it is suggested that clients

with low measured therapeutic self-care would be less likely to become engaged in self-care activities because of their lack of self-care knowledge and skills, and thus could experience poor health outcomes, including adverse events.

In summary, I proposed that therapeutic self-care entails the level of knowledge and skill of self-care that influence the processes and outcomes of disease management. The Stages of Patient Activation developed by Hibbard and Tusler (2007) were useful for conceptualizing the process that clients go through in becoming engaged in therapeutic self-care activities. I proposed that therapeutic self-care ability has an important role in influencing client's level of sufficiency in managing their condition and maintain their health, and thus resulting in better health outcomes. This conceptualization of therapeutic self-care was used as the basis for exploring the relationship between therapeutic self-care ability and adverse events experienced by home care clients with disease management.

2.2 Critique of Self-Care Movement in Home Care

Self-care has been described as a movement and began receiving greater interest in the latter half of the 20th century (Wilkinson & Whitehead, 2009). The movement towards participation in self-care is being driven by the following factors: an interest in autonomy; more available and accessible information; dissatisfaction with the formal health care setting; a shift from acute to chronic illness care, and an increase in aging population (McCormack, 2003). Some proponents of self-care hope that increased self-care activities in home care would decrease the need for expensive acute health care services (Health Council of Canada, 2012). While participation in self-care in the home settings has the potential to save the health care

system money, it may cost the clients and their families in many ways where they may pay a price in terms of cost, time away from work, anxiety and stress.

For instance, in the Valuing Home and Community Care (VHCC) project it was estimated the cost to caregivers in lost productivity is about \$5 million a year. This cost did not include emotional and other costs associated with the stress of caring for someone with chronic health needs at home (The Change Foundation, 2011). According to the analysis by Hollander, Liu and Chappell (2009), self-care and informal caregiving for the elderly saved the Canadian health care system \$25 million in 2007. On one hand, there is public preference for managing illness in the home settings, and there are savings to the health care system. On the other hand, the self-care movement puts pressure on clients and family members, and can take its toll on them physically, emotionally and financially (The Change Foundation, 2011). Self-care relies heavily on clients playing a strong role in monitoring and managing their own health and treatments. This is especially challenging when frail elderly clients are required to manage the complex needs and multiple chronic conditions on a long-term basis.

For many family members, caregiving is a full-time job. Ninety-eight percent of 131,000 home care clients 65 and older are getting help from their informal caregivers (Canadian Institute for Health Information, 2013). The average caregiver provides 22 hours of care a week in addition to the time spent on paid employment and on other family responsibilities (Posse et al, 2008). Fast (2007) indicated that 24% of Canadians missed full work days and 16% were working reduced hours in order to care for an elderly relative. The authors of the Deloitte 2009 Canadian Survey of Health Care Consumers estimated that 27% of Ontario families have been providing constant care for over two years and one in six Ontarians said the demands of informal caregiving were having a major impact on their ability to earn family income (The Change

Foundation, 2011). The long-term commitment of caregiving is especially challenging when 60% of caregivers age 65 and over are caring for a spouse, friend, parent or sibling, and adult children who raise children of their own are also caring for older parents and friends (Hollander, Liu, and Chappell, 2009).

The Change Foundation (2011) reported that nearly one in four (23%) informal caregivers reported signs and symptoms of stress, such as not being able to continue their caregiving activities; feeling distressed, angry or depressed; and overwhelmed by care demands. Duxbury, Higgins and Schroeder (2009) found caregivers suffered from hypertension, chronic back pain, and other health complications caused by informal caregiving. Keefe, Legare and Carriere (2007) suggested that there will be an increased burden on the health care system when informal caregivers become stressed or ill because they are more likely to take their loved ones to hospital or to place them in long-term care facilities. Therefore, putting more responsibility for care on families may reduce health care costs in the short term, but the costs may increase over time in the long-term.

Maintaining self-care activities in the home settings can be challenging when home care services have limited capacity to provide adequate support to the clients and their families. As pressures have mounted to discharge hospital patients sooner and sicker, greater proportions of home care resources have been directed towards post-acute care patients, with fewer resources available to support those with chronic needs, including many older adults at risk of losing independence in self-care (Ontario Association of Community Care Access Centres, 2008). Within the capped budgets set by the province, the Community Care Access Centres allocate services to clients within provincial ceilings that have limited the number of hours of service individuals can receive, regardless of assessed care needs (Williams et al., 2010). The

implication is that self-care in the home care settings is not simply a matter of client needs or choice, but rather it is determined by the capacity of home care to provide the needed services to support clients and their families to engage in self-care. Hollander and Tessaro (2001) reported that the average health expenditures were higher for clients who received service reductions from home care, and the differential in costs was attributable to a greater use of acute care beds and increased rates of admission to long-term care settings. Without adequate home care support, clients and their family caregivers' health status could deteriorate as a result of failure to cope, and result in a trajectory back to acute care settings (The Change Foundation, 2011).

The key implication that flows from this critique regarding self-care movement in home care is that we cannot assume all families are capable of caring, and not all homes are the most appropriate or desirable location for self-care. We need to consider the characteristics, needs and capacity of the client and their informal caregivers, as well as look beyond the direct costs of care to the indirect costs and burdens that fall on clients and families to maintain self-care in their homes. Failure to take these important considerations into account may result in unsafe care for the clients and families. As a result, home care safety should be examined in relation to the client's self-care ability and informal caregiving.

The purpose of this study was to investigate the enablement perspective of therapeutic self-care in the context of home care safety. The enablement perspective of therapeutic self-care is viewed as the knowledge and skill of self-care that may influence the processes (i.e. decision-making processes) and outcomes of disease management. Therapeutic self-care ability is referred to the level of knowledge and skill that enables clients to make informed choices regarding the management of their disease conditions. Therefore, therapeutic self-care ability is viewed as an enabling factor that protects clients against the occurrence of adverse events in

home care. It is important to study the enablement perspective of therapeutic self-care because of its potential role in risk mitigation, as well as its role in reducing the care burden for informal caregivers. The enablement perspective was investigated by examining the association between home care client's therapeutic self-care ability and the occurrence of adverse events, including caregiver distress.

In the following section, the empirical evidence on therapeutic self-care in home care were reviewed and summarized in relation to the following five concepts: (1) Self-care; (2) Patient activation; (3) Therapeutic self-care in acute care setting; (4) Self-management in chronic disease management; and (5) Adverse events in the context of home care. The review of the literature on the concepts of self-care, patient activation, self-management and adverse events were useful to expand the conceptualization of therapeutic self-care in home care setting.

2.3. Empirical Evidence on Self-Care

Self-care has gained the most attention in the management of chronic illness as a result of the shifting patterns of disease to chronic illnesses prevalent among the aging population. In particular, self-care has been identified as critical for the successful management of chronic conditions in home care settings. Chronic illnesses are associated with the changes in physical and social functioning, as well as emotional stresses of coping and lifestyle adjustments (Burks, 1999). Therefore, self-care is considered to be a key component of chronic disease management that emphasizes client's empowerment and acquisition of self-care skills (Baker et al., 2005).

Self-care is viewed as encompassing a broad set of practices that individuals perform on their own behalf for the purposes of maintaining quality of life and well-being (Jenerette & Murdaugh, 2008). Self-care refers to the ability to care for oneself and the performance of activities necessary to achieve, maintain, or promote optimal health, including activities specific

to acute and chronic health conditions (Richard & Shea, 2011). According to Orem (2001), self-care practice is defined in relation to the universal, developmental, and health-deviation requisites. Universal requisites are concerned with the basic life processes, such as maintaining an adequate intake of air and food, and a balance between activity and rest (Sidani, 2011). Developmental requisites focus on the continued developmental growth and healthy functioning. Health-deviation requisites are related to the changes in health condition that demand actions to manage, control, and prevent them (Kumar, 2007; Orem, 2001).

Qualitative researchers who investigated the clients' perception of self-care revealed that clients with chronic illnesses described self-care as taking care; not harming self; having control over treatment; managing social context and lifestyle (Leenerts & Megilvy, 2000; Thorne, Paterson & Russell, 2003). Elderly persons living at home viewed self-care as involving caring for health and illness, and carrying out activities of daily-living (Backman & Hentinen, 1999). These findings provided a view of self-care as the actual engagement and performance of health-related activities or behaviors. Through qualitative interviews with clients and nurses, Leenerts, Teels and Pendelton (2002) identified two categories of self-care activities required by clients with chronic illness in home care. The first category included the physical self-care activities related to: (1) general care, such as washing, dressing, eating/drinking, and bladder/bowel management; (2) nursing activities associated with a therapeutic regimen, such as injections; (3) mobility and exercises, such as walking, getting in and out of bed; and (4) household duties. Clients who received home care for the management of their chronic illnesses needed to perform the second category of self-care activities. This second category is referred to as the psychosocial self-care activities, including accepting illness, and managing marital, family and psychological problems (Leenerts, Teels and Pendelton, 2002).

2.3.1. Self-Care Skills and Behaviors

There were research studies about the relationships between selected factors and self-care skills in adults with chronic illnesses. For example, gender and age were reported to be associated with the performance of self-care behaviors in young and older adults (Sidani, 2011). Older clients with chronic illnesses tended to report minimal engagement in self-care behaviors (Carroll, 1995; Wang & Lee, 1999). In a sample of clients with first-time myocardial infarction, women were found to engage in self-care activities more than men (Rodeman, Conn, & Rose, 1995). Women also reported higher levels of self-care skills than men in a sample of clients with end-stage renal disease on dialysis (Horsburgh, 1999).

In addition to age and gender, socio-cultural factors were found to influence self-care skills. Increased socio-economic status and social support were positively correlated with the performance of self-care across samples of clients receiving radiation therapy (Nicholas, 1993), and elderly women living in rural areas (Wang & Lee, 1999). Furthermore, living with others and being married were associated with increased self-care behavior performance, and increased adherence to self-care recommendations in older clients with congestive heart failure (Ni, et al., 1999). Individual's physical status is another factor that had an effect on self-care performance. For instance, perceived health status was positively correlated with perceived effectiveness of self-care behaviors in elderly women in rural areas (Wang & Lee, 1999); and older adults with end-stage renal failure and cancer therapy (Horsburgh et al., 2000; Dodd, Thomas & Dibble, 1991). Various personality traits were found to be associated with the engagement in self-care behaviors. Clients reporting higher levels of consciousness, openness, extroversion and resourcefulness had higher self-care skill; whereas learned helplessness was negatively related to self-care ability (LeFort, 2000; Nelson McDermott, 1993).

2.3.2 Self-Care Knowledge and Confidence

There are a variety of cognitive factors that were reported to be associated with self-care knowledge and confidence. Ni et al. (1999) found a positive relationship between knowledge of self-care recommendations and adherence to self-care regimen in clients with congestive heart failure. Doran et al. (2006) found a negative, weak relationship between cognitive function and self-care where clients with cognitive impairment had low levels of self-care. In a sample of clients with hypertension, perceived locus of control and perceived self-efficacy were positively related to self-care practices (Chen, 1999).

Similarly, self-care confidence has been shown to moderate the relationship between disease management and health outcomes (Lee, Carlson, & Riegel, 2007). For instance, Schnell-Hoehn, Naimark, & Tate (2009) found that lower confidence in the ability to control symptoms and maintain health was associated with poor self-care of congestive heart failure. Further, perceived control was related to better self-care in men, but higher self-care confidence was related to better self-care in women (Heo, Moser, Lennie, Riegel, & Chung, 2008). Research also indicated a positive relationship between self-efficacy, preventive actions, and health outcomes (Bandura 1991; Grembowski et al., 1993; Day, Bodmer, & Dunn, 1996). Specifically, Carlson, Riegel, and Moser (2001) reported that a high level of perceived self-care efficacy was consistently related to the increased self-care behaviors among clients with renal disease, heart disease, chronic pain and congestive heart failure. These findings suggested that clients who perceived more control over their health and had higher self-efficacy had higher self-care scores.

2.3.3. Benefits of Self-Care

There were two studies that investigated the benefits of self-care behaviors at the individual patient level. Kreulen and Braden (2004) found that self-care predicted changes in the health status of women with stage 1 or 2 breast cancer, such as improved symptoms control and quality of life. The study findings supported the relationship between nursing interventions and self-care outcome, and self-care outcome and morbidity outcomes. Kreulen and Braden found that nursing interventions had a direct positive impact on self-care practices, which in turn had a direct effect on decreased risks of complications including client morbidity. Therefore, the greater self-care practice, the lower the level of client morbidity. In particular, client factors of age, social network size, disease stage, receipt of chemotherapy, resourcefulness, and uncertainty significantly influenced the predicted relationships between self-care and morbidity outcomes (Kreulen & Braden). Doran et al. (2006) reported a significant positive association between self-care practice and functional independence in hospitalized patients whereby those who engaged in self-care were able to perform activities of daily-living independently. The results of these studies suggested that self-care behavior in disease management was demonstrated to contribute to increased adjustment to illness, decreased risk of complications, and improved symptoms control, functioning and quality of life at the individual client level.

In addition to the benefits of self-care behavior at the individual client level, the performance of self-care practice is considered beneficial to the health care system. For instance, clients with heart failure showed modest improvement in physical function, and decreased health service utilization when they were assigned to a nurse-administered self-care program (Dunagan et al., 2005). Baker et al. (2005) found statistically significant but small effect of self-care knowledge, engagement in self-care practice and number of hospitalizations for those individuals

who were enrolled in a self-care program delivered by a nurse-physician team. The research evidence suggested that the benefits of self-care for the management of illness included decreased rates of hospital readmission, decreased health service utilization, and reduced health care costs (Dunbar, Jacobson & Deaton, 1998; & Leveille et al., 1998).

2.3.4. Summary of Evidence on Self-Care

The review of the literature on self-care identified that self-care is a critical concept in the home care setting where much of the required treatment and care are provided in the clients' homes for the management of chronic diseases. In particular, self-care enables clients with chronic illnesses to monitor and recognize changes in functioning and implement appropriate strategies for managing these changes (Sidani, 2011). The empirical evidence suggested that the performance of self-care behaviors was influenced by cognitive, psychological, physical, demographic, and socio-cultural factors. Self-care practice is considered beneficial at the individual client level and for the health care system. Benefits included reduced risk of complications; enhanced adjustment to illness; improved symptoms control and functioning; and consequently, improved quality of life and reduced health services utilization.

The research studies that investigated the concept of self-care revealed that there was a lack of consistent definition of self-care and conceptualization of its dimensions. The differences in the conceptualization of self-care resulted in diverse conceptual and operational definitions of this outcome. Dashiff, McCaleb, & Cull (2006) suggested that this theoretical limitation could result in variability of its operationalization, as well as the ability of the instruments to measure self-care in an accurate and comprehensive way. Client's perceived ability to perform self-care behaviors is a subjective phenomenon (Sidani, 2011). Therefore, a response bias such as social

desirability bias is a potential limitation when self-care is measured through survey methods (Horsburgh, 1999). Response burden is another issue in the measurement of self-care, especially in the acutely ill and frail elderly clients (Sidani, Doran, & Mitchell, 2004).

The majority of the studies that investigated self-care behaviors had a small sample size and was primarily descriptive in nature. These limitations prevented the generation of theories that explained the mechanism through which factors influenced self-care behaviors (Sidani, 2011). Similarly, the research designs that investigated the outcomes of self-care practices were primarily non-experimental in nature, which limited causal inference. Sidani and Braden (1998) suggested that future research needs to assess self-care outcome at pretest and posttest in an experimental design because follow-up posttest are useful to examine the changes in self-care behaviors over time, as well as providing evidence of the extent to which self-care practices were associated with changes in health outcomes. Finally, large-scale studies that evaluate the impact of self-care practices on health outcomes are needed to strengthen the empirical evidence supporting the benefits of self-care for different patient populations and across health care settings.

2.4. Empirical Evidence on Patient Activation

Patient activation is the process that clients go through in becoming fully competent self-managers of their own health (Hibbard & Tusler, 2007). The first stage of activation involves the beliefs about the importance of the client's role in self-care. The second stage involves the confidence and knowledge necessary to take action. This includes knowledge of medications and lifestyle changes; confidence in talking to the health care providers and following through on recommendations; knowing when to seek help, the nature and causes of the health condition, and

different medical treatment options (Hibbard et al, 2005). The third stage involves actually taking action, including maintaining lifestyle changes, knowing how to prevent further problems, and handling the symptoms on one's own. Finally, the fourth stage involves actually staying the course even when under stress. Clients at this stage are confident that they can maintain lifestyle changes when under stress, that they can handle problems on their own at home, and that they can keep their health problems from interfering with their life (Hibbard et al., 2004).

The literature indicated that being an engaged and active participant in one's own care was associated with better health outcomes. In particular, Glasgow et al. (2002) found that clients who collaborated with health care providers, and engaged in shared clinical decision-making were more likely to experience better health outcomes. Coaching clients to be more involved and to have more control in the medical encounter has been shown to produce better health and functioning in patients (Bennett, Coleman, Parry & Bodenheimer, 2010). The research on patient activation found that the clients with higher activation reported significantly better health as measured by the SF 8 ($r = .38$, $p < 0.01$), and had significantly lower rates of doctor office visits, emergency room visits, and hospital length of stay ($r = -.07$, $p < .01$) (Hibbard, Stockard, Mahoney & Tusler, 2004). The research evidence also indicated that the clients with higher activation were significantly more likely to engage in specific self-care and preventive behaviors, such as regular exercise, following a low-fat diet, eating more fruits and vegetables, and not smoking. Patient activation increased preventive behaviors such as colorectal cancer screening rates. Katz, Fisher, Fleming and Paskett (2012) found that more activated patients reported discussing screening with their provider (OR = 3.29, 95% CI: 1.95–5.56; $P < 0.001$) and had more screening tests ordered (OR = 3.40, 95% CI: 1.88–6.15; $P < 0.001$) compared with those in the control group.

In addition, those with higher activation who had a specific chronic disease were found to be more likely to engage in the self-care behaviors specific to their condition. For instance, diabetic clients with higher activation were more likely to keep a glucose journal; more activated clients with arthritis were more likely to exercise; and among those with cholesterol, those with higher activation were more likely to follow a low-fat diet (Hibbard et al., 2004). Finally, those with higher activation indicated a lower degree of fatalism about their health (Hibbard et al., 2005).

With the exception of Katz et al. (2012), much of the evidence noted above is based on correlational analysis, which precludes the ability to infer causal relationships. Also, studies that include a fuller range of disease-specific self-care behaviors and that cover a greater number of chronic diseases are needed to further validate and expand the findings reported by Hibbard et al., (2004) and Hibbard et al., (2005). Another limitation is that much of the evidence on patient activation relied on cross-sectional data from a convenience sample. Future studies that utilize larger representative samples and that follow patients over time are needed (Hibbard & Tusler, 2007).

2.5. Empirical Evidence on Therapeutic Self-Care

Sidani and Doran developed an instrument, Therapeutic Self-Care, to measure the elements of self-care practice that were relevant to various client populations seen in different practice settings (Sidani, 2001). Therapeutic self-care ability represents clients' readiness for self-care in relation to their disease and its treatment. Sidani (2011) proposed that the elements of self-care involve "recognition of changes in health condition; assessment of self-care activities for addressing the changes; selection and performance of appropriate activities, and evaluation of

the effectiveness of the activities in addressing the changes” (p.117). The Therapeutic Self-Care instrument consists of clients’ perception of their self-care ability related to the following areas: client’s knowledge of the prescribed medications and treatment; ability to recognize signs and symptoms; skills to carry out treatments as prescribed, and knowledge of what to do in case of an emergency (Sidani, 2008). The instrument is used to assess the clients’ perception of their level of self-sufficiency in caring for themselves and managing their therapeutic health care needs.

Therapeutic self-care ability was first assessed in an empirical test of Irvine et al. (1998)’s Nursing Role Effectiveness Model (NREM). Therapeutic self-care at hospital discharge was found to be associated with the quality of nurses’ role performance (Doran et al., 2003). There was also a direct relationship between therapeutic self-care and clients’ functional health outcome. Doran et al. (2002) reported that therapeutic self-care, as measured with the Therapeutic Self-Care scale, was correlated with the ability to resume ADL and role activities at hospital discharge. The findings from this study provided evidence of construct validity of the Therapeutic Self-Care scale, and internal consistency reliability based on Cronbach’s alpha of 0.88 (Doran, Sidani, Keatings & Doidge, 2002). The NREM model was used as a well-defined framework to guide the evaluation of outcomes of care in acute care and in-patient settings, and to examine the contribution of nurses to patient outcomes. However, a limitation of this study was that it only allowed the linking of adverse events to structural and process inputs that reflected nursing care. For example, the quality of nurses’ independent role performance was assessed indirectly through perceptual measures of the quality of nursing care (Doran et al, 2002). As a result, the validity of the perceptual measures is not known. A more direct measure of nurses’ independent role performance is needed to demonstrate nursing contribution to patient outcomes.

In an attempt to overcome the limitations in this previous study, Doran et al. (2006) examined the extent to which a broad set of self-care and functional health outcomes were associated with nursing interventions provided during hospitalization. Data were collected on 574 clients' outcomes at admission and discharge using the minimum data set (MDS) and the Therapeutic Self-Care scale. The results indicated that nursing interventions aimed at exercise promotion, positioning, and self-care assistance predicted functional status. There was a significant relationship between the clients' functional independence and therapeutic self-care ability. These findings were consistent with results reported in the earlier study by Doran et al. (2002).

Furthermore, Doran et al. (2006) examined the reliability of the Therapeutic Self-Care scale to determine whether the outcome measure was sensitive to changes in client's health, and whether it was associated with nursing interventions. The study sample consisted of 890 patients from acute care hospitals and long-term care facilities. Therapeutic self-care was assessed on discharge from acute care, and nursing interventions were assessed by documentation review. The study found that the Therapeutic Self-Care scale had high internal consistency reliability (0.93) in acute care (Doran et al., 2006). The authors concluded that the outcome tool was sensitive to changes in client condition, and the therapeutic self-care was related significantly to nursing interventions targeted at self-care assistance. Specifically, therapeutic self-care at discharge in acute care was related to assistance with bathing ($r = -0.15$), self-care assistance ($r = -0.14$), and pressure ulcer prevention ($r = -0.18$). One limitation of this study is that causal inferences about the relationship between specific nursing interventions and outcome achievement cannot be made because the study analysis was primarily correlational. However, the study findings provided valuable evidence about the use of nursing sensitive outcomes to

identify areas in which to target improvements in the quality of nursing care. The findings of this study also suggested that nurses are able to collect data on nursing sensitive outcomes, such as therapeutic self-care, in a reliable and valid way.

McGillis-Hall, Wodchis, Ma & Stacey (2013) examined the baseline and changes in patient health outcomes, including therapeutic self-care scores between admission and discharge from 44 acute care hospitals in Canada. The mean score on therapeutic self-care showed a small but statistically significant improvement from 4.17 (SD=1.26) on admission to 4.32 (SD=1.21) on discharge. McGillis-Hall et al. (2013) suggested that patients with the ability and knowledge to manage their health conditions demonstrated improvement during their hospitalization. Despite the evidence indicating that therapeutic self-care was instrumental in achieving better client outcomes in acute care, there was no study that specifically explored its impact on safety problems and adverse events in home care. The literature review on therapeutic self-care demonstrated that current research on this topic has focused on the acute care and in-patient settings. There is a lack of empirical evidence on the application of therapeutic self-care measures in the home care setting. Therefore, future work is needed to fill this research gap by examining the relationship between therapeutic self-care ability and the occurrence of adverse events experienced by home care clients.

2.6. Empirical Evidence on Self-Management

The concepts of self-care and self-management are often discussed interchangeably in the literature on chronic disease management, (Barlow et al., 2002). Self-management is conceptualized as a subset of self-care that focuses on managing the actual or potential impact of disease (Barlow et al., 2002; Wilkinson & Whitehead, 2009). Lorig (2003) defines self-

management as “learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition” (p13) and involves working actively with health care providers to develop at home strategies which will control or reduce the impact of the disease on health status.

Health practitioners described self-management as supporting clients to take an active role in managing self-care; helping clients to take care of their disease conditions; adopting approaches that prevent illnesses from getting worse; and reducing the risk of developing complications (Health Council of Canada, 2010). Clients defined self-management as having the skills and opportunity to be effective managers of their own health (Department of Health, 2001). Clients with self-management skills can recognize when they have a problem and have the confidence to take appropriate action (Bodenheimer, et al., 2002). It is important for clients to maintain effective self-management skill in order to prevent complications, control health-related costs, prevent early mortality, and improve quality of life (Krichbaum, Aarestad, & Buethe, 2003).

Within the context of home care, Lorig (2003) stated that self-management is learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition. It involves “working actively with health care providers to develop at home strategies that will control or reduce the impact of the disease on health status” (p.13). Similarly, Clark et al. (1991) described self-management as “the day-to-day tasks a client must undertake to control or reduce the impact of disease on physical health status while at-home management tasks and strategies are undertaken with the collaboration and guidance of the client’s health care providers” (p.5). The above definitions of self-management all emphasized the empowerment of the client and the role of the client in decision-making related to their health care. These

definitions also envisioned self-management as giving clients the knowledge, skill and self-confidence for disease management; having the ability to interact effectively with health care providers; as well as incorporating problem-solving skills and collaborative goal setting to manage disease and symptoms.

2.6.1. Self-Management Tasks

The client with chronic disease plays an integral role in undertaking self-management tasks because the nature of treatments vary over time and changes according to fluctuations in the disease process. There were three sets of self-management tasks delineated by the qualitative study by Corbin and Strauss (1988) on the work of people with chronic conditions. The first set of tasks involved the medical management of chronic conditions, such as taking medications. The second set of tasks was referred to as role management and involved maintaining, changing, and creating new life roles. The final set of tasks was emotional management by dealing with emotions such as anger, fear, frustration and depression that are commonly experienced by the client with a chronic disease.

Lorig and Holman (2003) described five core self-management skills: (1) problem solving; (2) decision making; (3) resource utilization; (4) forming of client/health care provider partnership; and (5) taking action. Specifically, clients with chronic illness must solve problems and make day-to-day decisions in response to changes in their health conditions. Clients also need to know how to find and utilize resources for support, and to build partnerships with their health care providers while taking action to cope with changes and make lifestyle adjustment.

2.6.2. Self-Management in Home Care

There are increasing numbers of clients who are discharged early from hospitals to the home care settings for continued care and support (Canadian Home Care Association, 2008). Leonard (2003) suggested that the goal of home care program should be to improve health by enabling the clients to make informed choices regarding his/her self-management behaviors. According to Corbett (2003), home care clients were at greatest risk for developing complications of chronic diseases secondary to factors such as, advanced age, co-morbidities and social isolation. For this reason, the client's home is considered the ideal setting for assessing, monitoring and providing self-management support. Wolf (2006) proposed that the objectives of self-management support for home care clients should be developed with the goal of promoting an understanding of the benefits of self-management in the prevention of chronic complications through improved self-care.

Six studies were found that investigated the effect of self-management programs on health outcomes. There were two descriptive studies (Clark et al., 1991; Barlow et al., 2002); two correlational studies (Ministry of Health and Long-Term Care, 2007; To et al., 2006); and two randomized control trials (RCT) (Chodosh et al., 2005; Huang et al., 2004). The strength of all of these studies is the use of objective and validated outcome measures, as described below. One limitation is that half of these studies were based on small sample sizes (i.e. Clark et al., 1991; Barlow et al., 2002; To et al., 2006). The two RCTs used short follow-up periods (4 to 6 months), and these time-frames are inadequate when considered against the duration of self-management of chronic conditions (Lorig & Holman, 2003).

Clark et al. (1991) found that successful self-management of chronic illness required that clients master three categories of activities at home. First, clients must be sufficiently

knowledgeable about their condition and its treatment to make informed decisions about their care. Second, they must perform self-management tasks aimed at management of the condition. Finally, they must apply self-management skills necessary for maintaining adequate psychosocial functioning in order to reduce the impact of chronic illness on daily life. Clark et al. (1991) described the following self-management themes that were found to be common among asthma, arthritis, chronic obstructive pulmonary disease, diabetes and heart disease: (1) identification of problems through symptoms recognition; (2) obtaining health through interactions with providers; and (3) reducing the psychological burden of illness by managing emotions. Clark et al.'s study concluded that there were strong commonalities in the nature of self-management tasks that existed across different chronic diseases, and that the context for self-management of chronic disease by older clients differed from the context for younger clients. For this reason, Barlow et al. (2002) explained that there is a need for home care to develop self-management support tailored to different age groups and different disease entities, and the support should be extended to include family members.

Research evidence suggested that self-management support from home care services made a difference in terms of changes in behavior, health status, and health care utilization. A review by Barlow et al. (2002) found that there was evidence that self-management approaches provided benefits for home care clients in terms of knowledge; symptoms management; performance of self-management behaviors; self-efficacy and aspects of health status such as depression. Chodosh et al. (2005) found that training clients with chronic diseases to self-manage their disease was effective in increasing functioning, reducing pain, and reducing health care costs. For instance, individuals with congestive heart failure who participated in a discharge home care program that coordinated care and provided education for them and their families had

over 60% fewer readmissions to the hospitals (Ministry of Health and Long-Term Care, 2007). Similarly, adults whose asthma care was managed by a community-based home care team using decision supports and guided self-management experienced 50% fewer emergency department visits after one year (To et al., 2006).

Furthermore, Huang et al. (2004) studied the efficacy of home care services for the elderly who had diabetes and were living alone. The results of their research demonstrated that self-management support provided by home care nursing services improved overall health in the elderly population. Specifically, the results of the study indicated a general improvement in blood glucose values, weight control, and self-management skills of the diabetic clients who received weekly nursing visits to provide support, supervision, and education. Huang et al.'s study demonstrated that home visits to elderly patients for the management of chronic diseases could have a positive impact on self-management skills that could lead to desired health outcomes.

2.6.3. Barriers to Self-Management

Despite the growing evidence that suggests the benefits of self-management, there are barriers that can have a negative impact on successful self-management. The empirical evidence on the barriers on self-management is primarily based on descriptive studies. The scope of these studies was limited, however the study findings contributed to a greater understanding of the barriers to effective self-management of chronic diseases at home (Aljasem, Peyrot, Wissow & Rubin, 2001). Lorig and Holman (2003) found that pain, disability, fear and depression were the major concerns among one hundred older arthritis clients, and suggested that self-management support from home care services could be directed at these concerns.

Among veterans with diabetes, Haddock and Bretous (2004) determined the barriers to self-management included a lack of family support, co-morbidities, as well as a lack of understanding regarding their diseases and treatment options. Haddock and Bretous suggested that providing home care clients with information regarding their illnesses could empower them to actively participate in their disease management. The study findings also highlighted the importance of involving the family or client support system when delivering self-management support to clients at home. Haddock and Bretous (2004) concluded that caregiver burden could be reduced if home care client was able to overcome perceived barriers to successful disease management, and to maintain his/her health through improved self-management skills.

Another barrier to successful self-management for home care clients is the deficit in the quality and safety of self-management support. The Health Council of Canada (2010) conducted surveys of 5000 adults with chronic conditions, and their findings suggested disturbing gaps in the delivery of self-management support in the community. In this survey, 40% of Canadians reported that the level of self-management support they received was low, and the older Canadians (aged 65 and up) reported the lowest level of self-management support although they are the group most likely to have multiple chronic conditions. Similarly, Naylor et al. (2004) suggested that older adults coping with multiple co-morbid conditions and complex care were particularly vulnerable during the transition from hospital to home. A review of 94 studies conducted between 1985 and 2001 revealed that the transition of older adults from hospital to home was associated with high rates of preventable poor outcomes (Naylor, 2003). Specifically, one-third of older clients and caregivers reported unmet self-management needs, and high levels of dissatisfaction (Jerant & von Friederichs-Fitzwater, 2005). Re-hospitalization rates for these clients were high, with one-quarter to one-third considered preventable (Naylor, 2006).

Furthermore, a descriptive review of the literature indicated that hospitals often discharge clients with insufficient care planning, poor home care instruction, inadequate self-care information, lack of coordination among members of the health care team, and poor communication between the hospital and home care sector (Dai, Chang, Hsieh and Tai, 2003). Two descriptive studies investigated the level of unmet needs of patients discharged from acute care, underscoring the importance of self-management support prior to discharge. For example researchers in the Netherlands found that 93% of clients had experienced one or more health problems, and 70% expressed a need for information two weeks after their discharge (Jerant & von Friederichs-Fitzwater, 2005). Similarly, clients in Taiwan experienced health problems, limitations in activities of daily living, and unmet social and self-care needs during the first four weeks after discharge (Coleman, Mahoney & Parry, 2005).

One limitation of the self-management studies concerns the relevance of the results beyond the specific setting in which these studies were carried out (Birch and Gafni, 2003). Another limitation concerns the comparability of the studies that represents the extent to which results from the different studies can be compared (Markle-Reid et al., 2006). For example, questions remaining to be addressed concern the comparative effectiveness of the different self-management approaches (Barlow et al., 2002). Particularly, there is a need to determine whether these approaches need to be tailored to different age group, different cultural settings, and should be extended to include the informal caregivers, such as family members (Barlow et al., 2002). The review of the literature on self-management highlighted the deficits in the quality and safety of support provided to clients living in the community for their disease management.

2.7. Adverse Events in the Context of Home Care

Adverse events in home care were the outcomes of interest in this research study. The World Health Organization (WHO) (2008) defines adverse events as the incidents that result in harm to a client. WHO considers health care-associated harm as “harm associated with plans or actions taken during the provision of health care rather than an underlying disease or injury” (WHO, 2008, p. 8). The WHO definition of adverse events is useful for studying safety in home care context because it recognizes that health care is not limited to medical care provided by the health professionals, and it includes self-care (Doran et al., 2009).

In the literature, adverse events are usually in reference to a breakdown in the process of care by the health care system. However, there is a significant portion of home care is provided by clients themselves and their informal caregivers at home, and not by health care professionals (Blais et al., 2013). As a result, my research focused on clients and their caregivers as the care system in home care, and examined the occurrence of two types of outcomes that were most likely sensitive to the therapeutic self-care ability: (1) use of health care resources, including new emergency room visits and unplanned hospital admissions; and (2) adverse events, including client falls; unintended weight loss; new urinary tract infection; ADL decline; new pressure ulcers; compliance/adherence with medications; and caregiver distress. The purpose of this section is to provide an overview of the home care safety research, and review the empirical evidence regarding the types of adverse events that occur in relation to self-care.

2.7.1. Home Care Safety Research

Home is an unpredictable site of care because home care providers are usually in the home for very short duration, and therefore home care requires the active involvement of the clients and their families (Madigan & Fortinsky, 1999). Client outcomes are dependent on the quality of self-care provided by clients and their families, in addition to that provided by health care professionals, because of the intermittent nature of home care services (Madigan & Tullai-McGuinness, 2004). Despite the growing reliance on home care, qualitative studies performed in the United States, Canada and Australia demonstrated that clients were unprepared for self-care in their homes after hospital discharge (Coleman, 2005). For instance, the clients reported that they had minimal input into their care plan, and they received conflicting advice regarding the self-care of their chronic illnesses. In addition, research on hospital readmissions found 9% to 48% of readmissions were associated with inadequate post-hospital discharge care (Benbassat & Taragin, 2000).

Underlying all of this is a recognized concern about the safety of home care clients. Resources for home care are scarce, but the quality and safety of care should not be compromised (Lang et al., 2011). While patient outcomes are well documented in the acute care settings, only limited data exist about client safety outcomes in the home care settings (Doran et al, 2009). In the past, much of the research specific to adverse events within home care focused on medication errors or adverse drug events (Frey & Rahan, 2003; Gray, Mahoney & Blough, 1999; Meredith et al., 2001; Friedman, 2005). Meredith et al. (2001) conducted a study that examined the possible medication errors in 6178 elderly home care clients in the U.S., and found that almost one third had some evidence of a potential medication problem, or were taking a drug considered inappropriate for older people. Ellenbecker et al. (2004) investigated medication

issues in a cohort of 1,400 home care clients and found that there were mistakes in the way one fifth of the clients self-administered their medications. The authors suggested that look-alike/sound-alike medications were a common source of error, and therefore prevention strategies needed to be in place to promote medication safety among the home care clients.

In the past, little work has been done on the complete spectrum of potential adverse events in home care and their contributing factors. As a result, recent efforts have been made by the researchers to develop a better understanding of the nature of adverse events among the home care population. Massotti et al. (2009) studied the factors that contributed to the adverse events in home care, and found the following contributing factors: communication problems, formal provider skill mix, client complexity, home environment, medical procedures and service delays. This study proposed that the above factors needed to be considered in the future agenda of home care safety research.

In addition, Lang and Edwards (2006) conducted an environmental scan of patient-safety issues among Canadian home care clients. In their study, the following five unique challenges relevant to the context of home care safety were identified: (1) the safety of the client, family, informal caregiver, and health care provider are closely linked; (2) the setting of client homes is unregulated and uncontrolled as opposed to the hospital setting; (3) there are different dimensions of safety in home care, including physical, emotional, social and functional safety; (4) there is greater autonomy and choice for clients and their families in the home than in the hospital settings; (5) a large percentage of clients receiving home care support are elderly and living alone (Lang et al., 2009). The implication of this environmental scan is that client safety in home care is not limited to medical care provided by health professionals, but it also includes self-care provided by clients and their families. This recognition is important to the context of

chronic disease management in home care because the client and their family members play an integral role in the day-to-day care over the course of the client's illness.

In order to develop a conceptual explanation of home care safety, Lang et al. (2009) conducted a pilot study to describe the experiences, challenges, and insights regarding home care safety from the perspectives of clients, family members, and health care providers. The findings from qualitative interviews revealed that the perspectives of clients regarding home care safety differed from those of health care providers. Specifically, family caregivers described making decisions, while recognizing that their decisions are not always congruent with or endorsed by the health care providers. On the other hand, the health care providers were found to focus exclusively on client's physical safety, and this finding is similar to patient safety concerns in hospital settings as reported in the literature (Lang et al.). The authors proposed that future research on home care safety needs to: (1) address the client, family caregiver and health care providers as the unit of care; (2) reflect the influences of an unregulated and uncontrollable home environment on the provision of care; and (3) tackle the challenges of communication and continuity of care among family caregivers and health care providers.

Lang et al. (2013) have subsequently conducted a qualitative study to examine the perceptions of safety from the perspectives of home care clients, unpaid caregivers and paid care providers. The findings revealed that the safety issues in home care included: (1) providing care in residential spaces not designed for it; (2) waiting for services, equipment and providers; (3) poor planning and communication by paid providers; (4) heavy demands on unpaid caregivers; (5) high turnover in health care providers; and (6) failure to include home maintenance and repair in home care services. Similar issues were highlighted in the recent Health Council of Canada (2012) report on home care priorities for seniors in Canada, as well as recent studies by

the Nexus Home Care Research (Sims-Gould, Byrne, & Martin-Matthews, 2013; Craven, Byrne, Sims-Gould, Martin-Matthews, 2012; Byrne, Sims-Gould, Frazee; Martin-Matthews, 2011). For example, the Nexus Home Care Research group published findings about the safety problems in home care system, including equipment availability, continuity of care; training of home support workers, and communication difficulties. The Health Council of Canada (2012) reported the safety concerns related to the declining health of both home care clients and their informal caregivers. These study findings revealed that clients, unpaid caregivers and paid providers are experiencing challenges in the home care system. These research studies provided policy-makers with priority areas to focus in order to meet the needs of clients, paid and unpaid caregivers, as well as providing implications into operating a safe and sustainable home care system.

The strength of these research evidence is its ability to demonstrate how home care differs from the hospital setting in terms of the nature of formal service provision, the role of family members, and the characteristics of the clients receiving care (Hirdes, et al., 2004; Lang et al., 2013). While many of the same risks and adverse events exist in both settings, the literature highlighted how the context in which the care is administered is vastly different, which necessitates unique solutions specific to the home care settings. For instance, home care clients may be particularly vulnerable given the intermittent nature of home care clinicians' visits, and the reliance on self-care and informal caregiving (Sears, 2008). Therefore, the care and safety of home care clients cannot be addressed without considering the family members, unpaid caregivers, and paid providers as important parts of the caregiving team (Harrison & Verhoef, 2002).

Researchers have recently begun to develop an understanding of the nature of adverse events among the home care populations. To date, the studies of home care clients are limited with regards to the populations studied (i.e. general as opposed to specific client groups); study methods (i.e. emphasis on quantitative methods approach); and failure to consider the client and caregiver's perspectives (Sears, 2008; Johnson, 2006; Lang et al., 2013). For example, there are limited data that exist about the types of adverse events experienced by the various chronic disease populations, such as those with diabetes and heart diseases. Future research will benefit from examining the specific safety problems that are unique to home care clients with different types of chronic diseases. The empirical evidence on the nature of adverse events in home care is reviewed next.

2.7.2. Empirical Evidence on Adverse Events in Home Care

Lang and Edwards (2006)'s environmental scan has prompted other researchers to expand understanding of the nature and burden of patient safety issues among Canadian home care clients. One of the first Canadian home care safety studies reported a 5.5% incidence rate of adverse events in a sample of 279 Winnipeg home care clients, of which injurious falls accounted for nearly half (46%) of the adverse events; followed by medication-related events (23%); non-injurious falls (15%); pressure ulcers (3.8 %); and mental harm/injury (3.8%) (Johnson, 2006). Two subsequent studies, one conducted in the United States (US), and one in Canada, reported that 13% of home care clients experienced an adverse event (Madigan 2007; Sears et al. 2013). A scoping review of adverse events experienced by home care clients reported overall rates of 3.5 to 15.1% which include the types of events such as adverse drug events, infections, wounds, and falls (Masotti, McColl & Green, 2010).

In the US study conducted by Madigan and Tullai-McGuinness (2004), descriptive information of reported adverse events was collected from 43 home care agencies in Ohio and Michigan. The results indicated that the types of adverse events experienced by home care clients were: unexpected death (3.4%); urinary tract infection (1.4%); fall or accident at home (1.7%); wound deterioration (1.6%); unexpected nursing home admission (1.4%); increase in the number of pressure ulcers (1.9%); improper medication administration or side effects (0.87%); and hypo/hyperglycemia (1.04%). However, the limitation of this study was that voluntarily reported events were thought to under-represent the adverse events that actually occurred in the home care settings (Walshe, 2000). Also, Madigan and Tullai-McGuinness (2004) suggested that seasonal variations might have influenced the types of adverse events to be expected in home care clients, such as higher incidents of falls or accidents in the winter months. Despite these limitations, the implication of the study results suggested that Canada and U.S experienced a similar range of client safety issues among the home care populations.

Much of the literature in home care safety research has concentrated on the retrospective identification of the incidence rates and types of adverse events that have occurred (Baker et al., 2004). To address this limitation, the Canadian study conducted by Sears (2008) used the forward selection multiple logistic regression procedures to identify a predictive model locating home care clients who were more or less prone to the development of adverse events. Sears proposed that early recognition of the presence of client factors associated with adverse events, followed by enhanced support for disease management, offers opportunities for improving the safety of home care clients.

Sears (2008) found that thirty-three per cent of the adverse events were rated as having more than a 50% probability of preventability. Analysis of the factors associated with adverse

events in a sample of 430 home care clients identified a number of client characteristics, diagnosis and aspects of functional status that were associated with a higher risk of adverse events. Specifically, client factors most significantly ($p \leq 0.01$) associated with adverse events included: age 65+; living with others; first language other than English; Parkinson's disease; a history of falls, psychotropic medication use; memory difficulties; lack of ability for independent decision-making; depression/anxiety/anger; and being left alone for short or long periods of time (Sears et al., 2013).

Furthermore, Sears (2008) found that unplanned visit to hospital or emergency department with inappropriate plan for home care discharge were strongly related to the presence of home care adverse events. Similarly, inappropriate/inaccurate home care or service provider assessment of client's actual or potential environmental risks were found to have a strong relationship with the occurrence of adverse events. The implication of the study findings is that it may be possible to improve the safety and quality of home care by prospectively identifying those clients at increased risk for adverse events. Early identification of client safety risks may provide significant opportunities to reduce the likelihood of adverse events, and to improve the effective self-care of chronic diseases in home care settings.

One of the limitations of the previous home care safety research was that the studies were limited in sample size, and the study sample only involved one jurisdiction. In the study by Sears (2008), three home care programs in Ontario were selected by convenience. Also, the overall incidence rate of 13 % adverse events within the home care population meant that the sample size of clients used in the model development was relatively small (Sears, et al.2013). This limitation could be overcome by repeating the analyses with a much larger sample size that could improve the estimation of model parameters. In an attempt to address this limitation, a

Canadian study conducted by Doran et al. (2009) investigated the patient safety outcomes in a large sample of 238,958 home care clients from three different jurisdictions: Ontario, Nova Scotia, and Winnipeg Regional Health authority.

The Doran et al. (2009) study examined the nature of patient safety problems among Canadian home care clients, using data collected through the RAI-HC (Resident Assessment Instrument-Home Care). The findings suggested that new fall (11%), unintended weight loss (9%), new emergency department visit (7%), and new hospital visit (8%) were the most prevalent adverse outcomes. One limitation of this study was that the risk adjustment was not conducted when determining regional differences in the adverse events rates (Doran et al., 2009). Dalby, Hirdes & Fries (2005) suggested that risk adjustment strategies are instrumental in adjusting for different populations of clients who may be at greater risk of experiencing adverse outcomes as a function of their clinical status rather than the quality of care.

In a subsequent paper, Doran et al. (2009) examined the role of age and client safety risk factors in explaining variations in adverse outcomes, with a focus on emergency room visits. Contrary to the previous research (Baker et al., 2004), the findings suggested that age was not helpful for explaining regional variations in adverse outcomes among long-term home care clients (Doran et al.). Specifically, a history of falls, a cancer diagnosis, polypharmacy, receiving an anxiolytic medication and anti-depressant medication were found to be associated with an increased risk of emergency room (ER) visits. These findings were consistent with the previous research by Sears (2008) and Madigan (2007), who found that receiving psychotropic medications was associated with adverse outcomes in home care clients. On the other hand, low self-reliance and limitation in activities of living were associated with a decreased risk of ER visits. A limitation of this study was that not all home care clients were represented in the

database because only long-term clients (on service for more than 30 days) qualified for an RAI-HC assessment. Therefore, the study findings could only be generalized to long-stay clients. Despite this limitation, this research advanced the understanding of adverse events in home care by identifying the specific factors that increased the risk of ER visits, so that interventions could be targeted at those risks in order to prevent unnecessary ER use among long-stay home care clients.

Doran et al. (2013) attempted to address the limitations identified in the previous literature by focusing on home care clients from regions in Canada where comparative data were available, as well as including the short and long-stay home care clients. The study findings revealed that the overall incidence rate of adverse event associated with hospitalization ranged from 6% to 9%. The most frequent adverse events associated with hospitalization were injurious falls, injuries from other than fall, and medication-related events, whereas new caregiver distress was the most frequent adverse event identified through RAI-HC. Doran et al. (2013) determined that an injurious fall was associated with a significant increase in the odds of a client requiring long-term care facility admission and of client death. Delirium, sepsis and medication-related incidents were associated directly with an increase in the odds of client death. The results of the study pointed to the need for increased resources to target strategies for addressing safety problems in the home care settings.

2.7.3. Self-Care, Informal Caregiving and Adverse Events in Home Care

No research was found that specifically investigated the impact of client's self-care or informal caregiving on adverse events in home care. However, Sears (2008) attempted to address this question by examining client characteristics most significantly associated with

adverse events. In particular, client self-care factors most significantly ($p \leq 0.01$) associated with adverse events included: (1) involvement of informal caregivers that live with the client; (2) the need for assistance with a variety of specific activities of daily living (ADLs) such as ambulation outside of the home, dressing, toilet use and bathing or hygiene; and (3) the need for assistance with instrumental ADLs including meal preparation, housework, finances, medication, telephone use and shopping.

Sears (2008) also conducted retrospective chart audits of 430 home care clients in Ontario to study the impact of health care management and informal care by family members on adverse events in home care. The results indicated that health care management (ie. decision-making, service provision) by health care professionals and allied health care workers was rated as being likely ($>50/50$) to virtually certain to have contributed to the adverse events in 29.5% of clients with adverse outcomes. Informal care by family members or friends was rated as being likely ($>50/50$) to virtually certain to have contributed to adverse events in 27.9% of clients with adverse events, as well as a contributing factor in two-thirds of adverse event associated deaths. On the other hand, self-care was rated as a contributing factor in over (52.6%) of adverse events.

The limitations of this study are that retrospective adverse events analyses may be prone to hindsight and attribution bias. As well, some home care practitioners may document more extensively, and increase the likelihood that adverse events were identified (Lilford, Mohammed, Braunholtz, Hofer, 2003). On the other hand, the rate of adverse events could have been under-reported because of information bias related to the diligence with which data and facts were recorded in the client chart. A recent study conducted by Blais et al. (2013) used similar approach to assess adverse events by using data from client health records or charts to identify factors contributing to the adverse events. Their research involved retrospective chart review of

1200 home care clients in Manitoba, Quebec and Nova Scotia. The results revealed that more comorbid conditions (OR 1.15; 95% CI 1.05 to 1.26) and a lower instrumental activities of daily living score (OR 1.54; 95% CI 1.16 to 2.04) were associated with higher risk of experiencing an adverse event. As home care clients became more dependent and were more functionally vulnerable, they were at greater risk of experiencing an adverse event. This finding points to the role of self-care ability as a potential contributing factor to adverse event. Furthermore, Blais et al. (2013) found that client's decisions or actions contributed to 48.4% of adverse events; informal caregivers 20.4% of adverse events; and health care personnel 46.2% of adverse events. These findings demonstrated the tri-partite contribution to adverse event where safety of home care is dependent upon clients, informal caregivers and home care personnel being aware of the safety risks, and possessing the skills to mitigate those risks.

2.7.4. Adverse Events in Care Transitions

In addition to studying the types of adverse events home care clients experience and identifying the underlying risk factors, the safety problems during care transitions also need to be examined (Parry et al., 2008). Madigan and Tullai-McGuinness (2004) caution that the silo approach to health care, where hospital and home care setting is primarily concerned about their practice setting without taking a broader view of client outcomes across the health continuum, contributes to a lack of continuity in system planning and support for self-care in the community. In the study by Forster et al. (2004), an estimated 23% of a total of 328 clients experienced at least one adverse event after being discharged from hospital, and that 50% of the total of such events were preventable or ameliorable. The authors concluded that more than 1 in 5 clients discharged from a Canadian teaching hospital's medical unit experienced an adverse event. The

study findings demonstrated that care transitions represented a high-risk time point for health care safety problems. For example, the Canadian Institute of Health Information (2012) reported that one in 12 patients was readmitted to hospital within 30 days of discharge. These results suggested that significant deficits exist in the quality and safety of care transitions from hospital to home care.

Furthermore, Madigan (2007) found that more than three fourths of the adverse events were associated with discharge to the community, suggesting home care clients required continued assistance. Specifically, clients who experienced adverse events were older, had more depressive symptoms and behavioral problems, and were more functionally impaired for both activities of daily living (ADLs) and Instrumental ADLs. In regards to gender and cultural differences, women had slightly lower relative risk (0.98) of an adverse event than men, whereas clients of minority ethnicity had a slightly higher relative risk (1.06) compared to white clients. The above study findings raised the question as to whether there is sufficient support from home care services to assist clients and their informal caregivers with disease management. The study findings also highlighted the importance of health care providers spending more time on discharge planning to improve client's self-care knowledge and skills, especially for those who were at greater risks for adverse events. Henderson and Zernicke (2001) suggested that discharge education by health care professionals could make a positive contribution toward client's health outcomes. Therefore, it is important that home care practitioners prepare the clients and their families to engage in self-care as a way of reducing their vulnerabilities to experiencing adverse events.

2.8. Conclusion for Chapter 2: Literature Review

The purpose of this chapter was to provide a literature review on what was already known about the concept of therapeutic self-care and adverse event in home care. This chapter provided an overview of the conceptualization of therapeutic self-care, and a critique of the self-care movement in home care. The empirical evidence on therapeutic self-care in home care was reviewed and summarized in relation to the five related concepts: (1) Self-care; (2) Patient activation; (3) Therapeutic self-care in acute care setting; (4) Self-management in chronic disease management; and (5) Adverse Events in the context of home care.

The review of the literature on self-care identified that self-care is a critical concept in the home care setting where much of the required treatment and care are provided in the clients' homes for the management of chronic diseases. In particular, self-care enables clients with chronic illnesses to monitor and recognize changes in functioning, and implement appropriate strategies for managing these changes (Sidani, 2011). Empirical evidences suggested that the performance of self-care behaviors was influenced by cognitive, psychological, physical, demographic, and socio-cultural factors. Self-care practice is considered beneficial at the individual client level and for the healthcare system, because it has been associated with reduced risk of complications; enhanced adjustment to illness; improved symptom control and functioning; and consequently, improved quality of life and reduced health services utilization (Baker et al., 2005; Doran et al., 2006; Dunbar, Jacobson & Deaton, 1998; Kreulen & Braden, 2004; and Leveille et al., 1998).

The review of literature on patient activation indicated that clients who were able to: (1) self-manage symptoms/problems; (2) engage in activities that maintain functioning and reduce health decline; (3) be involved in treatment choices; and (4) collaborate with health care

providers, were likely to have better health outcomes (Hibbard, Mahoney, Stockhard, & Tusler, 2005; Hibbard & Tusler, 2007; and Hibbard & Stockhard, Mahoney, & Tusler, 2004). Despite the evidence indicating that self-care was instrumental for achieving better client and health care outcomes, there was no study that specifically explored the impact of client's therapeutic self-care ability on safety problems and adverse events in home care. The literature review on therapeutic self-care demonstrated that current research on this topic has focused on the acute care and in-patient settings. There is a lack of empirical evidence on the application of therapeutic self-care measures in the home care setting. Therefore, my study attempted to fill this research gap by examining the relationship between therapeutic self-care ability and the occurrence of adverse events experienced by home care clients.

The empirical evidence on adverse events provided critical information on the risk profile of the home care client population, so that specific client factors can be considered when planning interventions, allocating resources, and setting priorities for home care service provision. The identification of types of risks and the clients most likely to be harmed represents a significant opportunity to avoid adverse outcomes, and thereby improve client safety through enhanced home care management and supportive care processes.

In the study by Sears (2008) and Blais et al. (2013), the identification of client's self-care as significant contributors to adverse events in home care raised the important question about whether therapeutic self-care ability predicts the frequency and types of adverse outcomes experienced by home care clients with chronic diseases. Similarly, the study by Lang et al. (2013) highlighted the importance of exploring the perspectives of clients and caregiver dyads because clients and informal caregivers are central to the success of home care. Family members who are unpaid caregivers are often untrained, and are older people with their own health

challenges. Informal caregivers often make promises out of love, and a sense of duty to keep the client at home, without being aware that this objective may be beyond their capacity (Stajduhar & Davies, 1998). Therefore, the physical environment, family dynamics, the cognitive and physical abilities of clients and their informal caregivers, are essential factors to consider when developing an understanding of home care safety (Harrison & Verhoef, 2002).

In the context of chronic disease management, shortened hospital stays, and increased complexity of home care clients, home care professionals continue to have an important role in supporting clients in the development of self-care skills. Understanding the relationship between therapeutic self-care and safety outcomes in home care has the potential to transform home care practice, and is an important avenue for future research. My research provides evidence to inform important clinical and policy issues related to the potential role of home care services in facilitating clients' readiness to engage in therapeutic self-care.

Chapter Three

Design and Methods

3.1 Overview of Mixed Methods Study Design

Mixed methods research is a research design with philosophical assumptions as well as methods of inquiry that employs the use of quantitative and qualitative methods (Creswell & Plano Clark, 2007). Pragmatism is the worldview that is guiding this research. Pragmatism draws on many ideas, using diverse approaches, and valuing both objective and subjective knowledge (Tashakkori & Teddlie, 2003). A researcher with a pragmatic worldview does not see the world as an absolute unity, and is not committed to any one system of philosophy and reality (Creswell, 2009). With this worldview, the researcher tests hypotheses and investigates multiple perspectives on the nature of realities by collecting both quantitative and qualitative data to provide the best understanding of a research problem. The purpose of this mixed methods study was to develop an understanding of the concept of therapeutic self-care in the context of home care. For the present study, a complementary mixed methods design was used, a type of design in which different but complementary data were collected on the same topic. For the quantitative method, secondary data analysis from multiple data sources was used to examine whether therapeutic self-care ability predicted the occurrence of adverse events in home care. Concurrent with this data collection, qualitative interviews were conducted to explore home care clients and their informal caregivers' perspectives on safety related to therapeutic self-care at home.

The reason for collecting quantitative and qualitative data was to bring together the strengths of both forms of research with the aim of more fully explaining the results of analyses. That is, the two methods were complementary. According to Caracelli & Green (1997), the goal of complementarity is to measure facets of a phenomenon to reveal an enriched, elaborated understanding. The selection of a mixed methods approach was important in this study because data analysis from the quantitative method was enhanced or clarified by results from the qualitative method and vice versa. There is a lack of empirical research that has examined the concept of therapeutic self-care in the context of home care, as well as its influence on the safety of home care clients and their informal caregivers. To understand fully the concept of therapeutic self-care, quantitative and qualitative techniques were employed to help illuminate different aspects of safety challenges and concerns related to therapeutic self-care. The mixed methods design was used to bring together the strengths of both forms of research to obtain a more comprehensive understanding of the different aspects of therapeutic self-care. The quantitative and qualitative methods provided complementary data by addressing the limitations of one method versus the other. For instance, the quantitative approach addressed the broader question about the nature of the relationship between therapeutic self-care and adverse events. On the other hand, the qualitative approach addressed the limitations of the quantitative approach by providing greater depth into the contextual details of home care safety in relation to therapeutic self-care among client populations who are vulnerable of experiencing safety challenges, such as older adults and informal caregivers. Therefore, both quantitative and qualitative data were needed to achieve the study purpose and address the research questions.

Results in this study were examined through complementarity where the analysis of quantitative and qualitative data helped to create a deeper understanding of the relationship

between therapeutic self-care and adverse events in home care, as well as the aspects of self-care and informal caregiving that support the safety of clients at home. The secondary data analysis provided an understanding of the prevalence of adverse events in home care and their relationship with therapeutic self-care, whereas the qualitative description provided an in-depth understanding of participants' perspectives and experiences in relation to managing their health at home. Quantitative methods may have limitations with regards to what can be learned about the meanings participants give to the events, whereas qualitative description enables researchers to further capture the elements of an event that come together to make it the event that it is (Sandelowski, 2000). Therefore, the analysis that is obtained by using qualitative and quantitative methods should be more comprehensive than what would have been achieved through quantitative or qualitative assessment alone (Yauch & Steudel, 2003). This complementarity approach offered different strengths that enhanced the understanding of therapeutic self-care in the context of home care, and therefore contributed to the overall completeness of the research study.

In this chapter, an overview of the quantitative study is presented, including a discussion of the study purpose, study design, study population, study measures, quantitative data analysis, and strengths and limitations related to the internal and external validity. Following the description of the quantitative method, an overview of the qualitative components of the study is presented by discussing the study sample, recruitment process, data collection and analysis methods, as well as approaches to assessing the quality of qualitative data. The chapter concludes with a discussion of the ethical considerations to protect the study participants in this mixed methods study.

3.2. Overview of Quantitative Method

3.2.1. Study Purpose and Design

The purpose of the quantitative analysis was to evaluate the relationship between therapeutic self-care, adverse events, and health system utilization; while controlling for client demographics and clinical characteristics. The aim of a quantitative analysis was to examine the relationship between therapeutic self-care ability, and the frequency and types of adverse events experienced by home care clients. The quantitative approach for this research employed a retrospective cohort design involving secondary data analysis to answer the following question: What is the relationship between home care clients' therapeutic self-care scores and adverse events? This was undertaken using the following data sources: 1) HOBIC-HC (Health Outcomes for Better Information and Care-Home Care); 2) Home Care Reporting System RAI-HC (Resident Assessment Instrument-Home Care); 3) NACRS (National Ambulatory Care Reporting System) for emergency admissions; 4) DAD (Discharge Abstract Database) for hospital admissions.

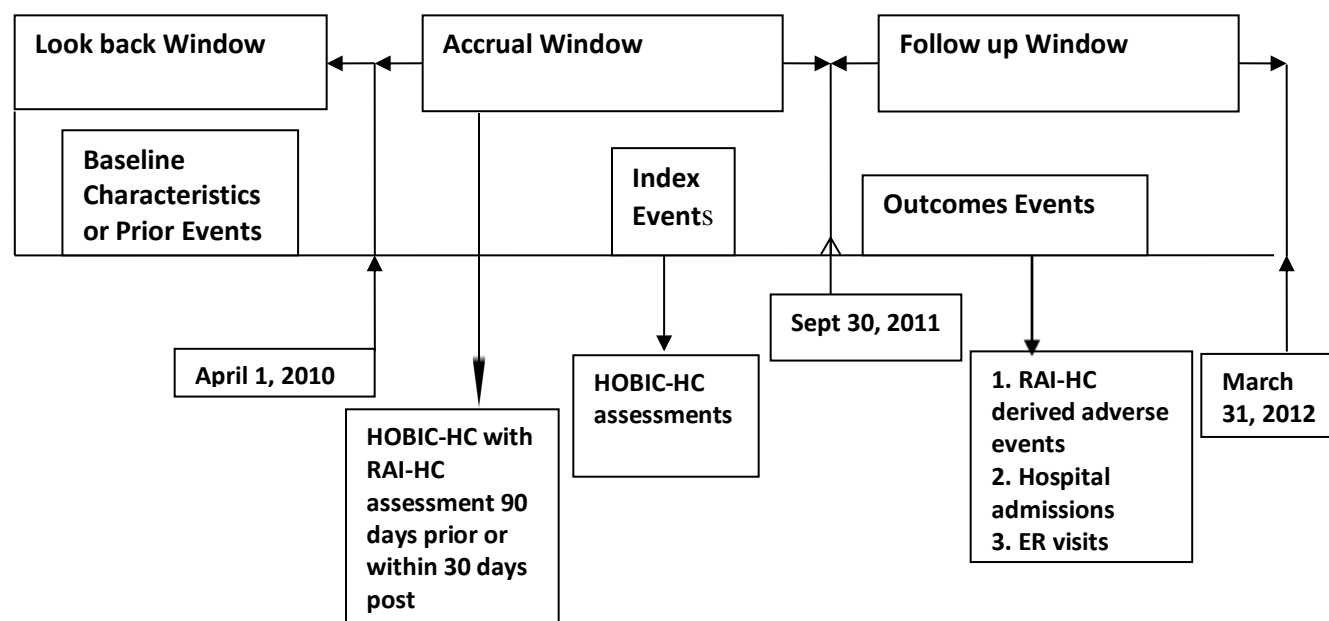
3.2.2. Study Cohort

The study population consisted of long stay home care clients who were adults with the age of 18 years or older. Long-stay home care clients were defined as those who were expected to receive home care services for 60 days or longer and were assessed using the RAI-HC assessment. The cohort was constructed by linking HOBIC-HC assessment where a baseline RAI-HC assessment was completed within 90 days prior to, or 30 days after the index HOBIC-HC assessment. The accrual of study cohort started from April 1, 2010 and ended on September 30, 2011, which resulted in a final sample of 1470 linked HOBIC-HC and baseline RAI-HC

assessments. After the creation of study cohort, the 1470 linked assessments were followed-up to investigate the occurrence of adverse events until March 31, 2012. The purpose of the cohort follow-up was to examine whether therapeutic self-care scores predicted the frequency and types of adverse events experienced by home care clients.

Specifically, 1,470 HOBIC-HC assessments on therapeutic self-care measures were linked with data from: (1) DAD to determine new acute care admissions; (2) NACRS to determine new ER visits; (3) subsequent RAI-HC assessments to determine adverse events including falls, unintended weight loss, urinary tract infection, ADL decline, new pressure ulcers or ulcer deterioration, compliance/adherence to medications, and new caregiver distress. The index RAI-HC assessment was used to measure client clinical characteristics and as the index date to look back in time for prior health system utilization. Subsequent RAI-HC assessments were used in the follow-up period, and were linked with the nearest therapeutic self-care score (admission or discharge) to examine the occurrence of adverse events and their relationship with therapeutic self-care. In particular, the assessment date of the subsequent RAI-HC, DAD and NACRS needed to occur after the baseline RAI-HC assessment date and the index HOBIC-HC assessment date for the measurement of outcomes. This approach ensured that all subsequent assessments used in the data analysis were outcome assessments, not assessments that had occurred before the index event. A visual diagram that outlines the components of this cohort study design can be found in Figure 1.

Figure 1. Cohort Study Design



3.2.3. Study Measures

Independent Variables:

(1) Therapeutic Self-Care

Therapeutic self-care was the independent variable that was posited to influence adverse events in home care. Specifically, the Therapeutic Self-Care Scale that was developed by Sidani and Doran (Doran et al., 2002), and collected as part of the HOBIC assessment was used to obtain data on clients' therapeutic self-care measures. The Therapeutic Self-Care scale is a 12-item instrument that captures the domains of self-care: taking prescribed medications; recognizing and managing symptoms; performing and adjusting regular activities; and managing changes in condition (Sidani, 2008). The items measure the clients' perceived ability to perform these self-care activities with a 5-point numeric rating scale anchored with "not at all" and "very

much”, with higher total scores indicating high levels of self-care ability. The Therapeutic Self-Care Scale is presented in Appendix B.

(2) Risk Adjustment Variables

Risk adjustment variables were included as the independent variables along with the therapeutic self-care measure. Risk adjustment is essential when comparing quality of care across providers where home care organizations provide services to populations with different characteristics (Dalby, Hirdes & Fries, 2005). In this study, risk adjustment was undertaken to adjust for different populations of clients who may be at greater risk of experiencing poor outcomes as a function of their demographic characteristics and clinical status. One approach to risk adjustment strategy is to provide adjustment for differences in the population at the client level (Dalby et al., 2005). Specifically, this study focused on risk adjustment at the individual client level to adjust for differences in client characteristics that may affect the occurrence of adverse events. The baseline assessment of RAI-HC completed 90 days prior to the HOBIC assessment was used to control for clinical characteristics such as co-morbidities, and prior ED use and acute care admissions within 90 days.

In the study by Jones et al. (2010) and Hirdes (2004), risk adjustment methods were derived and validated using data from Canadian and U.S. home care clients assessed with RAI-HC. These studies identified specific risk adjustment variables related to each of the following dependent variables of relevance to my study:

- (1) **Falls:** Not totally dependent in transferring; reduced physical activity in last 3 days; any wandering; unsteady gait; diagnosis of arthritis; cognitive impairment; age 55 years or older, polypharmacy, history of falls

- (2) **ER Visits:** history of falls; polypharmacy; diagnosis of cancer; taking anti-depressants and anxiolytic medications; Self-Reliance Index; Activities of Daily Living (ADL)
- (3) **Hospitalization:** Post-acute (recent hospitalization); edema; diagnosis of diabetes, polypharmacy, anti-depressants
- (4) **Unintended weight loss:** age less than 65; Activities of Daily Living (ADL) hierarchy scores; diagnosis of cancer
- (5) **New urinary tract infection:** age less than 65
- (6) **ADL decline:** Not totally dependent in transferring; locomotion problem; age less than 65; cognitive impairment
- (7) **Pressure Ulcer:** age less than 65; ADL Hierarchy scores

In addition to the specific risk adjustment variables related to the above seven dependent variables, Hirdes et al. (2004) identified a number of client characteristics that researchers should look into as additional risk adjustment variables to control for differences in client population at the individual level. These additional individual level risk-adjustment variables include: age as a continuous variable; gender; baseline physical and cognitive functioning; clinical complexity based on the Changes in Health, End-Stage Disease, and Symptoms and Signs (CHESS) scales. CHESS score is a composite measure of change in health status, end-stage disease and symptoms and signs (e.g. vomiting, dehydration, weight loss and shortness of breath), and has been shown to be a strong predictor of adverse event (Hirdes, Frijters, & Teare, 2003). Furthermore, Dalby, Hirdes, & Fries (2005) validated risk adjustment methods using data from Ontario and Winnipeg Regional Health Authority home care clients assessed with RAI-HC. When adjusting for differences at the individual client level, Dalby et al. (2005) recommended that researchers

should look into potential risk adjustment variables that include both individual assessment items and summary scales embedded within the RAI-HC, such as the Cognitive Performance Scale score; Activity of Daily Living Hierarchy score; Depression Rating Score; and pain scale.

In summary, I used specific risk adjustment variables related to the dependent variables because they were found to be sensitive to home care clients' adverse events, including client falls, unintended weight loss, ER visits, hospitalization, new urinary tract infection, ADL decline and new pressure ulcer or ulcer deterioration (Jones et al., 2010; Hirdes et al., 2004). In addition to these specific risk adjustment variables, additional risk adjustment variables were used to control for client demographics and clinical characteristics such as age, gender, education; living alone, comorbidities, the Cognitive Performance Scale; the ADL Hierarchy score; the Depression rating score; CHESS; and pain scale (Dalby et al., 2005). This approach ensured that the specific risk adjustment variables utilized were not limited to a particular research study. Rather, other relevant literature on risk adjustment variables were considered and reviewed to ensure that all relevant variables were included in the risk adjustment model to enhance the statistical validity of study results (Hirdes, Frijters, & Teare, 2003). Refer to Appendix H for a list of risk adjustment variables for each of the outcome variables in this study.

Dependent Variables:

There were a total of nine adverse events that were the dependent variables of interest in this study. The dependent variables included the following two types of outcomes: (1) use of health care resources, including a) new emergency room visits and b) new hospital visits; and (2) adverse events, including c) client falls; d) unintended weight loss; e) new urinary tract infection; f) ADL decline; g) new pressure ulcer or ulcer deterioration; h) non-compliance or adherence with medication; and i) new caregiver distress. Specifically, my study used the index HOBIC

assessment and the subsequent RAI-HC assessment as follow-up to identify the occurrence of client fall, unintended weight loss, new urinary tract infection, ADL decline, new pressure ulcer or ulcer deterioration, compliance/adherence to medication, and new caregiver distress. Client health system utilization during the follow-up period was captured using the data from NACRS for new emergency room visits and DAD for new hospital visits.

I examined the occurrence of two types of outcomes that were most likely sensitive to therapeutic self-care ability. Also, these two types of outcomes were chosen because they were the most prevalent adverse events identified by Doran et al. (2009) and Doran et al. (2013). The following section provides the empirical evidence based on the literature review that supports the rationale for choosing the dependent variables.

(1) Use of Health Care Resources:

- **New ER visit:** ER visit was found in previous research to be among the most prevalent adverse event for home care clients (7%) (Doran et al., 2009)
- **New hospital visit:** New hospital visit was found in previous research to be among the most prevalent adverse event for home care clients (8%) (Doran et al., 2009).

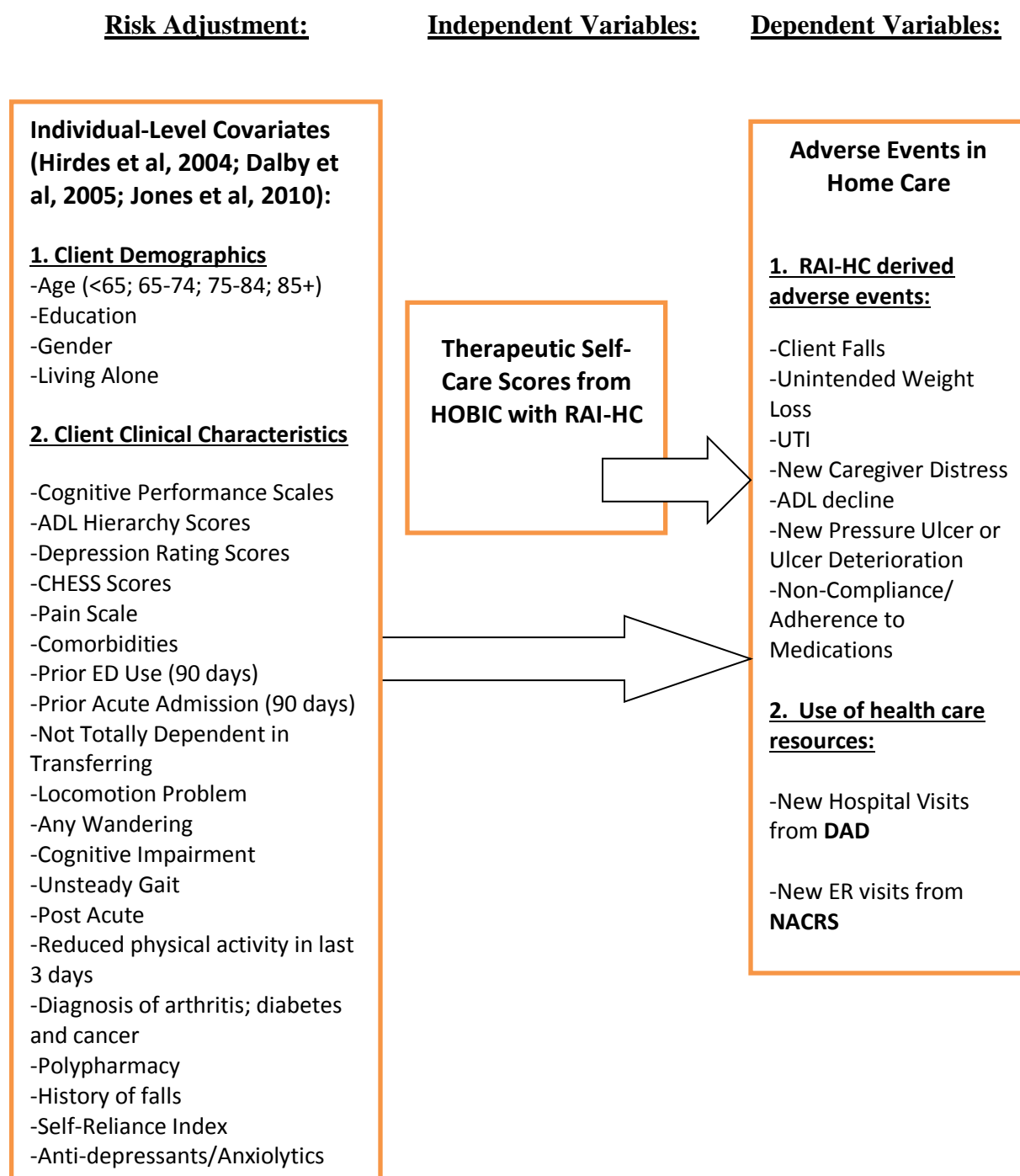
(2) Adverse Events:

- **Client falls:** Injurious falls and injuries from causes other than fall were the most frequent types of adverse events associated with hospitalization. Specifically, between 2% and 3% of home care clients had falls that resulted in injuries associated with hospitalization (Doran et al., 2013).
- **Unintended weight loss:** Unintended weight loss was found in previous research to be a prevalent adverse event for home care clients (9%) (Doran et al., 2009).

- **New urinary tract infection (UTI):** Home care clients with an indwelling urethral catheter were found to be at risk for a catheter-associated UTI (8%) (Doran et al., 2013).
- **ADL decline:** ADL decline was found to be associated with increased odds of experiencing an adverse event (Doran et al, 2013). ADL decline was also found to be an adverse event most significantly ($p \leq 0.01$) associated with client self-care factors (Sears, 2008).
- **New pressure ulcer/deterioration:** Doran et al. (2006) found that therapeutic self-care at discharge in acute care was related to pressure ulcer prevention ($r = -0.18$). Therefore I reasoned in this study that therapeutic self-care would be associated with pressure ulcer outcome for home care clients.
- **Compliance/adherence with medications:** Medication-related incidents were found to be the most frequent types of adverse events associated with hospitalization (2%) among a population of home care clients (Doran et al., 2013). A study of medication-related incidents associated with ER visits among community dwelling older patients reported a 12% rate (Zed et al., 2008), and another study reported a 4.7% rate (Hohl et al., 2010).
- **New caregiver distress:** Lang and Edwards (2006) suggested that the safety of the client and family caregivers is inextricably linked. Caregiver distress is a safety concern because caregivers need to make critical decisions regarding the care required by the client such as giving medications (Lang et al., 2009). Doran et al. (2013) found that the incidence of new caregiver distress ranged between 6% and 11%, and this rate was within the range of 6% rate reported by the Canadian Institute for Health Information (2004).

The operational definitions of adverse events and the information on how these adverse events were measured from the data sources are presented in Appendix A. The predicted model of hypothesized relationships is presented in Figure 2.

Figure 2. Predicted Model: Hypothesized Relationships



3.2.4. Data Sources

Prior to collecting the quantitative data, ethics approval was obtained from the University of Toronto Research Ethics Review Board (Protocol reference ID number 27223). Refer to Appendix C for the Ethics Approval Letter from the University of Toronto. Ethics approval was also obtained from ICES where secondary data analyses took place. The following section describes the data sources for this research study: (1) HOBIC-HC; (2) RAI-HC; (3) NACRS; and (4) DAD.

1. HOBIC-HC: Therapeutic Self-Care

The quantitative analysis involved using HOBIC-HC assessments to investigate the independent effect of Therapeutic Self-Care (TSC) on the above mentioned outcomes. HOBIC assessments are collected to capture standardized client outcome data related to nursing care in four sectors: acute care, long-term care, complex continuing care and home care (Nagle, White & Pringle, 2007). The focus of my study was the HOBIC-HC TSC, measured in the home care clients. The data on therapeutic self-care outcome was contained in HOBIC databases housed at the Institute of Clinical and Evaluative Sciences (ICES). Home care nurses are required to complete HOBIC documentation, including administering the Therapeutic Self-Care scale to their clients on the client's admission to home care services and on discharge. Home care organizations submit the HOBIC data to ICES on a monthly basis. ICES staff ensured all data were made anonymous by removing personal identifiers prior to sharing the data with me.

The Therapeutic Self-Care scale is a 12-item instrument that captures the domains of self-care: taking prescribed medications; recognizing and managing symptoms; performing and adjusting regular activities; and managing changes in condition (Sidani, 2008). The items measure the clients' perceived ability to perform these self-care activities with a 5-point numeric

rating scale anchored with “not at all” through to “very much”, with higher total scores indicating high levels of self-care ability. The Therapeutic Self-Care scale has been used in three studies in the acute care setting where it demonstrated acceptable construct validity and internal consistency reliability based on Cronbach’s alpha of 0.88 (Doran et al., 2006; Doran et al., 2003; Sidani, 2008).

2. RAI-HC (Resident Assessment Instrument-Home Care)

My study used the RAI-HC data to provide information on client demographics; client clinical characteristics; and other adverse events, including (1) client falls; (2) unintended weight loss; (3) new urinary tract infection; (4) ADL decline; (5) new pressure ulcer or ulcer deterioration; (6) compliance/adherence to medications; and (7) new caregiver distress.

The RAI-HC is part of the Resident Assessment Instrument (RAI) series of instruments that have been developed by Inter-RAI, a not-for-profit international consortium of researchers (MOHLTC, 2002). Each of the RAI-HC series of instruments contains the following: (1) an assessment form, called the Minimum Data Set (MDS); (2) detailed instructions on how to conduct the assessment in the RAI-Home Care; and (3) Client Assessment Protocols (CAPs) that are care planning guidelines to assist the clinicians in identifying problems, risk factors and areas of potential benefits. Refer to Appendix D for the RAI-HC assessment form.

The RAI-HC assessment is conducted by the case manager at the Community Care Access Centre to evaluate the care needs of long-stay home care clients in Ontario. Long-stay home care clients are individuals expected to receive services for longer than 60 days. The assessment consists of over 300 questions including detailed clinical and demographic information observed in the previous 7 days, cognitive status, mood and behavior patterns, informal support services, physical function, clinical diagnoses, prescription and non-

prescription medication use (Foebel, Hirdes, Heckman, Tyas, & Tjam, 2011). The RAI-HC was an appropriate data source for this study due to the breadth of information provided, allowing a comprehensive description of long-stay home care clients within Ontario.

The RAI-HC is considered reliable and valid, and the items contained within the RAI-HC assessment have good inter-rater reliability. In the study by Hirdes et al. (2008), the reliability of the items from the RAI-HC instrument was tested using weighted kappa coefficients. The study findings indicated that the average weighted kappa for the RAI-HC instrument was 0.69. For example, the average weighted kappa for the item on falls was 0.65, which is an outcome of interest in this study. Based on Landis and Koch (1977)'s convention for interpreting kappa values, the RAI-HC instrument can be considered to have substantial overall inter-rater reliability when the kappa values are ranging from 0.61 to 0.80.

Furthermore, the RAI-HC assessment scales have undergone criterion validity testing. Agreement between the RAI-HC scales and the gold standard scales was assessed with Pearson's correlation coefficient in the study by Landi et al. (2000). The study findings indicated excellent agreement with the coefficient of 0.74 for RAI-HC Activities for Daily Living (ADL) versus Barthel ADL index; 0.81 for RAI-HC Instrumental Activities for Daily Living (IADL) versus Lawton IADL index; and 0.81 for RAI-HC Cognitive Performance Scale versus the Mini Mental State Examination. These study findings support the overall reliability and validity of the functional and clinical data contained in the RAI-HC assessment.

3. National Ambulatory Care Reporting System (NACRS)

The therapeutic self-care scores from HOBIC assessments were examined in association with the National Ambulatory Care Reporting System (NACRS) to investigate the relationship between therapeutic self-care and emergency room visits (ED visits) during the follow-up period. NACRS is a data collection tool designed to capture information on client visits to facility and community-based ambulatory care, where data about visits are collected at the time of service in participating facilities (NACRS, 2011). This system is designed to provide valuable information that can help evaluate the management of ambulatory services in Canadian health care facilities.

The data elements that were of relevance to my study included the client demographics and administrative information about the dates of ED visits. These data elements were used to investigate the occurrence of ED visits for home care clients during the follow-up period for this study. The NACRS Data Quality Assessment Study Report (CIHI, 2010) provided quantitative evidence of measurement validity of the data elements for this study, including demographics, clinical, administrative, financial and service-specific. In particular, NACRS (2007) conducted a re-abstraction study to examine the charts for 7,500 ED visits at 15 Ontario facilities. High agreement rate was found in the inter-rater reliability study (87.3%) on dates and times for ED visits.

4. Discharge Abstract Database (DAD)

The therapeutic self-care scores from HOBIC assessments were examined in association with the Discharge Abstract Database (DAD) to investigate the relationship between therapeutic self-care and client health system utilization, specifically, acute care hospital admissions during the follow-up period.

The DAD contains clinical and administrative data relating to health care services provided to the clients. The DAD is a record of hospital activity that is completed for each instance of a hospital separation, including discharge, death, transfer to another facility (Richards, Brown & Homan, 2001). The data collected on each record includes coded diagnostic, intervention and client demographics and administrative information. The target population of the DAD includes individuals undergoing same-day surgeries, and inpatient hospital discharges from acute care. In Ontario, all hospital discharges are submitted to CIHI and are included in the DAD. The data elements that were of relevance to my study included client demographics and administrative information about the dates of any admission to hospital with an overnight stay. These data elements were used to investigate the occurrence of hospitalizations for home care clients during the follow-up period for this study.

In regards to the data quality of DAD, the general data limitations are detected and investigated through data processing and editing by staff at CIHI as well as through data quality activities within the DAD program area (CIHI, 2010). Using a standard data set, hospitals prepare a discharge summary that contains information retrieved from client charts, and then this information is subsequently forwarded to CIHI where it goes through extensive edits prior to being included in the database (Richards, Brown & Homan, 2001). The data submissions to DAD are monitored continually where CIHI will follow up with facilities when there are gaps in submissions or if there is a significant change in the total volume of abstracts received. According to the chart re-abstraction study conducted on the DAD during 2009-2010 (CIHI, 2010), the percentage of estimated error for the data element on admission date was 0 % among 1950 charts.

3.2.5. Quantitative Data Analysis

1. Data Linkage

All data linkage was performed by a data analyst at ICES. A common variable called the Identification Key Number (IKN) was used to perform the data linkage process. The process began by first selecting all HOBIC-HC assessments from April 1, 2010 to September 30, 2011. This resulted in a total of 5701 assessments. The HOBIC-HC assessments were then linked to the baseline RAI-HC assessments that were 90 days prior to or within 30 days after the HOBIC-HC assessment date. This data linkage resulted in a final sample of 1470 assessments that was included in the analysis. Among the 1470 assessments there were 615 individuals who had a subsequent RAI-HC assessment that allowed for identification of the occurrence of adverse events that were of interest in this study. Refer to Appendix E for a visual diagram of the data linkage process.

2. Missing Data

After the data linkage process, the quantitative data analysis began by assessing the quality of the secondary data in order to determine the extent of missing data. One limitation of the use of secondary data for research purposes is that records are frequently incomplete or inaccurate (Shi, 2008). There may be missing data as a result of non-rigorous data recording. There were a total of 178 HOBIC-HC assessments (12%) with missing Therapeutic Self-Care Scale scores among the full sample of 1470 HOBIC-HC assessments. It was important to address the missing data because missing values could reduce the overall sample size and thus affect internal validity of the study (i.e., the degree to which inferences about the effect of the independent variable on the dependent variable are warranted (Polit, 2010)).

I made the decision to address the missing data using imputation method instead of deletion method. Deletion method involves the removal of cases with missing data. This approach would result in study analyses that are based on fewer assessments than would have been in the full study sample. This, in turn, would lead to less statistical power, which could affect the statistical conclusion validity (Polit, 2010). On the other hand, imputation method allows the researcher to maintain full sample size with a more heterogeneous sample, and therefore the statistical power of the study is not compromised (Little & Rubin, 2002). Tabachnich and Fidell (2007) suggest that the increased sample size could result in a more stable point estimate, and the reduced variation in point estimate could result in reduced standard error.

Multiple imputation was chosen as the imputation strategy because this approach is becoming the gold standard for handling missing data (Little & Rubin, 2002). For example, this method was found to result in more accurate estimates of the standard errors and p values, and to deal with the issue of uncertainty (Van Buuren, 2010). Instead of filling in a single value for each missing value, Rubin's (1996) multiple imputation procedure replaces each missing value with a set of plausible values that represent the uncertainty about the right value to impute.

The multiple imputation process began with using the available data in the dataset to predict each missing individual items of the Therapeutic self-care scale, given his or her observed values on other variables. The process continued with using the selected variables from the baseline RAI-HC assessments as predictors to impute the missing overall Therapeutic self-care composite measures. The baseline RAI-HC assessment was used because it contained comprehensive data about the client's demographic characteristics and history of clinical status. To select the plausible imputation variables, I carefully examined the items of RAI-HC assessment that could predict self-care ability, particularly in the area of medication

management; symptoms recognition and management of health conditions, as well as ADL and IADL performance. For example, recent hospitalizations, living arrangement, cognitive patterns, sensory limitations, pain control, physical functioning and medication management were the relevant variables that could influence self-care ability. These variables were important considerations because they reflected the domains of self-care as captured by the Therapeutic Self-Care Scale.

As a result, there were a total of 11 variables from the baseline RAI-HC assessment that were chosen for the multiple imputation: (1) ADL performance; (2) IADL involvement; (3) Hearing limitation; (4) Communication decline; (5) Visual limitation; (6) Visual decline; (7) Living alone; (8) post-acute; (9) Cognitive skills for decision-making; (10) Pain scale; and (11) Medication performance. The selected 11 variables from the baseline RAI-HC assessments were used as predictors for the missing values in the regression model, which in turn provided an equation for estimating the missing Therapeutic Self-Care composite scores. The multiple imputation process was implemented using the Proc MI procedure in Statistical Analysis Software (SAS version 9.0). Sensitivity analyses were conducted by comparing study analyses with the final models of imputed data and non-imputed data to test the adequacy of multiple imputation approach. It was important to conduct sensitivity analyses in order to determine whether the imputation procedure had resulted in biased estimates for the missing Therapeutic Self-Care scores, such as magnitude and direction of the relationship between Therapeutic Self-Care and study variables.

The results of the sensitivity analyses indicated that the imputation strategy resulted in consistent statistical parameters in the models with imputed data and models with non-imputed data for all study outcomes. Specifically, the magnitude and direction of the relationship of

study variables did not change when comparing the final models with imputed data and non-imputed data. Refer to Appendix F for a list of sensitivity analyses for all the adverse events.

3. Reliability Testing

The reliability of the multi-item Therapeutic Self-Care Scale was assessed using Cronbach's alpha. The values of Cronbach's alpha above 0.70 customarily are regarded as indicative of acceptable internal consistency reliability (DeVellis, 1996). A Cronbach's alpha of 0.88 was found in an earlier study by Doran et al. (2006) in which the Therapeutic Self-Care Scale was correlated with ability to resume activities of daily living and role activities at hospital discharge, supporting its construct validity. The Therapeutic Self-Care scale in the home care setting was tested for internal consistency reliability where the results indicated acceptable reliability based on Cronbach's alpha of 0.97.

4. Descriptive Statistics and Statistical Testing

Descriptive statistics were used to describe the client population characteristics such as gender, age, baseline and subsequent RAI-HC assessment data. Logistic regression analysis was used to determine the relationship between HOBIC therapeutic self-care scores and adverse events experienced by home care clients. Logistic regression is based on the assumption that the logarithm of the odds of belonging to one population is a linear function of several predictors (independent variables) in the model (Shi, 2008). I adopted the statistical techniques developed by Xu and Kubilius (2010) to build the logistic regression models, which can accurately predict the outcomes while controlling for a number of statistically and clinically significant client risk factors. This process involved (1) variables preparation; (2) risk factors screening; (3) model building; and (4) model fit assessment. All of the statistical tests were carried out using the SAS system version 9.0.

5. Regression Model Building

A. Variables Preparation

There were a total of nine adverse events that were the dependent variables of interest in this study. The dependent variables included the following two types of outcomes: (1) use of health care resources, including a) new emergency room visits and b) new hospital visits; and (2) adverse events, including c) client falls; d) unintended weight loss; e) new urinary tract infection; f) ADL decline; g) new pressure ulcer or ulcer deterioration; h) non-compliance or adherence with medication; and i) new caregiver distress. The adverse events were coded as 0 (absent) or 1 (present).

Therapeutic self-care was the independent variable that was posited to influence adverse events in home care. The first step in variable preparation involved examining the frequency distribution of the 12-item therapeutic self-care scores. The result indicated that the distribution of therapeutic self-care scores was skewed with a high number of scores of 5 among this study cohort. Specifically, there were 45 % of individuals with the composite therapeutic self-care scores of 5 (Refer to appendix G for the diagram showing the distribution of composite therapeutic self-care scores). I made a decision to dichotomize this continuous variable into a binary variable by creating two groups for comparison in order to address the skewed distribution of therapeutic self-care scores. Sensitivity analysis was performed with different cut-off values including the scores of 5, 4 and 3. The score of 5 was determined to be the cut-off value that could create a balance between the low self-care group (820 individuals) and high self-care group (650 individuals). The cut-off value of score 5 was also determined to be the most sensitive to differentiate between high and low therapeutic self-care ability with regards to adverse events, and thus was better able to detect a relationship between therapeutic self-care and

outcomes of interest in this study. As a result, the therapeutic self-care scores were dichotomized into low self-care group (score 0 to 4) and high self-care group (score 5) where low self-care was coded as 0 and high self-care was coded as 1 in the logistic regression model.

Risk adjustment variables were included as the independent variables along with the therapeutic self-care measures. There were 44 variables from the baseline RAI-HC assessments selected as the potential risk adjustment variables. The selection of the 44 potential risk adjustment variables were based on the empirical evidences provided by Jones et al. (2010) and Hirdes et al. (2004). These potential risk adjustment variables were selected to control for client demographics and clinical characteristics that could have an effect on adverse events. Examples of risk adjustment variables included the following: Age, gender, education; living alone, disease comorbidities, the Cognitive Performance Scale; the ADL Hierarchy score; the Depression rating score; CHESS; and pain scale (Dalby et al., 2005; Doran et al., 2008). Refer to Appendix H for a full list of potential risk adjustment variables in this study.

B. Risk Factors Screening

Once a list of the potential risk adjustment variables was identified, the next step in model development involved using the likelihood Chi-square test to identify the relationship between the client risk factors and the outcomes of interest. This process involved further screening the 44 potential risk factors by reviewing the results of the likelihood Chi-square test. The purpose of this screening process was to identify those client risk factors that were able to predict the outcomes of interest with statistical significance. Xu and Kubilus (2010) recommended the more conservative p-value should be used in assessing the significance of the potential client risk factors, and suggested that only those client risk factors that were found to be significant with a p-value of 0.10 or less be selected for inclusion in the logistic regression

model. Following screening, all selected client risk factors were checked for multi-collinearity to ensure that the variables were not highly correlated among themselves. This process was achieved using Variance Inflation Factor (VIF) by the option in PROC REG in the SAS system. Refer to appendix I for a list of client risk factors that were selected for inclusion in the logistic regression model for each outcome of interest.

C. Initial Model Building

The adverse event was the dependent variable in the logistic regression model and was coded as 0 (absent) or 1 (present). The independent variables that were entered included the risk adjustment variables, followed by the binary variable of low and high therapeutic self-care, as well as interaction terms (described below). The initial logistic regression models were developed using backward stepwise selection, which involved dropping statistically non-significant risk factors from the regression model. This method was selected because stepwise selection dealt directly with redundancy and helped identify those client risk factors that strongly affected the probability of the outcome. Xu and Kubilus (2010) recommended the backward stepwise selection should be carried out using the “SLS=0.1” option in PROC LOGISTIC where only those risk factors whose regression coefficient estimates were significant at level 0.1 were retained in the model. While the non-significant risk factors ($p>0.1$) were dropped from the model, age and gender were the two variables that were always retained in each of the models. The reason for keeping age and gender in the model was that past research has found these two variables were considered important when adjusting for biological differences among individuals (Dalby et al., 2005; Doran et al., 2008; Hirdes, 2004; and Jones et al., 2010).

D. Final Model Building

Xu and Kubilius (2010) recommended that all of the statistically significant risk factors in the initial logistic regression models ($p < 0.05$) should be checked for collinearity with the therapeutic self-care variable by reviewing the results of the Chi-square tests. When collinearity existed, interaction terms for the risk factors and therapeutic self-care measures were added into the final logistic regression models. The reason for adding interaction terms to the final models was to control for collinearity and confounding effects of those risk factors that might distort the observed relationship between the independent variable (i.e., therapeutic self-care) and outcome of interests. The final logistic regression models were developed using backward stepwise selection, which involved dropping statistically non-significant risk factors and any interaction terms that were not significant. Cohen and Cohen (1983) suggested that the significance criteria for regression coefficient, $p \leq .05$ can be used in the logistic regression model. Multiple testing was not adjusted because this was an exploratory study without hypothesis testing (Tabachnick & Fidell, 2007). Refer to appendix I for a list of interaction terms that were added into the final models for each of the nine outcomes.

The parameters of the final model were reviewed for statistical significance, including regression coefficients, Wald Chi-Square, odds ratios, and 95% confidence intervals for each odds ratio. The Wald Chi-Square was used to evaluate the contribution of an individual predictor to a model. The odds ratios were computed to examine the ratio of the probability of an adverse event occurring where the independent variables and the outcome were not related when the value of an odds ratio was close to 1.

E. Model Fit Assessment

Two methods were used to assess model fit. The first method used to assess model fit was the Likelihood ratio chi-square test (-2 LOG L), which was used to assess the overall model performance. A significant p-value provided evidence that at least one of the regression coefficients for the independent variables was non-zero. This was also used to assess whether one risk factor increased the predictive power of the model when comparing the reduced model to the full model (Xu & Kubilius, 2010). The second method to assess model fit is the C-index, which was used to determine the predictive power of the logistic regression model. The C-index is derived by calculating the proportion of concordant pairs and is equivalent to the area under receiver operation characteristics curve (ROC curve) (Hosmer & Lemeshow, 1989). Xu and Kubilius proposed that C-index with a value of greater than 0.60 is considered to be an indicator of good model fit. The Likelihood ratio chi-square, C-index and ROC curve were obtained from the output of the SAS PROC LOGISTIC. In summary, the use of logistic regression analysis was an appropriate statistical test in this study because it provided an efficient way to estimate the probability of the occurrence of an adverse event, and the odds ratio of having that event.

3.2.6. Validity and Reliability Issues in Quantitative Data

1. Internal Validity

Assessing internal and external validity, as well as reliability of the instruments are crucial to instilling confidence in the quality of the data analyzed. Internal validity deals with the question of whether variable A did indeed have an effect on variable B. When there is a lack of internal validity, there is the situation in which a spurious event can be used as a plausible explanation for the relationship between variable A and variable B (Mitchell, 1985). Risk

adjustment strategy is one important way of ensuring the internal validity of the quantitative findings. Risk adjustment attempts to adjust for different populations of clients who may be at greater risk of experiencing a bad outcome as a function of their clinical status rather than the quality of care (Dalby, Hirdes, & Fries, 2005). The relationship between therapeutic self-care and adverse events could be confounded by the differences in the populations where client characteristics could be the cause of the observed relationship. Therefore, I attempted to control the threats to internal validity by using risk adjustment strategy to control for differences in the population at the individual client level.

To further ensure the internal validity of the study results, the statistical techniques developed by Xu and Kubilius (2010) were used to build each of the logistic regression models in order to ascertain the influence of therapeutic self-care scores on the outcomes of interest. This process involved the use of rigorous statistical techniques by preparing study variables; screening client risk factors; model building and assessing model fit which could accurately predict the outcomes while controlling for a number of statistically and clinically significant client risk factors. For example, interaction terms were added to control for collinearity that existed during the modelling process. Also, the quality of the secondary data sources could be another threat to the internal validity. Therefore, I examined all relevant aspects of the secondary data sources used. For example, I reviewed the literature regarding the validity of RAI-HC; NARCS and DAD. I also examined the reliability of HOBIC-HC for Therapeutic Self-Care Scale by testing the internal consistency reliability using Cronbach's alpha.

Missing values in the data set could be a threat to the internal validity. Simply removing all observations that contain the missing data may lead to biased statistical results and wrong conclusions (Van der Ark & Vermunt, 2010). Therefore, I chose to use imputation approach to

handle missing data. More specifically, I used multiple imputation rather than single imputation to impute scores for the missing values. Multiple imputation method is currently considered the most acceptable method for dealing with missing data (Tabachnick & Fidell, 2007). In single imputation, each missing value can be imputed from the variable mean of the complete cases (Shi, 2008). Therefore, the imputed values from single imputation are derived from the observed sample and the imputed sample is more homogeneous (Little & Rubin, 2002). When variances are under-estimated, single imputation method is more likely to yield a biased result. On the other hand, multiple imputation method does not attempt to estimate each missing value through simulated values, but rather to represent a random sample of the missing values (Van Buuren, 2010). This process is regarded as a more appropriate method for handling missing data, resulting in valid statistical inferences that properly reflect the uncertainty due to missing values. In order to test the adequacy of multiple imputation approach, sensitivity analyses were conducted to ensure the imputation procedure resulted in unbiased estimates of important statistical parameters, such as magnitude and direction of the relationship of study variables.

2. External Validity

External validity reflects the extent to which the inferences drawn from the study can be generalized across settings and persons (Mitchell, 1985). At the time of the study, there were only three home care organizations that were submitting HOBIC data to ICES. As a result, the potential threat to external validity in this study was that the study sample was limited to the home care clients from three self-selected organizations in specific geographical locations in Ontario. Despite this limitation, it was expected that this study could provide evidence to further understanding of the relationship between therapeutic self-care and adverse events in home care settings. Future research, involving more home care agencies across different geographical areas

could further validate the evidence generated from the present study. Another potential threat to external validity was that not all home care clients were represented in the database because only long-stay clients qualify for a RAI-HC assessment. Thus the quantitative study findings were only generalizable to long-stay clients, similar to those included in this study. However, it should be noted that the primary purpose of this study was to investigate therapeutic self-care among home care clients with long-term health care needs. Therefore, the sample of long-stay home care clients was considered appropriate according to the study purpose.

3. Reliability

Measurement error or the unreliability of measures can present a threat to the statistical conclusion validity (Mitchell, 1985). Shadish, Cook and Campbell (2002) explain that measurement error can increase random or error variance, which could decrease the statistical power for detecting significant effects or correlation, and thereby potentially lead to type II error. The instrument selected to measure the variable of interest, therapeutic self-care, was well established. The Therapeutic Self-Care Scale has demonstrated reliability and validity in previous studies conducted by Doran et al. (2006); Doran et al. (2003); and Sidani (2008) for the acute care samples. The Therapeutic Self-Care scale in the home care setting was tested for internal consistency reliability and the result indicated acceptable reliability based on Cronbach's alpha of 0.97. To ensure the reliability during the collection of secondary data, I worked collaboratively with a data analyst at ICES who was both in charge of reviewing the data sources and performing the reliability checks of entered data to identify missing or incorrect data during data monitoring and data quality checks. The above strategies for handling reliability issues helped minimize the extent of measurement error and contributed to enhancing the validity of the statistical conclusions in this study.

3.3. Overview of Qualitative Method

3.3.1. Study Purpose

In order to develop a richer description of the concept of therapeutic self-care, a qualitative method was chosen to provide complementary data with the goal of gaining in-depth information about clients and their informal caregivers' perspectives on home safety as it relates to therapeutic self-care. The purpose of the qualitative study was to explore the following four research questions:

1. What are the safety challenges and concerns home care clients and their informal caregivers report related to therapeutic self-care activities and informal caregiving?
2. What supports do the clients identify as needed to address their safety challenges and concerns related to therapeutic self-care?
3. What supports do the informal caregivers identify as needed to address their safety challenges and concerns related to informal caregiving?
4. What role do clients and their informal caregivers identify as important home care services in supporting therapeutic self-care and informal caregiving?

3.3.2. Design and Method

The qualitative approach utilized one-to-one, in-depth, semi-structured interviews with the clients and their informal caregivers to describe the safety challenges and concerns, and to identify the role for home care to provide support for therapeutic self-care and informal caregiving. Qualitative description was the analytic approach used to guide the client and caregiver interviews. The goal of a qualitative descriptive analysis was to provide a

comprehensive summary of descriptions of the phenomena of interest. According to Sandelowski (2000), qualitative descriptive studies tend to draw from the general tenets of naturalistic inquiry, without a priori commitment to any one theoretical view of a target phenomenon. The orientation of qualitative description was well suited to the pragmatic worldview of this study where pragmatism is not committed to any one system of philosophy or view of reality (Creswell, 2009).

3.3.3. Study Sample

I chose to focus on the client and caregiver dyads to explore the nature of safety challenges and concerns related to therapeutic self-care and informal care-giving in home care. Creswell & Plano Clark (2007) suggested the use of similar individuals in the quantitative and qualitative phases supports representativeness of the study findings in mixed methods study. To achieve this goal, the sampling of participants occurred from one of the designated home care agencies that was submitting HOBIC-HC data to ICES at the time of the research study. Purposeful sampling was used where the researcher strategically sought out participants to fit with the research goals and objectives (Patton, 1990). I identified clients and their informal caregivers who would be able to provide rich information and useful insight about home safety in relation to therapeutic self-care and informal caregiving at home. In particular, maximum variation sampling was used to select a diverse range of home care clients and their informal caregivers. According to Patton (1990), diverse study sample is important because it provides rich descriptions and shared patterns from across a wide variety of sources.

There were two types of participants: (1) geriatric home care clients and (2) their informal caregivers. Participants were selected using the following inclusion criteria: (a) clients

who were mentally capable of participating and able to communicate in English; (b) long-stay home care clients (>60 days) who were 65 years of age or older; and (c) had a primary caregiver such as a family member, friend, relative or neighbor. The inclusion criteria for the informal caregivers included: (a) the participants needed to be able to speak and understand English; (b) be providing care to a client who was receiving home care services and was expected to receive services for more than 60 days; and (c) a primary caregiver who was not a paid caregiver, such as a family member, friend, relative or neighbor, living with or without the client. To achieve maximum variation sampling, I sought variation in the study sample for the following areas: age; gender; types of chronic diseases; cultural background; and geographical location of where the participants resided, such as rural and urban areas.

The final study sample included 15 geriatric home care clients paired with 15 informal caregivers. Lincoln and Guba (1985) propose that one criterion for informing a decision to stop sampling is when data saturation is reached. The researcher stopped sampling after 15 home care clients and their informal caregivers because the final few interviews generated very little new information, and did not produce enough new information to justify further data collection efforts. Furthermore, fifteen sampling units are consistent with the literature where Riemen (1986) described that sampling units of 12 to 20 are generally required when aiming for maximum variation to describe emerging themes within a variation of study participants.

3.3.4. Participant Recruitment

One home care organization was contacted to help with the recruitment of eligible participants. Upon receiving ethics approval from the University of Toronto and the home care organization, I met with the home care supervisors to explain the study. Supervisors were

provided with the letter of information for clients and consent form, which provided information about the study and how clients could contact the researcher (Refer to Appendix J for letter of information and client consent form and Appendix K for letter of information and caregiver consent form). The home care supervisors were asked to identify eligible clients and their informal caregivers who were willing to participate and met the study inclusion criteria. To achieve maximum variation sampling, the home care supervisors were asked to identify diverse groups of clients and their informal caregivers. For example, home care supervisors were asked to seek variation in the study participants in regards to age; gender; types of chronic diseases; cultural background; and geographical location. Refer to appendix L Letter of Information for Home Care Supervisors which described what the supervisors were instructed to do including the sampling criteria they were to consider in selecting study participants.

Supervisors were asked to obtain the client's permission to release their name and contact information to me once they had obtained the client's permission to do so. Eligible clients and their caregivers were contacted by me via phone call to obtain informed consent. Clients and their informal caregivers gave verbal consent during initial confirmation of their interest in participation, and provided written consent by faxing the signed consent form to a fax machine in a restricted-access research unit at the Lawrence S. Bloomberg Faculty of Nursing. When faxing was not an option, I reviewed the requirements and implications of participating, and obtained written consent on the day of the meeting prior to the interview. Recruitment follow-up with the home care supervisors was on-going until the study sample reached 15 home care clients paired with 15 informal caregivers, as determined by data saturation.

3.3.5. Qualitative Data Collection

I collected data for the qualitative method through interviews. One-to-one semi-structured, in-depth interviews were conducted with 15 geriatric home care clients and 15 informal caregivers between January 2013 and April 2013. All the interviews took place face-to-face in the clients' homes, and they were scheduled at a time agreeable to the clients and their informal caregivers. The interviews were conducted separately with each client and his/her informal caregiver in order to better capture the differences in perspectives. This was achieved by physically separating the client and the informal caregiver apart from each other in the home when the interviews were conducted. Each interview lasted between 30 to 45 minutes, and was audio-taped using a digital recorder.

I began the interview session by obtaining demographic and descriptive information from the interview participants. I also completed the Home Care Therapeutic Self-Care Scale (Refer to Appendix B) with the client. The Therapeutic Self-Care Scale and descriptive information were collected simply for description of participants as a group, providing contextual detail for understanding client's clinical condition, as well as the type of dwelling, living arrangement, home care service utilization, and informal support that may influence therapeutic self-care and safety outcomes. Caregiver demographic and descriptive information were collected to provide information on their health conditions, employment status, number of hours and aspects of informal care giving at home. The demographic and descriptive data forms for client and informal caregiver are presented in Appendix M and Appendix N.

Each interview was initiated by asking the clients and their informal caregivers some general questions on self-care and care-giving experience, such as "Tell me about a typical day of what you need to do to take care of yourself or to care for your loved one at home" and "What

has it been like for you to care for yourself at home or to care for your loved one at home?” An interview guide with open-ended questions was used to facilitate the interview process. The interview guide contained a list of questions to be explored to ensure that the same material was covered in each interview, but also allowed for probing to elucidate more information about the study topic (Patton, 1987). The interview guide was first pilot-tested with three individuals who were doctoral students. The goal of the pilot test was to obtain feedback on the interview questions, as well as interviewing techniques. The interview guide was refined based on the feedback from the pilot-tests. It was kept open to additional modifications as themes were identified during the data analysis. The details of the interview guide are presented in Appendix O for client interview and Appendix P for informal caregiver interview.

I assumed the role of a facilitator during interviews to help the participants speak freely and openly. Also, listening, interaction and observation were of utmost importance during the one-on-one transactions between the researcher and the participant (Wojnar & Swanson, 2007). Following Patton’s (1987) suggestions for sequencing interviews, I began the interviews with easy-to-answer questions that asked for simple factual information followed by more challenging questions that asked about participant’s opinion or interpretation about what they had described. For example, I first asked the home care clients and their informal caregivers how they defined safety at home, self-care and informal caregiving. Probing questions were used throughout the interviews to invite participants to provide more details or elaborate on a response, or to clarify their perspectives using their own language. As suggested by Britten (1995), the researcher used the participants’ wording when asking follow-up or probing questions in the interviews.

As a result of these probing questions, the following four areas were explored in the interview: (1) client and informal caregiver perspectives on therapeutic self-care; (2) safety

challenges and concerns related to therapeutic self-care and informal care-giving activities; (3) support needed to address safety challenges and concerns; (4) the role of home care services in supporting therapeutic self-care and informal care-giving experiences. Before each interview was ended, I asked “Is there anything else you would like to share that we haven’t talked about?” This enabled participants to discuss anything else related to the research question that the interview had not covered up to that point. Following each interview, field notes were recorded to allow me to note observations that were made about each participant during the interview, as well as personal reflections on the interview itself. Example of observations included whether the participant seemed rushed, relaxed or preoccupied, as well as personal impressions of how the interview went and what could be done differently next time.

3.3.6. Qualitative Data Analysis

Qualitative description was the method of choice because a comprehensive summary of straight descriptions of the phenomena of interest was the goal of this study. The benefit of conducting qualitative descriptive analysis was to allow the researcher to stay close to the data and to the surface of words and events using an interpretive lens. Therefore, the description in qualitative descriptive analysis entails the presentation of the facts of the case in everyday language, with a straight descriptive summary of the informational content of data that could serve as entry points for further study (Sandelowski, 2000).

This qualitative phase was characterized by the simultaneous collection and analysis of interview data whereby both mutually shaped each other. I started to analyze the data after the first two data collection interviews were completed. Patton (2002) suggested that data analysis can be improved by collecting and analyzing data simultaneously. For example, the first two

data analyses informed additional probing questions during the interview. Also, the information reported by the participants informed areas of potential interest to look for in the data, as well as challenging preliminary insights during data analysis.

Conventional thematic analysis was the analysis strategy of choice. Hsieh and Shannon (2005) suggested that conventional thematic analysis is appropriate when existing theory or research literature on a phenomenon is limited. Specifically, I used thematic analysis to identify prevalent patterns, and interpret themes across the dataset by reviewing all the interviews by home care clients and their informal caregivers. A theme represents a critical idea that appears throughout the data and relates back to the overarching research question (Braun and Clarke, 2013). The overarching research question in this study was to understand the concept of home safety in relation to therapeutic self-care and informal caregiving. An inductive approach was used to identify themes in the data whereby the identified codes and themes were derived from the interview data, and not from a pre-existing coding or theoretical framework as in a deductive approach (Braun & Clarke, 2013). The inductive approach to thematic analysis was consistent with the orientation of qualitative description where naturalistic inquiry guided the study.

Consistent with what Sandelowski (1995) has suggested, qualitative data analysis was reflexive and interactive as the researcher continuously modified her treatment of data to accommodate new data. As a result, I conducted the data analysis by moving back and forth through the six phases of thematic analysis, as described by Braun and Clarke (2013). The first phase of thematic analysis involved immersion whereby I became deeply familiar with the data. In this phase, I immersed myself in the data by transcribing the audio files verbatim, proofing the transcripts against the audio files for accuracy, and repeatedly reading the data.

When transcribing the audio files verbatim, Creswell and Plano Clark (2007) suggest that both verbal and non-verbal communication are important observations that should be noted from the interviews, such as long silences or pauses in the conversations; body languages or gesturing; laughs and coughs; changes in volume, pitch and speed of the participant's responses. When checking the transcripts for accuracy, I reviewed the interview as a whole and identified critical pieces of data. After proofing the transcripts, I re-read the transcript and began to identify prevalence of patterns by searching for areas of interest, such as issues, words, phrases and examples. To further explore the interview data, I manually underlined these areas of interests in the transcript with black ink, and formed possible codes in the margins of the transcripts. In order to further develop a general understanding of the dataset, short memos, field notes and written reflections of the transcripts were created to briefly paraphrase the interview data with descriptive summaries.

The second phase of the thematic analysis involved generating initial codes by systematically assigning labels to segments of data in each interview, and then across all of the interviews. Codes are potential patterns and themes related to the research question, and these are labeled noting interesting features in the data, such as words, phrases, sentences, paragraphs, ideas and concepts (Miles, Huberman, & Saldana, 2014). Coding was conducted by manually writing notes in different colored pens in the margins of the interview transcripts, followed by typing the code. The text of data was copied to an electronic spreadsheet. A list of initial codes was identified from across the dataset in which the data extracts were coded for multiple potential themes and patterns. This coding process was useful in grouping evidence and labeling ideas so that they reflect the broader perspectives of the research phenomenon (Creswell, 2009).

The third phase of the thematic analysis involved identifying themes in the data by sorting the codes and their accompanying data extracts (Braun & Clarke, 2013). This process involved reflecting on how the coding could be sorted, how they were related, which codes could be combined, and what possible themes tied the codes together. Sandelowski (1995) proposed that visual representation of data helps the researcher to look at their data and can direct them onto analytic paths as to what to look for in their data. I organized the coding into possible themes using an electronic spreadsheet table, and then constructed a visual representation of data by creating a thematic tree to help visualize patterns in the data, and their connections. Miles, Huberman, & Saldana (2014) suggested that a thematic map or tree helps the researcher identify the relationships between codes, themes and their potential meanings. As a result of this process, I was able to see suggestive patterns or relationships both within and across cases, such as identifying the similarities and differing perspectives of clients and their informal caregivers regarding safety concerns and needs in relation to therapeutic self-care at home.

The fourth phase of the thematic analysis involved reviewing and revising the candidate themes (Braun & Clarke, 2013). Patton (2002) suggested that internal homogeneity and external homogeneity are two important criteria that are needed to determine whether to keep the existing themes or to revise them. I assessed internal homogeneity by reviewing the identified themes and the accompanying data extracts in order to determine whether the data in the themes were related in a coherent and meaningful way. Once the data extracts within the themes were assessed for internal homogeneity, the data were assessed for external homogeneity by examining whether the themes appeared too similar or distinct from one another. As a result of this process, some overlapping data extracts were combined into a theme while others were re-assigned to new themes when the data in the theme were not related in a coherent and

meaningful way. After the themes were assessed for both internal and external homogeneity, the thematic tree based on the revised themes was re-examined to ensure the entire data set was represented in an accurate and meaningful way. The thematic tree about the themes from the interview data is presented in Figure 3.

Phase five of the thematic analysis was described as defining and refining themes by identifying the overarching theme, subthemes and themes-within-a-theme (Braun and Clarke, 2013). This process involved identifying what was important about the data extract for each theme in relation to the study purpose and research questions. For example, I identified the core meaning of each theme about what the clients and their informal caregivers were telling in regards to safety challenges for therapeutic self-care and informal caregiving in the context of home care.

Finally, the last phase of thematic analysis involved reporting the data in a way that demonstrates the analysis had merit and was valid (Braun & Clarke, 2013). Sandelowski (1995) suggested that the researcher be faithful to the interview data by using data extracts to exemplify themes and subthemes to illustrate data analysis. The results of the data analysis were presented in a way of telling the story of the data by using data extracts to demonstrate the identified themes that were prevalent across the data set. The themes and subthemes were also well related to the overarching research objective. They provided insight into the nature of safety challenges and concerns as it related to therapeutic self-care, as well as the role of informal caregiving and home care services in improving therapeutic self-care to reduce safety related risks and burden for home care recipients.

3.3.7. Assessing Quality of Qualitative Data

Patton (2002) writes that the researcher is the instrument in qualitative research. Therefore, the qualitative researcher needs to be reflexive, to be self-aware, and self-reflecting (Patton, 1990). Throughout the study, I reflected on the potential sources of bias, on my assumptions and professional experiences that may have affected the interview process, as well as the data analysis and interpretation. In particular, I examined how my previous background as a Community Care Assess Centre Case Manager provided me with an understanding of the existing home care issues, but this background also had the potential to prevent me from seeing the data as an outsider. To address this potential problem, I reflected on my own assumptions to ensure that they did not color my view throughout the research process. For example, I distanced myself from the role as a case manager, and assumed the role as a researcher with a focus of inquiry to explore what was important to the participants in relation to their self-care experiences. When negative comments were made about the home care services, I stayed open-minded by not offering my own judgment, but rather I allowed the participants to discuss their challenges openly and freely. This process of self-reflection enabled me to become sensitive to my own biases, as well as revealing my own preconceptions to ensure the codes and themes of the analysis were data-derived. Self-reflecting enhances the credibility of the research because it enables the qualitative researcher to become aware of what influences data collection, analysis and interpretation throughout the research process (Braun & Clarke, 2013).

In qualitative descriptive study, researchers seek descriptive validity (an accurate accounting of events) and interpretive validity (an accurate accounting of the meanings participants attributed to those events) (Sandelowski, 2000). I sought both descriptive validity and interpretive validity throughout the stages of the research study, including sampling, data

collection and data analysis. I made efforts to enhance descriptive validity by using maximum variation sampling to select a diverse range of individuals to capture common themes within the variation. This sampling approach was designed to yield rich descriptions and shared patterns from across a wide variety of sources.

Another way to seek descriptive validity was the use of peer debriefing to enhance the accuracy of the account by having a peer review and ask questions about the study (Creswell, 2009). Three doctoral candidates were invited to pilot-test the interview guide and provided feedback on the interview techniques and questions. These individuals were selected as the interviewees because of their methodological expertise in qualitative research. Furthermore, the use of debriefing was achieved by having my supervisor and committee members look over the different aspects of the study, including the relationship between the research questions and data, and the level of data analysis from the interview data through interpretation.

In order to ensure interpretive validity, I conducted the data analysis by moving back and forth through the six phases of thematic analysis as described by Braun and Clarke (2013). This process of data analysis was designed to provide a rigorous and standardized approach to thematic analysis. This process of thematic analysis also contributed to interpretive validity as the researcher became reflexive and interactive by moving throughout the phases of data collection and data analysis, whereby both mutually shaped each other in order to tell the story of the data. Further, I was faithful to the interview data by using data extracts to exemplify themes and sub-themes to illustrate interpretive validity of the data analysis. Finally, auditability is an example of a process to ensure trustworthiness of a qualitative study. Auditability can be achieved when researchers describe and justify their research process, leaving a clear decision trail for the study from inception to conclusion (Sandelowski, 1995). Memos, field notes, and

descriptive summaries were used to add to the validity of the study findings by describing the methodological decisions and the analytic insights made by me during qualitative data analysis.

3.4. Ethics/Protection of Human Subjects

1. Quantitative Method:

Ethics approval was obtained from the University of Toronto Research Ethics Review Board on March 13, 2012 prior to collecting any data. Ethics approval was also obtained from ICES, which is where the quantitative study took place. All the secondary data analyses were conducted at ICES. The secondary data were provided to me via access at ICES, using a secure computer and workstation. Health information held at ICES was used solely for research and statistical purposes.

All data were kept confidential to protect the privacy of clients through the use of the following methods (ICES, 2011):

1. Anonymous data: All data held at ICES were made anonymous by removing personal identifiers.
2. Physical measures: ICES is a locked facility and the premises are video-monitored 24 hours a day. Tracked key access is required to move through the building. All staff and researchers must wear identification, and are required to sign in and out of the facility.
3. Technological measures: Data are housed on an isolated, secure system that can only be assessed by ICES staff and researchers within the building. Data cannot be copied, and frequently changed passwords, data encryption and specialized software were used to enhance security.

2. Qualitative Method:

Ethics approval was obtained from the University of Toronto on March 13, 2012 and the participating home care organization on May 29, 2012.

Risk/ Benefits:

Although involvement in this study did not result in additional treatment services for study participants, study findings may provide useful information to health care practitioners and home care services with an increased understanding of what clients and informal caregivers need to manage self-care and care-giving safely at home.

There may be emotional/psychological risk involved in participating in the study. For instance, some clients and their informal caregivers might have become emotional when they discussed their self-care and care-giving experiences during the interview. I was aware of verbal and non-verbal cues to observe how participants were feeling as the interview was progressing, and frequently asked if they would like to stop or take a break at any time. I also mitigated psychological risk by moving onto a less sensitive subject to lower the emotional pitch of the conversation when needed. At the end of the interview, I spent time with the participants to ensure that they were comfortable before leaving their homes. None of the study participants was found to be in need of further care and support. But if there had been a need for follow-up, I had a plan in place to ask participants' permission to contact their case manager at the Community Care Access Centre for follow-up. Participants could also be referred to the Home Care Hot Line at 1-866-876-7658 for additional care and support.

Informed Consent:

Written consent for participation was obtained using a signed informed consent form and letter of information detailing study purpose, study involvement, confidentiality protocol, potential risks and benefits. Participants were given the opportunity to ask questions about the study before beginning the key informant interviews. Client and caregiver participation in the qualitative interview was completely voluntary. Participants were informed they could refuse to participate, withdraw at any time, and decline to answer any question without negative consequences. Participants were told they could notify me that they wish to withdraw from the study at any point. None of the participants requested to withdraw from this study.

Confidentiality:

All information obtained during the qualitative interview was treated in a confidential manner. Participant's names were not linked with any of their health information. Participants were identified with a code number so that I could keep track of who had participated. A master code list was kept in safekeeping in a separate locked filing cabinet from where the data were stored. Participants' name and contact information were stored in a file, away from the interview data. All interview data was kept electronically in a password-protected file. The data collected during this study were analyzed and presented in summary form in a way that did not identify any individual. Participants were never named in any presentation or report about this study. All information obtained in this study was used for research purposes only.

Data Management:

With the permission of the participants, the qualitative interviews were digitally recorded and the audio files were transcribed. All of the interview data were managed on desktop computers with physical and electronic security features at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto. Backup copies of interview data were stored on a server with restricted access, password-protected computer. All hard copies of research-related materials with de-identified data were stored in a locked file within a restricted-access research office. Only I had access to the raw data. The interview participant contact sheets and consent forms were kept separate from the interview data, to protect participant confidentiality. There were no identifying data on the data collection forms or in the database that could link data to a specific client.

Chapter Four

Summary of Study Results

A complementary mixed methods design was used in which complementary data were collected on therapeutic self-care using quantitative and qualitative approaches. Secondary data analysis from multiple data sources were used to examine whether therapeutic self-care ability predicted the occurrence of adverse events in home care. Concurrent with this data collection, qualitative interviews were conducted to explore home care clients and informal caregivers' perspectives on safety related to therapeutic self-care at home. In this chapter, a summary of study results from the quantitative research is presented, and is followed by the summary of findings from the qualitative analysis. The summary of the quantitative results focused on the following four areas: (1) characteristics of study cohort; (2) comparison of characteristics between high and low self-care group; (3) prevalence of adverse events; and (4) analysis of association between therapeutic self-care and adverse events.

4. 1. Summary of Quantitative Results

4.1.1. Characteristics of Study Cohort

The results presented in Table 4.1 describe the characteristics of study cohort. The 1470 study cohort consisted of a majority of home care clients who were female and were in the age range of 65+ with the average age of 71.9 years (standard deviation 14.9). During the one-year follow-up period, 48.8% of home care clients had a new hospital visit that was urgent or non-elective admission with an overnight stay, while 56.9% of home care clients had a new emergency room visit. There were 615 individuals out of 1470 study cohort who had a

subsequent RAI-HC assessment that allowed for follow-up on the occurrence of adverse events. For those individuals who did not have a subsequent RAI-HC assessment, 81 home care clients were admitted to long-term care facility and 230 individuals died during the one-year follow-up period.

Table 4.1. Characteristics of Study Cohort and Follow-Up from 2011 to 2012

Cohort Characteristics	N=1470	%
Age over 65	1025	69.8
Age over 75	734	49.9
Female	832	56.6
With Subsequent RAI-HC Assessments	615	41.8
Long-Term Care Admissions in one year follow-up	81	5.5
Death in one year follow-up	230	15.6
New Hospital Visits	717	48.8
New ER Visits	836	56.9

4.1.2. Therapeutic Self-Care: High Self-Care vs. Low Self-Care

The study cohort consisted of 820 individuals who were in the low self-care group and 650 individuals who were in the high self-care group. The majority were female who were over the age of 65 and living with their informal caregivers at home. The low self-care group was found to be more functionally dependent in nearly all measures. Specifically, the low self-care individuals were characterized as having more complexity in clinical status such as having recent hospitalizations; multiple chronic diseases, polypharmacy; higher CHES scores; and physical symptoms such as edema. They also demonstrated poor functional status with impaired self-reliance and difficulties with ADL activities such as mobility issues, as well as difficulties with IADL activities such as medication management. Further, the low self-care individuals were found to be more cognitively impaired than the high self-care group, with depressive symptoms,

and behavioral symptoms including wandering, verbally abusive and resistive to care. The results presented in Table 4.2. summarize the chi-square statistics comparing the baseline characteristics of low Therapeutic self-care and high Therapeutic self-care individuals identified from the RAI-HC assessment tool.

Table 4.2. Comparison of Characteristics between Low and High Therapeutic Self-Care Individuals

Baseline Client Characteristics	Low Self-Care Group % (n) n= 820	High Self-Care Group % (n) n= 650	Chi-Square p-value
Age 65+	60.4%	39.6%	<0.00
Age 75+	62.1%	37.9%	<0.00
Female	55.4%	44.6%	0.74
Self-Reliance Index	78.2%	56.9%	<0.00
Polypharmacy	59.9%	50.6%	<0.00
Difficulty in Managing Medication	54.8%	36.0%	<0.00
Difficulty in ADL Performance	43.5%	28.3%	<0.00
Difficulty in IADL Performance	77.2%	61.1%	<0.00
CHESS Scores	58.5%	46.5%	<0.00
Wandering	1.71%	0.31%	0.01
Depression Rating Scale	18.8%	10.2%	<0.00
Cognitive Performance Scale	11.6%	5.2%	<0.00
Impaired Cognitive Skill in Daily Decision Making	20.8%	8.5%	<0.00
History of ADL Decline	62.1%	51.4%	<0.00

Baseline Client Characteristics	Low Self-Care Group % (n) n= 820	High Self-Care Group % (n) n= 650	Chi-Square p-value
Difficulty in locomotion at Home	31.0%	21.1%	<0.00
Difficulty in locomotion Outside of Home	56.8%	41.5%	<0.00
History of Falls	40.8%	31.5%	<0.00
Unsteady Gait	67.0%	52.8%	<0.00
Difficulty Transfer	32.6%	22.6%	<0.00
Dementia	10.2%	4.9%	<0.00
Cancer	28.3%	39.4%	<0.00
Arthritis	45.4%	38.8%	0.01
Osteoporosis	19.0%	15.1%	0.05
Verbally abusive behavioral symptoms	1.83%	0.62%	0.04
Resists care	2.84%	0.77%	<0.00
Alzheimer's	2.7%	1.0%	<0.00
Hypertension	56.2%	49.6%	<0.01
CAD	28.5%	23.0%	<0.01
Living with caregiver	41.5%	35.5%	0.02
Recent hospitalization	38.15%	29.2%	<0.00
Edema	36.1%	30.3%	0.02

4.1.3. Prevalence of Adverse Events

New ER visit, new ADL decline, new hospital visit (any urgent/non-elective admission to hospital with an overnight stay), new client fall, and new caregiver distress were ranked among the top most frequently occurring adverse events. Unintended weight loss, non-compliance or adherence with medications, newly detected urinary tract infection, and new pressure ulcer/ulcer deterioration were less frequently identified events. The prevalence rates of adverse events identified in RAI-HC, DAD and NACRS for the home care clients are presented in Table 4.3. for 2011 to 2012. Table 4.4 provides the prevalence rates of each adverse event among low self-care individuals in comparison with high self-care individuals during the follow-up. The prevalence rates for ADL decline; new hospital visit; client fall; unintended weight loss; and medication non-compliance were higher among low self-care individuals. High self-care group was found to experience more ER visits, urinary tract infections and pressure ulcers. There were no differential in the prevalent rates for caregiver distress among high and low self-care group.

Table 4.3. Prevalence Rates of Adverse Events identified in RAI-HC, DAD and NACRS for Home Care Clients from 2011 to 2012

Adverse Event	N=Number of home care clients follow-up from 2010 to 2011	n=Number of home care clients with adverse events	Prevalence Rates % (n/N)
New ER Visit	1470	836	56.9%
New ADL Decline	615	318	51.7%
New Hospital Visit	1470	717	48.8%
New Fall	615	215	35.0%
New Caregiver Distress	615	166	27.0%
Unintended Weight Loss	615	83	13.5%
Non-Compliance/Adherence with Medications	615	68	11.0%
Newly Detected Urinary Tract Infection	615	40	6.5%
New Pressure Ulcer/Ulcer Deterioration	615	34	6.0%

Table 4.4. Prevalence Rates of Adverse Event among Low Therapeutic Self-Care Group in comparison with High Therapeutic Self-Care Group from 2011 to 2012.

Adverse Event	N=Number of home care clients with adverse events	Low Therapeutic Self-Care Group Prevalence Rate	High Therapeutic Self-Care Group Prevalence Rate
New ER Visit	836	53.9%	60.6%
New ADL Decline	318	53.1%	40.0%
New Hospital Visit	717	53.2%	47.4%
New Fall	215	42.9%	32.0%
New Caregiver Distress	166	27.0%	26.9%
Unintended Weight Loss	83	15.5%	10.3%
Non-Compliance/Adherence with Medications	68	17.2%	8.8%
Newly Detected Urinary Tract Infection	40	5.4%	8.3%
New Pressure Ulcer/Ulcer Deterioration	34	3.1%	6.4%

4.1.4. Results of Initial Models: Therapeutic Self-Care and Adverse Events

Each logistic regression model was built using backward stepwise selection process for the nine adverse events: (1) use of health care resources, including new emergency room visits and new hospital visits; (2) adverse events, including ADL decline; new fall; unintended weight loss; non-compliance/adherence with medication; new urinary tract infection; new pressure ulcer or ulcer deterioration; and new caregiver distress.

The results of the initial models revealed that new ER visit, new ADL decline, new client fall, unintended weight loss, and compliance/adherence with medication were the five outcomes

that were found to have association with therapeutic self-care scores. In particular, high therapeutic self-care group was associated with increased odds of new ER visit whereas low therapeutic self-care group was associated with increased odds of new ADL decline, new fall, unintended weight loss and non-compliance/adherence with medication. Table 4.5 summarizes the initial logistic regression analyses with adjusted odds ratio estimates for therapeutic self-care scores in relation to each adverse event.

Table 4.5. Initial Models: Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Adverse Events

Adverse Events	Adjusted Odds Ratio for Therapeutic Self-Care	95% Confidence Interval	p-value
New ER Visit	1.26	1.02, 1.57	0.04
New Hospital Visit	0.85	0.66, 1.09	0.19
New ADL Decline	0.58	0.40, 0.84	0.04
New Fall	0.64	0.42, 0.99	0.05
Unintended Weight Loss	0.58	0.34, 0.99	0.05
Non-Compliance/Adherence with Medication	0.45	0.25, 0.78	≤ 0.00
Newly Detected Urinary Tract Infection	1.74	0.90, 3.36	0.09
New Pressure Ulcer/Ulcer Deterioration	3.15	0.72, 13.87	0.13
New Caregiver Distress	1.34	0.89, 2.00	0.16

4.1.5. Comparison between the initial model and interaction model for new ER visit and new hospital visit:

All of the significant risk factors in the initial logistic regression models ($p < 0.05$) were checked for collinearity with the therapeutic self-care variable by reviewing the results of the Chi-square tests. When collinearity existed, interaction terms between the risk factors and therapeutic self-care variable were added into the final logistic regression models. The reason for adding interaction terms to the final models was to control for collinearity and confounding effects of those risk factors that might distort the observed relationship between the independent variable and outcome of interest. Refer to appendix I for a list of client risk factors that were added as interaction terms into the final models for each outcome. The final logistic regression models were developed using backward stepwise selection, which involved dropping statistically non-significant risk factors and interaction terms from the regression model. Only those risk factors and interaction terms whose regression coefficient estimates were significant at level 0.1 were retained in the final model.

There was no change in the magnitude and direction of the relationship between study variables for all of the outcomes in the final model that included significant interaction terms, except for new ER visit and new hospital visit. Specifically, statistically non-significant result was found for ER visit, whereas new hospital visit became statistically significant with low self-care individuals found to have more hospitalizations than high self-care group.

1. New ER Visit (Initial Model without Interaction Terms)

The result of the initial logistic regression model indicated that the odds of having ER visits for high self-care group were 26% higher than low self-care group (see Table 4.6). Home care clients who were male and younger than 75 years of age were found to have higher odds of ER visits, particularly individuals with diabetes, any psychiatric illness and respiratory conditions including emphysema/COPD/asthma. On the other hand, the factors that decreased the odds of ER visits were higher educational level, having prior history of ADL decline, poor locomotion outside of home, and having a diagnosis of Parkinson's disease. Model fit assessment indicated that the likelihood ratio chi-square test had a significant p-value, as well as the C-index with a value of 0.62. Both model fit statistics revealed an acceptable indicator of good model fit.

Table 4.6. Initial Logistic Regression Model with Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to ER Visit

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	1.26	1.02, 1.57	0.04
Over age 75	0.73	0.55, 0.98	0.03
Female	0.76	0.61, 0.95	0.02
Diabetes	1.31	1.03, 1.65	0.03
Education	0.77	0.59, 0.10	0.05
History of ADL Decline	0.76	0.60, 0.95	0.02
Locomotion Outside of Home	0.77	0.61, 0.97	0.03

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Any Psychiatry Illness	1.45	1.06, 1.99	0.02
Parkinson's	0.43	0.23, 0.82	0.01
Emphysema/COPD/Asthma	1.31	1.01, 1.70	0.04
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	63.03	10	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.62		

2. New ER Visit (Final Interaction Model)

When interaction terms were added into the final logistic regression model, the relationship between therapeutic self-care ability and the occurrence of new ER visit changed. The model revealed a statistically non-significant result for the ER outcome, as well as a change in the direction of relationship where high self-care group had a lower likelihood of ER visits. The interaction model was not shown below because the final model was not significant, but can be seen in appendix I for a list of interaction terms that were added into the final model.

3. New Hospital Visit (Initial Model without Interaction Terms)

The result of the initial logistic regression model indicated a statistically non-significant relationship for new hospital visit in relation to therapeutic self-care scores. Table 4.7 provides the results of the initial logistic regression model with adjusted odds ratio estimates for therapeutic self-care scores in relation to new hospital visit.

Table 4.7. Initial Logistic Regression Model with Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Hospital Visit

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.84	0.65, 1.08	0.16
Over age 75	1.01	0.79, 1.37	0.80
Female	0.77	0.63, 0.95	0.02
Polypharmacy	1.34	1.12, 1.72	<0.00
CHESS scores	1.47	1.20, 1.82	<0.00
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	30.68	5	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.60		

4. New Hospital Visit (Final Interaction Model)

When interaction terms were added into the final logistic regression model, the relationship between therapeutic self-care ability and the occurrence of new hospital visit changed. When significant interaction terms were included, a statistically significant relationship was found between hospital visit and therapeutic self-care. More specifically, high self-care group was found to have lower likelihood of new hospital visit than low self-care group. There were 47.4% of home care clients with high therapeutic self-care ability who had unplanned hospital visits when compared with 53.2% of individuals in low self-care group. The result of

the final interaction model indicated that the odds of having hospital visits for high self-care group were 26% lower than low self-care group.

The final model with interaction terms indicated that the client factors that increased the odds of hospital visit were: home care clients who were male; an increase in health instability as indicated by high CHESS scores, as well as having the diagnoses of Congestive Heart Failure and Alzheimer's disease. In particular, the interaction term for polypharmacy (taking nine or more medications) and therapeutic self-care was found to be significant, which indicated that there was interaction between polypharmacy and self-care ability in the occurrence of new hospital visits. High polypharmacy was associated with the increased odds of experiencing new hospital visit among the individuals with low therapeutic self-care ability. Sixty one percent of home care clients with polypharmacy were found to have unplanned hospitalizations. Model fit assessment indicated that the likelihood ratio chi-square test had a significant p-value, as well as the C-index with a value of 0.62. Both model fit statistics revealed a good model fit. Table 4.8 provides the results of the final model with the significant interaction term included.

Table 4.8. Interaction Model with Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Hospital Visit

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.74	0.56, 0.96	0.03
Over age 75	1.01	0.77, 1.34	0.93
Female	0.77	0.63, 0.96	0.02
Polypharmacy	1.11	0.87, 1.44	0.40
Polypharmacy*Therapeutic Self-Care	1.48	1.10, 2.02	0.01
CHESS Scores	1.42	1.14, 1.76	<0.00
Congestive Heart Failure	1.66	1.20, 2.30	<0.00
Alzheimer's Disease	1.31	1.01, 1.70	0.02
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	68.28	10	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-index	0.62		

4.1.6. Final interaction models for new ADL decline; client falls; unintended weight loss and medication non-compliance:

1. New ADL Decline

The results of the initial and final interaction model indicated that the odds of having further ADL decline among high self-care group were 42% lower than low self-care group. Fourty percent of home care clients with high therapeutic self-care ability experienced further ADL decline compared to 53.1% of individuals in low self-care group. Home care clients who were female and older than 75 years of age were found to have higher odds of new ADL decline. In particular, the factors that increased the risks of further ADL decline were individuals with an increase in heath instability as indicated by high CHESS scores, history of falls, unsteady gait, receiving an anxiolytic medication and polypharmacy. Model fit assessment indicated that the likelihood ratio chi-square test had a significant p-value, as well as the C-index with a value of 0.70. Both model fit statistics revealed an acceptable indicator of model fit. Table 4.9 provides the results of the final logistic regression model with adjusted odds ratio estimates for therapeutic self-care scores in relation to new ADL decline. The relationship between therapeutic self-care ability and the occurrence of ADL decline did not change when interaction terms were added into the final logistic regression model. The interaction model was not shown below because the interaction terms were not significant, but can be seen in appendix I for a list of interaction terms that were added into the final model.

Table 4.9. Final Logistic Regression Model with Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to New ADL Decline

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.58	0.40, 0.84	0.04
Over age 75	1.75	1.14, 2.68	0.01
Female	1.52	1.07, 2.15	0.02
Chess	2.21	1.55, 3.15	<0.00
History of falls	1.48	1.03, 2.14	0.03
Unsteady gait	1.82	1.21, 2.73	<0.00
Polypharmacy	1.23	1.13, 2.68	<0.00
Anxiolytic medications	1.56	1.02, 2.40	0.04
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	77.21	10	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-index	0.70		

2. Client Falls

The results of the initial and final interaction model both indicated that the odds of having new client fall among high self-care group were 36% lower than low self-care group. There was 32% of home care clients with high therapeutic self-care ability experienced new falls when compared with 42.9% of individuals in low self-care group. Gender was not found to be a significant predictor of client fall. On the other hand, older home care clients (>age 65) who were taking anti-depressants and had prior history of falls had the increased odds of having a

new fall. Model fit assessment indicated that the likelihood ratio chi-square test was significant, as well as the C-index with a value of 0.72. Both model fit statistics revealed an acceptable model fit. Table 4.10 provides the results of the final logistic regression model with adjusted odds ratio estimates for therapeutic self-care scores in relation to new client fall. The relationship between therapeutic self-care ability and the occurrence of client fall did not change when the interaction terms were added into the final logistic regression model (Refer to Appendix I for the list of interaction terms).

Table 4.10. Final Logistic Regression Model with Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to New Client Fall

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.64	0.42, 0.99	0.05
Over age 65	0.67	0.45, 1.00	0.05
Female	0.98	0.66, 1.45	0.92
Anti-depressant medications	1.63	1.07, 2.49	0.02
History of falls	1.95	1.16, 3.27	0.01
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	96.10	6	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.72		

3. Unintended Weight Loss

The results of the initial and final interaction model indicated that the odds of having unintended weight loss among high self-care group were 42% lower than low self-care group. Ten percent of home care clients with high therapeutic self-care experienced unintended weight loss compared to 15.5% of individuals in low self-care group. Age and gender were not found to be significant predictors of unintended weight loss. Specifically, home care clients with health instability as indicated by high CHESS scores, who also had difficulty with locomotion outside of home and a cancer diagnosis had the increased odds of unintended weight loss. Model fit assessment indicated that the likelihood ratio chi-square test had a significant p-value, as well as the C-index with a value of 0.73. Both model fit statistics revealed an acceptable model fit. Table 4.11 provides the results of the final logistic regression model with adjusted odds ratio estimates for therapeutic self-care scores in relation to unintended weight loss. The relationship between therapeutic self-care ability and the occurrence of unintended weight loss did not change when the interaction terms were added into the final logistic regression model (Refer to Appendix I for the list of interaction terms).

Table 4.11. Final Logistic Regression Model with Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Unintended Weight Loss

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.58	0.34, 0.99	0.05
Over age 75	1.02	0.54, 1.95	0.95
Female	0.75	0.46, 1.24	0.27
Chess	2.15	1.26, 3.64	<0.00
Locomotion Outside of Home	2.58	1.39, 4.78	<0.00
Cancer	2.20	1.29, 3.75	<0.00
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	47.41	11	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.73		

4. Medication Non-Compliance

The results of the initial and final interaction model indicated that the odds of having medication non-compliance among high self-care group were 54% lower than low self-care group. There were 8.8% of home care clients with high therapeutic self-care ability who were non-compliant with medications when compared with 17.2% of individuals in low self-care group. Home care clients who were female and older than 75 years of age were found to have higher odds of medication non-compliance. In particular, the factors that increased the risks of

medication non-compliance were individuals with difficulty in managing medications, history of falls and skin problems. On the other hand, independence in ADL self-performance decreased the odds of medication non-compliance. Model fit assessment indicated that the likelihood ratio chi-square test had a significant p-value, as well as the C-index with a value of 0.72. Both model fit statistics revealed an acceptable model fit. Table 4.12 provides the results of the final logistic regression model with adjusted odds ratio estimates for therapeutic self-care scores in relation to medication non-compliance. The relationship between therapeutic self-care ability and the occurrence of medication non-compliance did not change when the interaction terms were added into the final logistic regression model (Refer Appendix I for the list of interaction terms).

Table 4.12. Final Logistic Regression Model with Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Medication Non-Compliance

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.46	0.26, 0.81	<0.00
Over age 75	1.75	1.14, 2.68	0.01
Female	1.52	1.07, 2.15	0.02
ADL Self-Performance	0.35	0.19, 0.65	<0.00
History of falls	1.82	1.01, 3.28	0.05
Difficulty in Managing Medications	2.53	1.35, 4.73	<0.00
Skin Problems	2.66	1.54, 4.59	<0.00
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	42.08	8	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-index	0.72		

4.1.7. Summary of Quantitative Findings

The prevalence rates of adverse events identified in RAI-HC, DAD and NACRS for the home care clients for 2011 to 2012 revealed that new ER visit, new ADL decline, new hospital visit, new client fall, and new caregiver distress were ranked among the most frequently occurring adverse events. Unintended weight loss, non-compliance or adherence with medications, newly detected urinary tract infection, and new pressure ulcer/ulcer deterioration were less frequently identified events.

The relationship between home care clients' therapeutic self-care ability was investigated in relation to two types of outcomes: (1) use of health care resources, including new emergency room visits and unplanned hospital admissions; (2) adverse events, including ADL decline; client falls; unintended weight loss; non-compliance/adherence with medications; new urinary tract infection; new pressure ulcer or ulcer deterioration; and new caregiver distress. There was no change in the magnitude and direction of the relationship between study variables for all of the outcomes of interest when interaction terms were added into the final models, except for new ER visit and new hospital visit. Specifically, a statistically non-significant result was found for ER visit, whereas new hospital visits became statistically significant with high self-care individuals experiencing less likelihood of unplanned hospitalizations than low self-care group. In particular, the interaction term for polypharmacy and therapeutic self-care was found to be significant, which indicated that there was interaction between polypharmacy and self-care ability in the occurrence of new hospital visits. High polypharmacy was associated with the increased odds of experiencing new hospital visits among individuals with low therapeutic self-care ability.

In summary, there were five adverse events that were found to have association with therapeutic self-care scores: (1) new hospital visit; (2) new ADL decline; (3) new fall; (4) unintended weight loss; and (5) compliance/adherence with medication. In particular, high therapeutic self-care group was associated with the decreased odds of adverse events whereas the low therapeutic self-care group was associated with the increased occurrence of a hospital visit, ADL decline, client fall, unintended weight loss and non-compliance with medication.

4. 2. Summary of Qualitative Findings

The qualitative part of the mixed methods research was used to develop a richer description on the concept of therapeutic self-care. The qualitative findings were able to provide complementary data by gaining in-depth information about clients and their informal caregivers' perspectives on home safety as it relates to therapeutic self-care and informal caregiving. The presentation of qualitative findings focuses on the following four areas: (1) characteristics of study sample; (2) concept of safety, self-care and informal caregiving; (3) overview of thematic tree; and (4) presentation of over-arching themes and sub-themes

4.2.1. Characteristics of Study Sample

I used purposeful sampling to strategically seek out participants to fit with the research goals and objectives. The final study sample consisted of a total of fifteen home care dyads: older home care clients paired with their informal caregivers who were recruited from one home care organization in Ontario. Maximum variation sampling was achieved by seeking variation in the study sample in regards to age, gender, types of chronic diseases, cultural background and geographical location of where the participants resided, such as rural and urban areas. The mean age of home care clients was 72 years, with more than half were female (53%) and were married (53%). The majority of the home care clients were born in Canada (60%) with the rest of the individuals coming from countries such as Asia and Europe. There was a balanced representation of home care clients from both rural areas (47%) and urban areas (53%). The average length of time of home care clients receiving home care services was 4.5 years with all of them receiving personal support services, and some of them receiving professional services,

such as nursing, physiotherapy and occupational therapy. All of the home care clients had multiple chronic diseases, particularly with the diagnosis of stroke (40%), as well as a number of individuals who had polypharmacy because they were taking more than nine medications (40%). The therapeutic self-care scale conducted during the interview resulted in an average score of 3.5 (from 0 to 5), which indicated a medium self-care level.

The mean age of the informal caregivers was 54 years with the majority of them being female (67%). The majority of the informal caregivers were spouses (47%) and son/daughters (40%) who were living together with their loved ones in the same household. These informal caregivers had been responsible for the care of their loved ones for an average of five years, and a majority of them had full-time or part-time employment (60%). These informal caregivers received respite care from a home care organization for an average of five hours per week. Respite care is defined as a break, time out or relief for the informal caregiver provided through a home care worker coming to the home to allow the informal caregiver time off. There were 40% of respondents who reported poor health status when they were asked to rate their perceived health status, while 40% of them rated their health status as fairly good. The profile presented in Table 4.13 and 4.14 describe the characteristics of the study sample of home care clients and informal caregivers.

Table 4.13. Characteristics of Study Sample among Home Care Clients

<i>Home Care Clients Demographics (n=15)</i>	<i>N</i>	<i>%</i>
Age		
• Over age 65	8	53
• Over age 75	7	47
Gender		
• Male	7	47
• Female	8	53
Marital Status		
• Married or common-law	8	53
• Separated or divorced	1	7
• Widowed	5	33
• Never married	1	7
Primary Caregiver at Home		
• Wife	4	27
• Husband	3	20
• Daughter	4	27
• Son	2	13
• Daughter-in-law	1	7
• Sister	1	7
Living Arrangement		
• Alone in separate dwelling	5	33
• With informal caregiver	10	67
Length of Time Receiving Home Care Services		
• Less than 1 year	5	33
• One to 2 years	4	27
• Three to 5 years	5	33
• Five to 10 years	1	7
Number of Medications		
• One to 2	1	7
• Three to 5	3	20
• Five to 9	5	33
• Over 9	6	40

<i>Home Care Clients Demographics (n=15)</i>	<i>N</i>	<i>%</i>
Types of Primary Diagnosis <ul style="list-style-type: none"> • Stroke • Cancer • Diabetes • Hypertension • Parkinson's • Back Pain • Seizures • Depression • Arthritis • Hip/Knee Replacement 	6 1 2 1 2 2 1 1 1 1	40 7 13 7 13 13 7 7 7 7
Types of Home Care Services <ul style="list-style-type: none"> • Nursing • Physiotherapy • Occupational Therapy • Speech Therapist • Social Worker • Nutritionist • Personal Support Worker 	10 8 7 8 7 5 15	67 53 47 53 47 33 100
Therapeutic Self-Care Scale Scores <ul style="list-style-type: none"> • Zero to 1 • Two to 3 • Three to 4 • Five 	1 6 7 1	7 40 47 7

Table 4.14. Characteristics of Study Sample among Informal Caregivers

<i>Characteristics of Informal Caregivers (n=15)</i>	<i>Average</i>	<i>Range</i>
Age	54 years	30 to 84 years
Number of Years of Informal Caregiving	5 years	1 to 10 years
Number of Respite Hours from Home Care	5 hours/week	1 to 10 hours/week
Number of Dependents	3	1-6
<i>Characteristics of Informal Caregivers (n=15)</i>	<i>Number</i>	<i>Percentage</i>
Gender		
• Male	5	33
• Female	10	67
Marital Status		
• Married or common-law	9	60
• Separated or divorced	2	13
• Widowed	1	7
• Single	3	20
Employment Status		
• Full time	4	27
• Part time	2	13
• Not Employed	2	13
• Retired	7	47
Location of Residence		
• Urban	8	53
• Rural	7	47
Place of Birth		
• Canada	9	60
• Asia	2	13
• Europe	3	20
• Other	1	7
Informal Caregiver Perceived Health Status		
• Poor	6	40
• Fairly good	6	40
• Very good/Excellent	3	20

4.2.2. Concept of Home Care Safety, Self-Care and Informal Caregiving

The qualitative interview began by asking the participants to describe the general meaning of safety, self-care and informal caregiving. The findings revealed that both clients and informal caregivers had similar perspectives of what safety meant. For example, they described safety as having a sense of security by being in control, as well as a sense of stability and certainty. One client explained that “I don’t feel safe when I lost my sense of control over things... it makes me feel insecure”. An informal caregiver explained that “feeling safe is like when things are stable and secure... Uncertainty makes you feel unsafe and confused.”

Older home care clients described self-care as being capable of looking after oneself independently, as well as taking actions and control over day-to-day life. One participant explained that “self-care means independence and being capable”. Another participant explained self-care meant “when I’m actively involved and taking control in everyday living...not having to rely on others... it makes me feel good”. A home care client further elaborated on the meaning of self-care by describing that “self-care seems easy when you are not sick, but it becomes extreme hard work and it takes time to do it when you become ill. Some days I can do more, some days less. You never know what to expect”. Self-care can become challenging at times of illness, but clients stated that self-care was very important to them despite the challenges because it gave them a sense of dignity and autonomy. It should be noted that not all home care clients embraced the idea of self-care. For example, a client commented that “I know the government is pushing us into taking care of ourselves at home...But is it really for the sake of our own health benefits? Or is it really just about saving health care money...” Home care clients pointed out that not all clients are physically or mentally capable of engaging in self-care.

Also, some clients explained that there may be cases where clients do not want self-care, and these wishes need to be respected by health care professionals.

Some clients and caregivers described themselves as mutual caregivers when they were asked to explain the nature of their informal caregiving relationship. Mutual caregivers occurred when both clients and caregivers were taking turns to function as a caregiver for the other. For example, a caregiver explained that: “I’m the caregiver of my wife, but my wife is also my caregiver... we take turn looking after one another. So not only my wife needs help from home care... I also need help as a caregiver! I’m as old as my wife, I’m as vulnerable as my wife, and I have my own health problems too”. Some clients described the involvement of multiple caregivers who shared care and responsibilities in looking after their loved ones at home. For instance, a client described that “I’m lucky to have a team of helpers who take turns caring for me at home. I have my daughter who helped me with medications, shopping and meal preparation while my older son shared housework duties with my younger son”.

Caregivers described informal caregiving as an unpaid, unconditional work that involved looking after the care recipient on an ongoing basis. Particularly, caregivers described it as taking care of the loved ones by helping them in becoming independent. An informal caregiver explained “I care for her but I also try to encourage her to do things on her own...just let her do it...letting her having the independence is important”. Another perspective of informal caregiving is being an advocate on behalf of the care recipient by fulfilling their needs. A caregiver explained “I constantly think of her needs and well-being before my own...if I don’t speak up or look out for her, who would?”

Despite the duties and obligations of informal caregiving, participants described that it is a truly rewarding work which give them a sense of satisfaction and pleasure. One caregiver

elaborated on this perspective by explaining that “caregiving is hard work because it is really a full-time job. But we are family. It is expected of you to care for your family...it is a necessity and it is out of love. It’s my pleasure to do this because I love her”. On the other hand, there were some caregivers who expressed the negative aspects of informal caregiving. Some caregivers described how informal caregiving placed a lot of tension between them and their loved ones. Also, some caregivers pointed out that societal expectations placed a lot of pressure on informal caregivers into keeping their loved ones at home. A caregiver explained that “I think people nowadays are being pressured into looking after your loved ones at home. If you send your parents to a nursing home, then you get blamed for not loving your parents. People need to look at the circumstances...not every situation is feasible for caregiving at home...People need to have realistic expectations”. Finally, informal caregivers indicated that informal caregiving involved both looking after oneself and others. One caregiver explained that “If you don’t know how to take care of yourself, how can you care for others?”

Once the general meaning of safety, self-care and informal caregiving were explored, participants were asked to provide further insight into their perspectives on home care safety as it related to therapeutic self-care and caregiving activities by exploring the following four research questions:

1. What are the safety challenges and concerns home care clients and their informal caregivers report related to therapeutic self-care and informal caregiving activities?
2. What supports do the clients identify as needed to address their safety challenges and concerns related to therapeutic self-care?
3. What supports do the informal caregivers identify as needed to address their safety challenges and concerns related to informal caregiving?

4. What role do clients and their caregivers identify as important home care services in supporting therapeutic self-care and informal caregiving?

Analyses of the interview data revealed four over-arching themes: (1) Struggling through multiple aspects of safety challenges; (2) Managing therapeutic self-care by developing knowledge, competency and self-confidence; (3) Coping with informal caregiving through problem-solving, stress management and caregiver relief; (4) Seeking education, support and collaboration from health care professionals.

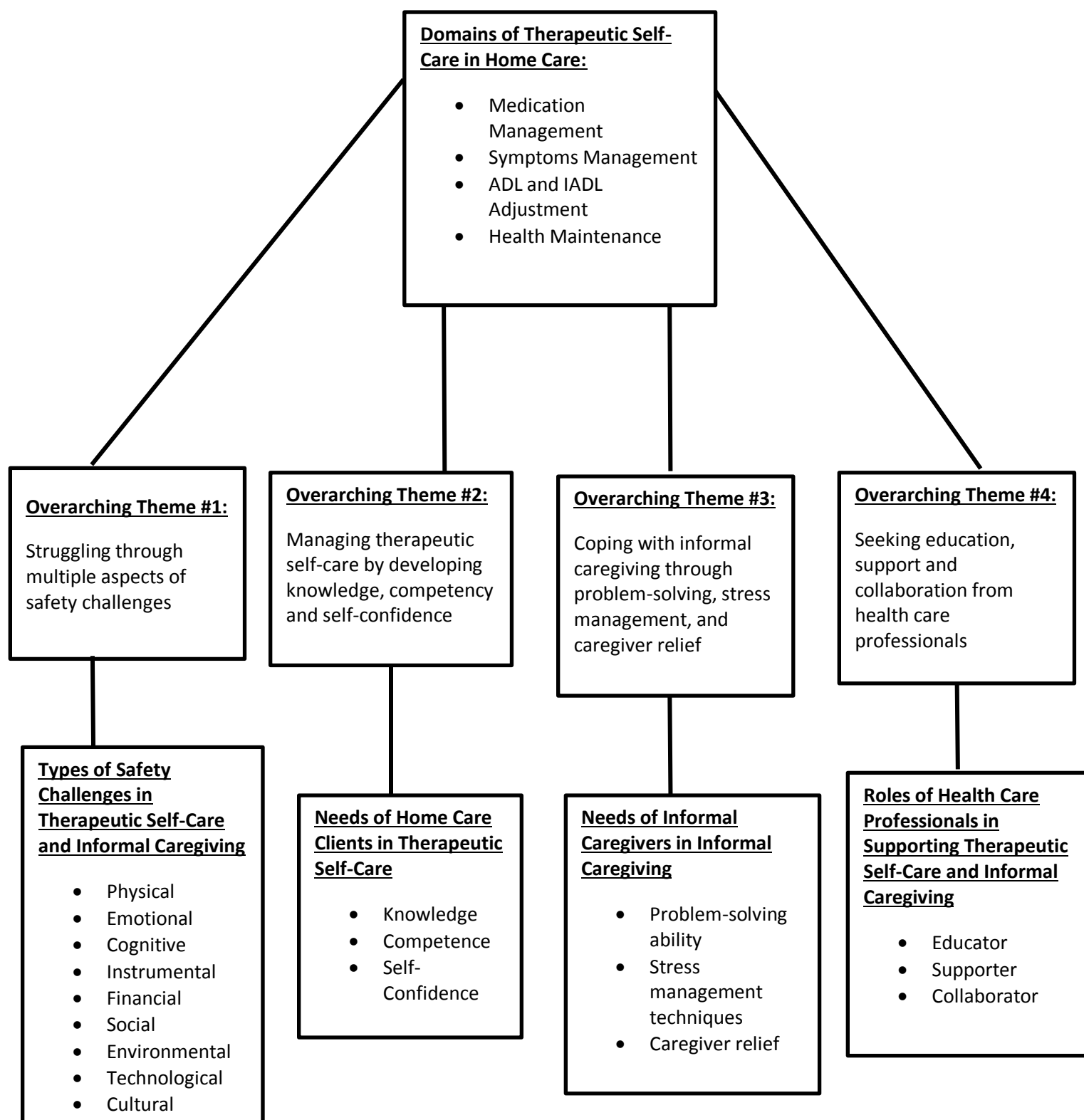
4.2.3. Overview of Thematic Tree

A thematic tree that summarizes the overarching themes and sub-themes about the central concept of home care safety in therapeutic self-care and informal caregiving is presented below in figure 3. First, the thematic tree demonstrates the multiple aspects of safety challenges in relation to therapeutic self-care and informal caregiving: (1) physical; (2) emotional; (3) cognitive; (4) instrumental; (5) financial; (6) social; (7) environmental; (8) technology; (9) cultural. Secondly, both home care clients and informal caregivers indicated the need to work together in addressing the different domains of therapeutic self-care, such as medication management; symptoms management; ADL and IADL adjustment; and health maintenance. More specifically, home care clients indicated the need to have knowledge, competencies and self-confidence when carrying out therapeutic self-care, whereas informal caregivers described the importance of having problem-solving ability, stress management techniques and caregiver relief to cope with informal caregiving. Furthermore, home care professionals were viewed as having an integral role in addressing the needs of home care clients and their informal caregivers by being an educator, supporter and collaborator. The results of the interview data highlighted

the relational interaction between the client, informal caregiver and healthcare professional. The findings revealed that the nature of the inter-dependent relationships among the clients, informal caregivers and healthcare professionals played a vital role in supporting home care safety in relation to therapeutic self-care and informal caregiving.

Figure 3. Thematic Tree:

The Concept of Home Care Safety in Relation to Therapeutic Self-Care and Informal Caregiving



4.2.4 Presentation of Over-Arching Themes and Sub-Themes:

Over-Arching Theme #1: Struggling Through Multiple Aspects of Safety Challenges

The first theme addressed the first research question by exploring the types of safety challenges and concerns related to therapeutic self-care and informal caregiving. From the perspectives of home care clients and informal caregivers, safety in the context of home care meant struggling through the different types of challenges encountered at home. Clients elaborated on this by explaining that “When you are dealing with a disease at home, every day is a struggle and you never know what’s going to happen next because each day there is a new challenge. Just when you think it is over, another type of challenge comes around... To live safely at home, you need to deal with these problems... it’s no easy work.” There were a total of nine different types of safety challenges identified by the participants: (1) Physical; (2) Emotional; (3) Cognitive; (4) Instrumental; (5) Financial; (6) Social; (7) Environmental; (8) Technological; and (9) Cultural.

Sub-Theme#1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Physical Challenges

The physical challenges refer to the physical work of self-care and informal caregiving at home. The physical aspects of self-care involved activities of daily living including mobility, transfer, stair climbing, eating, toileting, personal hygiene such as bathing and dressing. Older home care clients described these aspects of physical care created challenges to their physical well-being. For example, the risk for falls was the most commonly identified physical challenge for home care clients. The client explained that “my number one concern is falling... I

constantly worry that I'll fall when I take a bath or climb the stairs. I don't want to break my hips or bones... People like me at my age can't afford to fall".

Another common concern for home care clients was pain management. Clients explained that their level of pain could greatly affect their ability to carry out activities of daily living, and therefore these limitations could bring challenges in safely performing self-care activities. For example, a client described that "I have arthritis and do you know how hard it is to have a bath or dress yourself when you are in pain? I fell in the bathtub in the past because I was in so much pain that I was shaking so much...then I fell and broke my hip." This quote demonstrated how a physical challenge such as uncontrolled pain can lead to another safety concern such as risk for falls, and may result in physical injuries that affect the client's well-being.

The physical challenges not only affected the physical well-being of home care clients, but also the physical health of their informal caregivers. The physical aspects of caregiving included assistance with activities of daily living such as mobility, transfer, feeding, toileting and personal hygiene. Informal caregivers reported that the delivery of physical care to their loved ones could bring challenges to their physical well-being. In particular, informal caregivers highlighted that the physical challenges that they experienced were profoundly interconnected to their care recipient's physical challenges. For example, risk for falls was the most commonly reported concern for home care clients, while the informal caregivers reported back injury related to client fall was their priority concern. The interconnectedness of the physical challenges between client and caregiver was exemplified in the following quote by an informal caregiver who had back injury after her mom fell: "One time my mom fell under the table. Lifeline called me right away, so I rushed into her house. I had a hard time getting her up by myself because I had a neck injury after my car accident. But there was no one here could help us, so I managed

to get her up by myself somehow, but then I hurt my back so badly that time”. This example demonstrated how informal caregivers were at risk for injury or aggravating pre-existing health issues as a result of their caregiving responsibilities.

Fatigue as a result of the physical demands of caregiving was another major challenge. The physical demands of caregiving not only included assistance with activities of daily living, but also included the delivery of client’s medical treatment such as dialysis treatment, wound management or oxygen therapy. The caregiver reported that fatigue could be resulted from lack of sleep due to the physical workload of caregiving: “I’m so tired all the time. I feel like home becomes my workplace...there is no break, no end of shift work. I’m on call 24/7, and wake up in the middle of night every so often to check on her... No wonder why I don’t sleep well”. Informal caregiver reported the most fatigue when they were dealing with their loved ones who resisted the care: “It would be easier if my husband cooperates with me all the time, but the reality it’s that he doesn’t. So that’s the most frustrating and tiring”. Informal caregiver further described that “When I don’t have enough sleep or energy, this makes me worried because I’m afraid that I could do something harmful to him. When I’m not focused enough, I might do the wrong thing like pushing the wrong button on the machine or forgetting to do something for him”. This quote demonstrated how the consequences of caregiver fatigue not only had negative impact on their health, but could potentially bring safety risks to client’s physical well-being.

Sub-Theme #1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Emotional Challenges

The emotional challenges refer to the feelings and psychological stress associated with self-care and informal caregiving at home. The feeling most commonly identified by the home

care clients was the fear of being alone at home. In particular, older home care clients were concerned about being alone when they performed self-care because of their increasing frailty and health instability. Clients described that “I used to be able to do everything by myself, but now I’m so weak. I’m afraid to take a bath by myself because I might fall, and then no one is around to help me.” Clients reported that the fear of being alone also brought about the sense of insecurity. For example, client explained that “when I’m alone in the house, I only feel safe in certain parts of the house. I feel safer sitting closer to the front door just in case there is a fire, so I can get out quicker... I also like to be sitting closer to the telephones in the house, so I can call for help when I needed. Otherwise, I feel very insecure”.

Psychological stress in relation to managing self-care was identified as a major emotional challenge for home care clients. The stress associated with learning new things after an illness was exemplified in the following quote from a client with stroke: “do you know how hard it is to learn basic things all over again like walking, talking and eating...it is especially stressful when you need to learn new things at my age.” Another psychological stress identified by a home care client was associated with making lifestyle adjustments. A client who was diagnosed with diabetes explained that “I remember the stress I had when I was newly diagnosed with diabetes... I had to look after myself differently like changing my eating habits; taking care of my feet; doing more exercises; checking my sugar level and blood pressure. Lots of changes, and I don’t like changes because they make me feel stressed”.

The emotional concerns identified by the clients were found to be interconnected to the emotional challenges reported by the informal caregivers. While the clients reported the fear of being alone at home, informal caregivers reported feelings of anxiety about the safety of their loved ones when they were being left alone. The feeling of anxiety about the safety of the client

was exemplified in the following quote by a caregiver: “Psychologically, I’m constantly anxious about her safety when she is by herself at home...What if she falls? What if there is a power outage? Who is going to help her...I’m constantly worried about her”. The caregivers not only experienced anxiety over the safety of their loved ones, but also experienced fear of the unknown due to lack of knowledge in providing caregiving tasks. A caregiver reported that “I’m so anxious about not knowing how to do things for her like checking her blood pressure or changing her oxygen tank...I always ask myself...did I do this right or not?”

As a result of anxiety, some informal caregivers reported psychological distress associated with the burden of care. In particular, informal caregivers reported the most psychological distress associated with client’s negative behaviors such as verbal abuse, disruptive behaviors and resistance to care. An informal caregiver described that “it is most stressful when I try to do something for him and he fights back when taking a bath or feeding... It takes twice the time to feed him because his head moves around... and I’m so worried that he might be choking one day”. This quote demonstrated how the client’s resistance to care not only brought psychological distress to the caregivers, but also the client’s disruptive behaviors may have a negative impact on the safety of their own physical health.

Sub-Theme #1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Cognitive Challenges

The cognitive challenges refer to the cognitive ability in making informed decisions by the clients and informal caregivers in regards to the treatment and care at home. Home care clients described the challenges of having adequate cognitive skills for daily decision-making, such as making decisions about organizing the day. A client described this perspective in the

following quote: “For me, my biggest challenge is making decisions about my daily routines like when to get up or have meals, which clothes to wear or what activities to do on that day...”

Particularly, older home care clients identified challenges in their memory recall ability when learning to provide care for themselves. For example, one client explained that “the physiotherapist tried to teach me some leg exercises to reduce the swelling of my feet... As soon as she was gone, I forgot everything...I don’t have Alzheimer’s disease, but I still can’t remember much... I guess I’m old.” Furthermore, older home care clients identified challenges in their problem solving ability in managing their disease condition. They reported the difficulty in knowing what to do when new situations or problems arise with their health condition. A client diagnosed with diabetes described that “When there is no problem, things are going well and everything seems OK. But when I have problems...like my blood sugar goes up, then I need to figure out how to deal with it...I need to figure out what to do to prevent more problems, and decide when it’s needed to call my family doctor to get help”.

At the same time, informal caregivers reported the burden of making care decisions on behalf of their loved ones. For example, a caregiver described that “the biggest responsibility in looking after my mom is that I need to make decisions for her from time to time... Some decisions are small, but some decisions are big that have major implications on her health... Should she try this new medication or should she go for this surgery at her age? What if I make the wrong decision for her, then I’ll feel very guilty”. In particular, the informal caregivers reported challenges in having to make informed decisions when the health care professionals offer multiple treatment or diagnostic choices. The caregivers reported that this challenge was particularly evident when the clients became cognitively impaired or when they encountered unexpected health events. A caregiver elaborated on this perspective in the following quote:

“My mom has some dementia, so I am making more and more decisions for her. One time, I have to decide if she should have a hip surgery. It’s so hard when the doctor tell you all the possible options and all the medical terms that you don’t understand, and yet you have to make a life and death decision for your loved one...” The above example indicated how informal caregivers experienced major challenges in making informed decisions on behalf of their care recipient because these decisions have safety implications that could affect the client’s physical health.

Sub-Theme#1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Instrumental Challenges

Instrumental challenges refer to the instrumental activities of daily living associated with self-care and informal caregiving at home. The instrumental aspects of self-care involved routine activities around the home such as meal preparation, ordinary housework, managing medications, shopping and transportation. Older home care clients described that these aspects of instrumental care activities could bring challenges to their day-to-day life. A client described that “Every day, there are lots of daily routines to manage...like planning my meals, doing dishes, dusting, making my bed, tidying up here and there, laundry, or grocery shopping...Thank God I have my daughter here to help out, or else how could I manage all these by myself?”. With regards to instrumental activities of daily living, safety in meal preparation was one major challenge identified by older home care clients. Clients explained that: “My memory is getting poor and poor, so my son doesn’t trust me when I work in the kitchen to make meals for myself... Well, there were several times I forgot to turn off the stove and I let the tap running...My son got very concerned, so now I have my PSW to cook for me when she’s here”.

Medication management was identified as the most difficult instrumental task for older home care clients. Clients explained that “My doctor gave me lots of pills to take... I have at least ten pills to take every day at different times throughout the day. My daughter-in-law gave me a dosette pill box to help me remember when to take the medicines. One time, I dropped the pill box on the floor. That was a nightmare because everything got mixed up. I didn’t know what these yellow, white or blue pills were, and when to take these or how much. I didn’t want to take the wrong dose... so I had to wait for my daughter-in-law to get me another pill box... that was frustrating!” This example indicated that clients often relied on devices such as dosette to help cope with polypharmacy at home. Without the pill box, clients indicated difficulty in managing medications because they didn’t have sufficient knowledge about what pills they were taking, as well as why and how to take these medications. This situation could potentially lead to medication errors that could put clients’ health safety at risk.

Informal caregivers reported similar concerns with regards to managing the medications for their loved ones. Evidence of this concern was exemplified in the following quote by a husband who needed to provide daily insulin injection to his wife: “I need to give the shot to my wife every morning... I have to be careful that I don’t make a mistake of giving her an overdose of insulin. I just can’t make that kind of mistake...it’s a big responsibility.” The informal caregivers indicated that medication errors were their major concerns because of the safety impact on the physical well-being of their loved ones. Transportation was identified as a safety challenge among the informal caregivers, especially when their loved ones had difficulty with mobility. In particular, caregivers reported the most difficulty with taking their loved ones to and from medical appointments: “My mom had stroke a few years ago, so getting outside is becoming a huge challenge for her. She only goes out when it is absolutely needed like going to

see the doctor. Every time she goes out, she needs lots of help with getting in and out from the car. She gets very unsteady when I transfer her in and out, so I'm always concerned that she might fall. Now I have my husband to help me with the transfer, so it is easier.” This is an example of how transportation can become a challenging aspect in the instrumental activities of daily living for both home care clients and their informal caregivers, especially when the clients have limited mobility, unsteady gait and difficulty with transfer.

Sub-Theme#1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Financial Challenges

Financial challenges refer to the financial implications associated with managing self-care and informal caregiving at home. For home care clients, loss of employment, loss of financial control, and limited funding support for medical equipment and supplies were examples of financial implications associated with managing self-care at home. As a result of managing their illness at home, some clients experienced loss of employment which created financial challenges in their life. A client elaborated on this experience: “I used to work full-time, but ever since I had a stroke...it was no longer possible. It has created a lot of financial stress for me and my wife... I didn't expect to retire this early”.

Loss of financial control was identified as another challenge by the older home care clients, especially those with cognitive impairment: “I have mild dementia, and I can get very forgetful. I used to do my own finances like paying the bills, managing my cheques and dealing with household expenses...but now I get my son to do all that for me... Sometimes I feel so useless for not being able to manage my own finances”. Furthermore, the limited funding support for medical supplies and equipment has created financial burden among home care

clients. Some clients had to desperately look for funding sources to help support the purchase of the medical supplies and equipment to help maintain self-care activities. A client reported that: “I had Parkinson’s disease. So the OT suggested that I got equipment like wheelchair, bath chair, commode, grab bars, transfer pole and walker...I was concerned about having to get these expensive stuffs. Then my friend told me I could get funding from the March of Dimes because I was a veteran. I was lucky to get this funding, but what about those people who can’t get funding? It’s a lot of money”.

Informal caregivers indicated that having to look after their loved ones at home involved financial challenges as a result of taking time off work, loss of income, as well as the burden of managing the finances for their loved ones. For example, caregivers are obligated to take time off work in order to accompany their loved ones to their medical appointments. Caregivers also reported the need to take time off work in order to deal with emergency situations, such as client falls. A caregiver reported that: “Every time my mom fell, I needed to rush home from work to help her because I’m the only caregiver... My boss didn’t like it, but what can I do?” Therefore, caregivers reported that their commitment to caregiving tasks have resulted in job insecurity and loss of income due to the frequency of time away from work. While the clients indicated the loss of financial control as a result of their inability to manage own finances, caregivers reported the stress and burden associated with managing the finances for their loved ones. Caregivers reported this financial responsibility can bring challenges to their relationship with the care recipients, such as conflict and argument over financial decisions, which could bring about detrimental effects on the emotional well-being for both informal caregivers and home care clients.

Sub-Theme#1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Social Challenges

Social challenges refer to the socialization and lifestyle adjustment associated with self-care and informal caregiving at home. As a result of the health changes associated with disease management, home care clients reported significant challenges in their social life, such as loss of enjoyment in hobbies, interests and travel. A client explained that “I used to be very active in life... like doing gardening, knitting and baking. But after I had stroke, things that I used to enjoy doing become a safety issue...like I can’t do gardening because my daughter is afraid that I would fall. I can’t do baking because my children are concerned that I would forget to turn off the stove... and they think that I can’t handle the needles when I knit... so what else is there for me to do?” This example demonstrated how enjoyment of hobbies and interests could be viewed as potential sources of safety risks to clients who were coping with disease conditions at home.

When there were bodily changes related to their health condition, home care clients expressed the difficulty in making lifestyle adjustment by limiting the amount of social activities, such as travelling outdoor or having a vacation. Evidence of this concern was exemplified in the following quote by a client with the respiratory illness: “Ever since I have COPD and need oxygen therapy, I can’t go out and socialize with friends anymore... I used to go out and have coffee with my friends two or three times a week. But now that I need to go out with this oxygen tank... it is such a hassle. I don’t want to bump into those smokers outside of the coffee shop... smoking and oxygen tank don’t mix, so I’d rather stay home now.” Some home care clients reported a sense of social isolation and loneliness as a result of limiting the amount of social activities. A client elaborated on this experience: “I used to go out a lot and travel to different

places for vacation. But with my arthritis, it's not possible anymore...A lot of times, I feel very lonely and depressed because I stay home too much". This example demonstrated how physical challenges can lead to social challenges such as social isolation, and social challenges can have a safety impact on the emotional well-being of older home care clients such as loneliness and depression.

Informal caregivers reported similar challenges related to the socialization and lifestyle adjustment associated with informal caregiving for their loved ones at home. Specifically, caregivers reported that they were unable to spend quality social time with their own spouse or children as a result of their commitment with client care. For example, caregivers described that "I only have 24 hours a day, but now my 24 hours are almost completely devoted to my mom. I don't even have enough time for myself... how am I supposed to find time and spend with own family like my husband and kids? My social life is very different than before". The informal caregivers reported that their biggest lifestyle adjustment was to schedule their daily activities according to the schedule of their loved ones: "In the past, I used to have control of what I want to do on a daily basis, but now, I need to think of my dad's schedule first and then adjusting my own schedule to meet his needs...like his medical appointment should always come first".

Furthermore, caregivers expressed having difficulty in going away for vacation because they were concerned over the safety of their loved ones at home while they were away. As a result of a deprived social life, informal caregivers indicated feelings of stress and emotional burden: "I haven't gone out with my friends for a long time... things have been so much different ever since my mom needs my care at home. Sometimes I wish I could take a break and relax, but then my mom didn't want anyone else to stay with her except me and my husband". Therefore, social challenges associated with socialization and lifestyle adjustment can have a

safety impact on both clients and informal caregivers that put them at risk for negative emotional outcomes such as social isolation, loneliness, depression or caregiver distress.

Sub-Theme#1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Environmental Challenges

Environmental challenges refer to the environmental hazards associated with self-care and informal caregiving at home. Older home care clients described the need to make home modifications in order to make their home suitable to their health needs. For example, a client with a diagnosis of stroke described that: “After I had stroke, it seems like everything in my house can be a safety hazard...like the carpet, stairs and bathtub. So my wife got me a bath chair, raised toilet seat and grab bars for my bathroom. And then she changed the flooring of the house and added electric chair for the stairs so I won’t fall and don’t need to climb up...Well, my house had a complete make-over!” Some home care clients decided to make home modifications to make it safer for their health needs, while others decided to move closer to or live with their informal caregivers, so that their health needs could be met.

For instance, a client with a diagnosis of Parkinson’s disease described that: “Before my health condition went downhill, I used to live in the rural areas with my wife. I really enjoyed living in the country side, but it wasn’t possible for me to live in my old home anymore when I had Parkinson’s disease. My daughter said that it would be safer for me to live closer to her in the city...So I gave up my old home... I really miss it!” In addition to the desire of moving closer to their informal caregivers, clients explained that the geographical locations of where they resided could affect their ability to access medical and community services. Therefore, some home care clients indicated that they made the sacrifice of making the adjustment to

relocate from rural to more urban areas in order to have more options and better access to health services.

Informal caregivers also reported concerns in regards to the environmental hazards associated with informal caregiving at home. Fall hazards were the most commonly identified safety concerns reported by informal caregivers, such as scatter rugs, inadequate lighting and icy walkway. Informal caregiver identified their concern over fire safety related to client's use of oxygen therapy at home. In particular, those caregivers whose care recipients had diabetes expressed great concern over the proper use of disposal container for syringes and needles at home. In addition to home safety hazards, informal caregivers indicated that another type of environmental challenge in home care was the invasion of privacy: "I am happy to have home care workers to help my dad. But sometimes, it made me feel very uncomfortable when the workers invaded into my house and made my home into their workplace... I lost my privacy completely".

The weather conditions and the geographical areas could become an environmental challenge because it could affect their ability to visit their loved ones or influence the ability of the formal health providers to visit clients at home. For example, the caregiver who lived in the rural area explained that: "In the winter, the roads could be very unsafe in the countryside which made it very hard for me to visit my father. If I can't get there, it means the workers can't get there... Then my father would be alone by himself...that's a big concern for me!" Further, informal caregivers indicated that environmental challenges included their concern about wheelchair accessibility when they travelled outside with their care recipient. For instance, a caregiver indicated that "when there's no wheelchair accessible area in those places, then my mom would choose to stay home and not go out at all...that's sad! She said she didn't want to

fall and then rely on me getting her up because it's challenging". Environmental hazards at home not only affected the physical safety of clients, but the outside environment such as weather conditions, geographical areas or wheelchair accessibility could bring challenges to clients who wish to travel outside. Also, environmental hazards could affect client's ability to access services to meet their health needs, as well as putting limitations on the ability of both informal caregivers and formal care providers in visiting the clients at home.

Sub-Theme#1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Technological Challenges

Technological challenges refer to the use of technology in self-care and informal caregiving at home. Home care clients indicated that technology can be a good way to improve their home safety, such as monitoring falls through the use of Lifeline system. They also indicated that the use of technology reduced their sense of social isolation, such as the use of social media to help them stay connected with their family members, friends and relatives. On one hand, clients were grateful for being able to receive medical treatment such as dialysis and intravenous therapy in the comfort of their own home; on the other hand, clients were concerned about the difficulty of managing the complex, highly technical equipment at home. An example of this concern was highlighted by a client with home dialysis: "I'm so old and I don't learn things fast...All these high tech stuffs are so hard to learn and they make me feel nervous...I hope I don't press the wrong button... I hate it when the equipment makes those peeping noises. It's so annoying!" At the same time, clients were concerned about the consequences of malfunction equipment which could put them at risk: "I don't have one hundred percent trust on

these machines... One time, my oxygen saturation monitor broke down...So I guess I was getting the wrong dose of oxygen”.

Similarly, informal caregivers reported caregiver burden in regards to the use of technology at home. Caregivers explained that performing care for their loved ones using technology was costly and complex: “First, medical equipment is expensive. Second, I’m not a medical professional and I don’t know a lot about these medical technologies. It’s very stressful to be dealing with a machine that you don’t really know what to do...it’s especially frustrating when there’s a lack of technical support”. Therefore, both home care clients and informal caregivers indicated mixed feelings about the use of technology at home. On one hand, technology was identified as an important way to maintain home safety. On the other hand, the lack of technical support regarding the use of technology brought challenges to the well-being of both clients and caregivers, such as emotional stress and burden.

Sub-Theme#1: Types of Safety Challenges

Home Care Clients and Informal Caregivers: Cultural Challenges

Cultural challenges refer to the culturally sensitive issues associated with self-care and informal caregiving at home. Language barrier was reported as the most important challenge among home care clients with diverse cultural background. A client described his experience when he first moved to Canada: “When I first moved here, I had a hard time communicating with the care workers because I didn’t speak English quite well...so there were lots of misunderstanding. They didn’t know what I really wanted, or how things should be done for me...Very frustrating for both of us!” Language barrier may result in misunderstanding which could lead to caregiver’s inability to meet client’s self-care needs. Home care clients also

reported that communication barrier affected their ability to navigate the health care system, such as accessing community services, primary health care and emergency care. As a result of the challenges in health literacy, clients reported that they had a difficult time finding out what kinds of services were available in the community that could best suit their health needs.

Informal caregivers indicated that their cultural background played a role in what they can do or cannot do for their loved ones at home. A caregiver with a European background indicated that “For my culture, daughters are not allowed to give personal care to their fathers...But unfortunately, some of the health care workers didn’t understand this and they thought that I was just being lazy”. On the other hand, the cultural expectations regarding their obligation and commitment to providing care to their loved ones was very strong among some cultures. For instance, an informal caregiver with an Asian background indicated that “it is the expectation that we care for our parents... being the daughter in the family is definitely a must. There is no way I would send my parents to a nursing home... no way...it is just not acceptable! I would do everything I can to keep them with me at home until they die”. Further, caregivers discussed the importance of delivering culturally sensitive care to their loved ones. A caregiver explained that “Some workers don’t understand why we use herbal medicine or old folk remedies at home, and they think that it is not safe. But this is just part of our culture... this is what we do from generations to generations!” Therefore, language barriers, difficulty in communication, cultural expectations and practices were examples of cultural challenges that could have impact on both clients and caregivers in managing self-care and informal caregiving at home.

Overarching Theme #2: Managing Therapeutic Self-Care by Developing Knowledge, Competency and Self-Confidence

The second overarching theme addressed the second research question by exploring home care clients' perspectives on the types of support that facilitated safety in therapeutic self-care. To achieve this goal, I asked the clients to describe their experiences of how they managed their illness conditions at home. For example, the clients were asked to describe the types of activities they had to manage in relation to their disease conditions, and then provide their perspectives on the types of support needed to address these disease-specific self-care activities. The analyses of the interview data revealed the theme: Managing Therapeutic Self-Care by Developing Knowledge, Competency and Self-Confidence. In order to manage the different aspects of therapeutic self-care activities, clients discussed the importance of having (1) knowledge; (2) a sense of competency; and (3) self-confidence in maintaining their health safely at home. Each of these sub-themes is discussed below.

Sub-Theme#2: Needs of Home Care Client in Therapeutic Self-Care

Knowledge in Therapeutic Self-Care:

Home care clients indicated that having adequate knowledge in therapeutic self-care was important for managing the multiple aspects of safety challenges. Home care clients explained that “the more you understand your body and the more you know how to look after yourself, then the less likely you’ll make mistakes”. With regards to knowledge in therapeutic self-care, home care clients indicated the following three areas of concern: (1) Knowledge in medication management; (2) Knowledge of “how to read your body”; and (3) Prevention of further health problems. Evidence about the need for increased medication knowledge was exemplified in the

following quote by a home care client: “You asked me if I know what medications I’m taking... Unfortunately no... I wish I could tell you, but nobody really took the time to explain this to me...It would have been nice to know why I was taking this and that...so I would have a better idea of why it is important for me to take these. Then maybe I won’t get these medications all mixed-up”. This example demonstrated how an increased knowledge in medication management may help clients reduce possible medication errors and enhance their medication compliance.

In addition to medication knowledge, clients indicated their need for understanding how to recognize changes in their body that are related to their illnesses. For example, a client with recurrent urinary tract infections explained that “I think the most important thing is getting to know how to read my own body. What I mean is that I need to know some cues that tell me what is normal for me or not. With having multiple urinary tract infections, it’s important to get to know myself, and know what it feels like to be developing an infection... what are the cues I should watch out for, so I could do something about it”. This example demonstrates that knowledge about symptoms recognition may provide home care clients with “cues” to help them understand what actions must be taken to manage health symptoms.

Another important need identified by home care clients was the knowledge on how to prevent further health problems. A client with recurrent pressure ulcers explained that “I believe in prevention. The best thing to deal with pressure ulcers is to prevent it from happening in the first place”. A client with chronic obstructive pulmonary disease highlighted the need for focusing on prevention: “With COPD, my problem with breathing is so unpredictable...some days are good, some days are bad. To have more good days...I think I need to know more about what things I should be doing, and knowing what aggravate or help with my breathing, so I could

control my activities accordingly... When things go downhill, I need to know when to go see a doctor or go to emergency instead". These examples demonstrated that developing the knowledge about how to prevent health problems is important to home care clients in making the appropriate lifestyle adjustment and health monitoring. In particular, this knowledge was helpful to controlling client's bodily symptoms through adjustment in daily activities, as well as helping client decide when and how to access appropriate care to prevent further health declines.

Sub-Theme#2: Needs of Home Care Client in Therapeutic Self-Care

Competence in Therapeutic Self-Care:

Home care clients indicated the need to develop a sense of competence in managing therapeutic self-care. Evidence of this need was exemplified in the following quote by a home care client: "After I had a stroke, I felt so down at first because I felt like I was so incompetent in everything. I had trouble eating, talking, walking, taking a bath...It felt like I had to start learning everything again". Clients described three things that were important to developing a sense of competence in therapeutic self-care: (1) Developing care routines; (2) Active participation; and (3) Setting-goal. A home care client described the importance of developing care routines: "Having a regular routine is important because it helps organize my day. Looking after myself at home needs lots of planning like what's a good time to take a bath, when to prepare my meals, what time should I take my medications and do my exercises... If I don't have a schedule, then I feel lost and confused".

Home care clients identified the importance of actively participating in care activities in order to become competent in therapeutic self-care. A client with diabetes explained that: "I think the workers need to know that I won't learn to do this by myself unless I tried it. I wanted

to do my own needles, but they just did it for me every time. So one day, I told the worker and said... can I try doing the needle myself? And I did it... now I'm doing my own injection!"

Home care clients further described that goal-setting helped them develop a sense of competency. A client with arthritis described her experience with learning how to do housework by herself: "I remember taking small steps every day and setting up some targets as my goals...like today I tried doing some dishes, then tomorrow I tried making my own bed, and then after that I tried preparing my own breakfast...Trying, keep trying until I get it!" This example indicated how setting up small, achievable goals helped the home care clients in developing competence in therapeutic self-care activities.

Sub-Theme#2: Needs of Home Care Client in Therapeutic Self-Care

Self-Confidence in Therapeutic Self-Care:

Home care clients indicated the need to develop self-confidence in managing therapeutic self-care in addition to developing competence. Evidence of this need was exemplified in the following quote by a home care client: "What I need the most is to believe that I can do this. Sometimes I doubt myself too much like... Do I have enough energy to make my own meal or take a bath by myself? I need to have less doubt and more belief in my ability..." Specifically, home care clients described three things that were important to developing self-confidence: (1) Time; (2) Self-determination; and (3) Positive feedback. One important thing that clients described was the need to have time to develop their therapeutic self-care skills. For example, a client with ostomy care explained that: "Any type of learning takes time and it doesn't come overnight...like changing my own ostomy bag. The workers used to change it for me in a rush and they didn't have time to teach me. I guess it was faster and easier for them to do it for me

instead of teaching me how to do it. But how will I ever learn to do it myself if they kept doing this for me all the time? I need time to learn”.

Clients described that having self-determination helped build self-confidence in therapeutic self-care. A client with diabetes explained that: “Determination, pure determination! Knowing that making new adjustment takes a lot of effort...like trying to change my own diet habits after I was diagnosed with diabetes. It was tough, but I was very committed to making changes to my diet habits because I believe it was important to my health.” Further, home care clients explained that getting positive feedback from their caregivers helped build self-confidence in their management of care at home. The importance of receiving positive feedback was particularly important as clients were making behavioral changes specific to their illness conditions. The following quote was provided by a client who attempted to quit smoking after his diagnosis of chronic obstructive pulmonary diseases: “I had been smoking for over 40 years... when I was told I need to quit smoking, I said it was impossible! But the home care nurse was very supportive and always encouraging me to try quitting. Every time I made some progress, the nurse pointed out to me how I did gradually reduce the amount of cigarettes I took every day ... Her simple words of encouragement were just what I needed to hear... She made me believe I could do this, and I felt more confident in making these changes”. Therefore, having time; self-determination; and positive feedback were identified as important to building self-confidence in home care clients, which in turn helped support their management of therapeutic self-care at home.

Over-Arching Theme #3: Coping with Informal Caregiving through Problem-Solving, Stress Management and Caregiver Relief

The third theme addressed the third research question by exploring the informal caregivers' perspectives on the types of support that facilitated safety in informal caregiving at home. In order to cope with informal caregiving to support therapeutic self-care, caregivers discussed the importance of having: (1) Problem-Solving; (2) Stress Management; and (3) Caregiver Relief.

Sub-Theme#3: Needs of Informal Caregivers in Informal Caregiving

Problem-Solving in Informal Caregiving:

Informal caregivers described three areas of their responsibilities in supporting therapeutic self-care: delivery of care such as giving medications; monitoring of care such as monitoring risk for falls; and management of care including pain management. Problem-solving ability was considered to be important when caregivers provided the responsibilities of therapeutic self-care at home. Evidence of this need was exemplified in the following quote by an informal caregiver: "To help my husband at home, the most important thing I need to know is how to problem-solve. Unlike the hospital, there is always someone around you... Here at home, I'm just by myself with my husband. When there's a problem, no one is here to give us a hand. To look after my husband's colostomy bag, it would be useful if someone could inform me of the kinds of problems I may encounter. For example, how to prevent colostomy leakage and the tools I need to fix these problems, such as what to do when the colostomy bag leaks or what to do when there is too much gas in the bag". This example demonstrated how having the ability to problem-solve can help caregivers feel more confident in coping with the unexpected

events associated with informal caregiving at home. In particular, being informed of the anticipated barriers was an important problem-solving tool for caregivers. Informal caregivers reported the need for overcoming barriers when providing care, as well as the need for finding out solutions to problems safely and independently at home.

Sub-Theme#3: Needs of Informal Caregivers in Informal Caregiving

Stress Management in Informal Caregiving:

Informal caregivers described the need to develop stress management techniques to cope with the competing demands of their familial care responsibilities and employment commitment. Caregivers explained that one way of dealing with the stress associated with informal caregiving was time management. A caregiver with full-time employment described the importance of time management: “My biggest struggle is to find time for my mom, my full-time job, my own family and myself. There is only 24 hours in a day... I can only do so much in a day... so time management is the key”. For example, informal caregivers described the use of activity log as a way to prioritize their care responsibilities and to schedule care routines that would make the best use of their time.

Another stress management technique described by the caregivers was learning how to deal with difficult situations in informal caregiving. Examples of these difficult situations included medication non-compliance, resisting care routines, verbally abusive behaviors, and wandering. Caregivers indicated that these difficult behaviors could put a great deal of stress on their relationship with the care-recipient. For example, a caregiver described that “my father has mild dementia, and he can get very uncooperative when I give him a bath. He can get quite verbally abusive to me at times, and this created a lot of tension in our relationship”.

Specifically, referral to support group or counselling services was identified by the informal caregiver as a useful resource for stress management. A caregiver elaborated on the usefulness of counselling offered by the support groups: “The nurse referred me to the caregiver support group last year. I was grateful to be part of the group because every one of them could understand exactly how I felt and the stress I’ve been through... It was good to be able to share my feelings with other caregivers. I also got some counselling advices from a social worker to discuss how to safely deal with these conflict situations”. This example demonstrated how caregiver support group or counselling services can be important coping strategies that help informal caregivers to safely and effectively manage the stress associated with informal caregiving.

Sub-Theme#3: Needs of Informal Caregivers in Informal Caregiving

Caregiver Relief in Informal Caregiving:

Caregivers described the need for caregiver relief to manage their multi-tasking responsibilities in order to cope with the competing care demands of informal caregiving. Evidence of this need was exemplified in the following quote by a caregiver: “Being a caregiver, feeling burnout is a big challenge to my health because I’m constantly multi-tasking...doing two or three things at one time... like I would be cooking while giving out the medications to my mom and helping my daughter with her homework. What if I made medication errors because I was multi-tasking or I was too tired? I need help... I need someone to share the workload”. This example highlighted the demands of caregiving can affect the health and safety of both caregivers and care-recipients, such as burnout for the caregivers and medication errors for the care-recipients.

Specifically, informal caregivers indicated the need for respite care to relieve the burden of care: “Having some respite hours was the best thing that happened to me...even just a few hours in a week...I can be on my own, go out to do some shopping, and take a break”. In addition to receiving respite care, informal caregivers highlighted the importance of having caregiver recognition. A caregiver described the importance of being acknowledged for their hard work: “Sometimes people take for granted of what we do... I gave up my full-time job and became fully committed to taking care of my mom 24/7... it’s a lot of sacrifice but people don’t see it. Having a health care provider acknowledged the value of my work would mean a lot to me!” These examples highlighted the need for respite care and caregiver recognition to help informal caregivers cope with the burden of care at home.

Over-Arching Theme #4: Seeking Education, Support and Collaboration from Health Care Professionals

The last theme addressed the final research question by exploring the role of health care professionals in supporting clients and their caregivers in therapeutic self-care and informal caregiving. The analyses of the interview data revealed the theme: Seeking Education, Support and Collaboration from Health Care Professionals. To facilitate the management of therapeutic self-care and informal caregiving, both clients and informal caregivers discussed the importance of seeking (1) Education; (2) Support; and (3) Collaboration from health care professionals. Evidence of this need was exemplified in the following quote from a caregiver: “The purpose of home care is not to prove that we can’t cope at home... We need to feel that the workers are here to help us by educating, collaborating and supporting us, so we can cope at home!”

Sub-Theme#4: Role of Home Care Professionals: Educator

Clients and Informal Caregivers: Seeking Education from Home Care

Clients and informal caregivers indicated that seeking education from home care was identified as important in managing the safety challenges in therapeutic self-care and informal caregiving. Home care clients indicated that education on medication management and fall prevention were identified as the priority areas whereas informal caregivers identified the need for increased education in the areas of symptoms recognition and health monitoring. An informal caregiver highlighted the importance of education in the following quote: “I think that teaching from health care professionals can make me feel more proactive rather than reactive... like I don’t want to sit and wait for problems...I want to be fully informed and be prepared to deal with these issues. I want to know what to do when my father has another angina attack, so I’m fully prepared and not afraid”. This example described how increased education can empower caregivers in becoming more proactive in anticipating barriers to care, and finding solutions to overcoming the problems.

Home care clients discussed the need for education in knowing the what, how and why in their journey of developing therapeutic self-care skills. A client highlighted the importance of home care education: “I appreciated the workers who came and did all the work for me during every visit, but they need to realize that I can’t rely on their help all the time because they are not with me 24/7. I needed to have the skills where I could look after myself independently at home. I think the workers were sometimes too task-oriented... I mean they were too focused on finishing their tasks rather than spending time with their patients and teaching them how to do things on their own.” Another home care client further explained that: “when I’m learning something new, it would have been useful for the home care workers to teach me not just what to

do, but also how to do it and why it is important...like how to have a healthy heart diet? How far will I walk, for how long and when? Why is it important to take these medications and how will these affect my body such as side effects? Every little detail helps me get motivated to make changes”. This example described how home care education about the what, how and why can help support clients in making lifestyle changes, and thus facilitating increased compliance in therapeutic self-care.

Sub-Theme#4: Role of Health Care Professionals: Supporter

Clients and Informal Caregivers: Seeking Support from Home Care

Seeking support from home care was identified as important in managing the safety challenges in therapeutic self-care and informal caregiving. Evidence of this need was exemplified in the following quote from a client: “I see home care as an advocate in supporting client’s needs by providing appropriate and adequate services. Our needs should come first, and the focus shouldn’t be on cutting down our services.” At the same time, clients described the need for more timely access to home care services that would support their safety needs. For example, a client explained her frustration about the long waiting time for professional health services, such as in-home Physiotherapy: “After my knee replacement surgery, I waited for three weeks for the Physiotherapist to come and teach me leg exercises and walking techniques. Guess what? I fell in the second week after my surgery...This long waiting time is not ideal...it puts us at risk for more problems to occur”. These examples demonstrated the importance for home care to provide appropriate, adequate and timely services to the clients that would support their health care needs.

Clients believed that home care services should be geared towards supporting not only their physical needs, but also addressing their emotional well-being or other aspects of challenges at home. For example, a client discussed the importance of having social worker from home care to discuss financial support for supplies and equipment. Another example was a client with psychosocial needs related to the diagnosis of depression: “My PSW comes to my house for one hour every day to help me bathe... I truly appreciate her help... not only because she helps with my personal care and medications, but most importantly her companionship means a lot to me when I’m battling with depression!”

From the informal caregiver’s perspectives, the biggest support from home care was the respite services to help relieve their burden of care. A caregiver described that: “The adult day program was a good respite support to me...Not only my father could get some social time, but it also gave me time to take a break and attend to my own personal needs while knowing that my father was in good hands and being well looked after”. In addition to the respite care, caregivers believed that home care plays an important role in supporting them by identifying their needs for appropriate referral to the community resources. Some caregivers described their lack of knowledge in regards to what community services were available to them, and how to access these resources for support. For instance, a caregiver indicated the importance of community referral made by home care: “I was grateful for joining the caregiver support group at the Alzheimer’s Society. The home care nurse made the referral and she believed that I would benefit from participating in this community group as a good source of support network.” These examples demonstrated that home care personnel were viewed as important advocates in supporting therapeutic self-care and informal caregiving through the provision of services, interventions, respite support and referrals to resources in the community.

Sub-Theme#4: Role of Home Care Professionals: Collaborator

Clients and Informal Caregivers: Seeking Collaboration from Home Care

Seeking collaboration from home care was identified as important in facilitating safety in therapeutic self-care and informal caregiving. Evidence of this need was exemplified in the following quote from a client: “I think home care needs to realize that they need to work with me and my family... They need to listen to us and include us in the decision-making process because every single decision affects how we manage at home independently”. In particular, home care clients discussed the importance of establishing collaboration with home care through continuity of care. A client described that: “the biggest challenge for me is to deal with the inconsistent schedule of the home care workers. For example, I may be getting familiar with one PSW for one week, but then home care would send me another PSW the next week. There’s a lack of continuing care... How am I supposed to establish a good rapport with the workers when they just come and go like this?”

Further, client identified the major barrier to collaborating with home care was the lack of communication and follow-up. A home care client explained that: “To help me manage better at home, I think it is important for the workers to listen to my needs...taking the time to follow-up with my concerns. Unfortunately, some workers rushed through the home visit because of their busy schedule, so I didn’t get the chance to communicate my problems”. These examples demonstrated how continuity of care, good communication and follow-up were crucial to facilitating a collaborative relationship between clients and health care providers.

Similar to home care clients, caregivers discussed the need for seeking collaboration from health care providers to support their informal caregiving activities. Caregivers discussed the need for more flexibility in the scheduling of home visits from the health care professionals, such

as nursing, physiotherapist or occupational therapist. Caregivers indicated that these home visits were rarely scheduled in the evening, but rather the visits were mostly scheduled during the day time when they were at work. Consequently, caregivers felt that they were unaware of the kinds of interventions provided by the health professionals, and didn't know how to provide support to their loved ones for follow-up. A caregiver explained that: "it would have been nice if the physiotherapist could come visit my mom when I came back from work in the evening. The therapist always came during the day when I was gone to work...so I didn't know what she did with my mom. This made it difficult for me to follow-up with mom regarding her exercise plan".

Home care clients reported that instead of having one primary caregiver, they had multiple informal caregivers who shared the caregiving tasks and had significant input into the treatment decisions. Therefore, informal caregivers suggested that home care not only should focus on the needs of the primary caregiver, but should also support the needs of these multiple caregivers. In particular, informal caregivers indicated the need for home care to be more integrated and coordinated in a way that could include multiple caregivers and their loved ones in care planning decisions. Caregivers would like home care to reduce care fragmentation by supporting them through care coordination. This could be achieved by having a designated person to discuss the care of their loved ones, as well as assisting with navigating the health care services and accessing community resources. A caregiver explained that "my biggest challenge as a caregiver is to be responsible for coordinating the care of my husband. Navigating the health care system is not easy... so having home care as a point of access for advice, information and support is truly helpful". These examples demonstrated how home care can support

informal caregiving by collaborating with the multiple caregivers and playing a coordinating role to facilitate continuity of care.

4.2.5 Summary

The qualitative interviews provided insight into the perspectives of home care clients and their informal caregivers on home care safety as it related to therapeutic self-care and caregiving activities. The analysis of interview data began by exploring the general meaning of safety, self-care and informal caregiving. The findings revealed four over-arching themes: (1) Struggling through multiple aspects of safety challenges; (2) Managing therapeutic self-care by developing knowledge, competency and self-confidence; (3) Coping with informal caregiving through problem-solving, stress management and caregiver relief; and (4) Seeking education, support and collaboration from home care. First, there were multiple aspects of safety challenges in relation to self-care and informal caregiving: (1) physical; (2) emotional; (3) cognitive; (4) instrumental; (5) financial; (6) social; (7) environmental; (8) technological; and (9) cultural. Secondly, home care clients identified that having the knowledge, competence and self-confidence were important in carrying out therapeutic self-care, whereas informal caregivers described the need for having problem-solving ability, stress management techniques and caregiver relief to cope with informal caregiving. Finally, both clients and caregivers highlighted the importance of seeking education, support and collaboration from home care that would help facilitate safety in therapeutic self-care and informal caregiving.

Chapter Five

Discussion

The focus of the discussion chapter is to examine the significant impact of using mixed methods approach to address the purpose of the study and research questions. Results in this study were examined through complementarity where the data analysis of quantitative and qualitative data created a deeper understanding of the relationship between therapeutic self-care and adverse events experienced by home care clients, as well as the aspects of safety that support self-care and informal caregiving at home. This chapter begins by a theoretical discussion and comparison of findings with the literature. I will compare and contrast differences in the findings of each method, and discuss the impact of mixed methods to the overall completeness of the research study. The final part of the discussion elaborates on the strengths and limitations of the mixed methods study.

5.1 Theoretical Discussion:

The purpose of this study was to investigate the enablement perspective of therapeutic self-care in the context of home care safety. The enablement perspective was investigated by examining the association between home care client's therapeutic self-care ability and the occurrence of adverse events. There were five adverse events in home care that were found to be associated with therapeutic self-care ability: (1) New hospital visit; (2) ADL decline; (3) Unintended weight loss; (4) Client fall; and (5) Medication non-compliance. Specifically, home care clients with low measured therapeutic self-care level were found to experience increased

likelihood of having adverse events when compared with the individuals who possessed high therapeutic self-care ability.

The level of home care client's engagement in therapeutic self-care may be influenced by patient activation. Patient Activation is the process that clients go through in becoming fully competent self-managers of their own health (Hibbard, Mahoney, Stockhard & Tusler, 2005). This process involves (1) Believing active role is important; (2) Having confidence and knowledge to take action; (3) Taking action; and (4) Staying the course under stress. Hibbard et al. (2004) proposed that being an engaged and active participant in one's own care is associated with better health outcomes. Clients who are engaged in self-care possess high level of self-sufficiency in caring for themselves, and thus they are better able to manage their health care needs (Hibbard & Tusler, 2007). Therefore, home care clients with a high level of therapeutic self-care ability were less likely to experience adverse events due to their active engagement in disease management. For example, home care clients with high level of therapeutic self-care ability may have the necessary knowledge and skills to handle problems on their own at home, and access appropriate care to prevent unplanned hospitalizations. Individuals with a high level of therapeutic self-care ability may have the necessary knowledge to manage their health conditions and prevent further ADL decline.

This conceptualization of therapeutic self-care is consistent with Sidani and Doran (2011)'s definition where they defined therapeutic self-care as the clients' knowledge and ability to manage their health condition, manage symptoms, and follow the prescribed treatments. The domains of therapeutic self-care activities include the following areas: client's knowledge of the prescribed medications and treatment; ability to recognize signs and symptoms; skills to carry out treatments as prescribed, and knowledge of what to do in case of an emergency (Sidani,

2011). Based on this conceptualization, therapeutic self-care is viewed as the knowledge and skill that facilitate self-care practice in relation to the management of health deviation.

Therapeutic self-care ability enables the clients to make informed choices regarding their self-care tasks and behaviors. This conceptualization suggests that individuals with low measured therapeutic self-care may indicate a lack of engagement in self-care and readiness for disease management. For example, home care clients with low therapeutic self-care ability may lack the knowledge and skills needed to maintain their health functioning to prevent unintended weight loss and risk for falls. Similarly, individuals with low therapeutic self-care ability may lack the ability or knowledge to follow through on recommendations and comply with medication regimens. Therefore, the lack of self-sufficiency in therapeutic self-care may lead to the increased risk for adverse events among home care clients.

In summary, the study findings revealed that a low level of therapeutic self-care ability could be a risk factor associated with the occurrence of adverse events in home care. The reasons why clients with high levels of therapeutic self-care were less likely to experience adverse events could be related to their active engagement in disease management. Therapeutic self-care ability is the level of knowledge and skill that enables clients to make informed choices regarding the management of their disease conditions. As a result, high therapeutic self-care ability is viewed as an enabling factor that could protect the clients against safety problems in home care. It was important to study the enablement perspective of therapeutic self-care because of its potential role in risk mitigation, as well as its role in reducing the care burden of informal caregivers. The study findings underscore the importance of assessing client's readiness for therapeutic self-care, and supporting their level of self-sufficiency in caring for themselves and managing their self-care needs at home.

5.2. Comparison of Findings with Literature

The prevalence rate of adverse events for home care clients was identified during the study period from 2011 to 2012. The quantitative study found the five most prevalent adverse events were: ADL decline (51.7%); Client falls (35%); Caregiver distress (27%); Unintended weight loss (13.5%); and Medication non-compliance (11%). Previous research found similar findings in which client falls, medication-related events and caregiver distress were the most frequent types of adverse events in home care observed through chart review and secondary data analysis during 2008 and 2009 (Doran et al., 2013). Similarly, my qualitative findings revealed that home care clients struggled through the multiple aspects of safety challenges in relation to their therapeutic self-care ability. For example, client falls, ADL decline and medication non-compliance were found to be the safety challenges commonly reported by home care clients.

These findings are consistent with the results of another study in which individuals were found to be at greatest risk of adverse events as they became functionally more vulnerable or more dependent (Blais et al., 2013). For example, my mixed methods study results indicated that older home care clients were at greatest risk of having new falls as a result of having challenges in therapeutic self-care ability. Client falls were among the most common adverse events found in other home care safety research (Doran et al., 2009; Blais et al., 2013; Doran et al., 2013). Approximately one in three Canadians aged 65 and older will fall each year, which results in a total of 13 million seniors experiencing a fall (Scott, Wagar & Elliott, 2012). The Canadian Institute for Health Information (2009) noted that unintentional falls will account for 84% of all hospitalizations due to injury among the seniors. My study finding highlights the importance of targeting fall prevention strategies among those individuals with low therapeutic self-care ability.

Medication non-compliance among older home care clients was another common adverse events found through both the quantitative and qualitative methods. This finding is consistent with previous research in which more than half of the medication problems occurred in the individuals age 60 years or older (Stoppler, 2006). A recent review on home care safety that explored the nature of adverse events in home care, reported 44 adverse events in which medication management accounted for 59% (Harrison et al., 2013). Blais et al. (2013) reported that medication-related events can contribute to other types of adverse events, such as ER visits and hospitalizations. For example, a client who refused to take prescribed medication may develop a psychotic episode, leading to ER visits and hospitalizations. Therefore, improvement in medication management, particularly targeting older clients with low therapeutic self-care ability is a high priority issue for home care safety.

5.3. Comparison of Findings in Mixed Methods Study

Caregiver distress refers to the primary caregiver's inability to continue in caring activities. For example a decline in the health of the caregiver may result in the caregiver's inability to continue caregiving activities (Hirdes et al., 2004). The findings from the quantitative approach revealed a statistically non-significant relationship between therapeutic self-care ability and the occurrence of caregiver distress. However, the qualitative description revealed that caregiver distress was a commonly reported concern for caregivers who provided assistance to support client's therapeutic self-care activities.

The differences of findings between the qualitative and quantitative methods could be a function of the sampling differences in which the quantitative sample included home care clients who were over the age of 18 with higher therapeutic self-care ability. On the other hand, the

qualitative sample included home care clients aged 65 and older with lower therapeutic self-care ability compared to those in the quantitative sample. As a result, the differences in the age-related sampling inclusion could have an impact on the assessment of caregiver distress in relation to therapeutic self-care. Another reason for the differences of findings between the qualitative and quantitative methods could be the methodological differences in the way caregiver distress was assessed. In the quantitative method caregiver distress was determined through the RAI-HC assessment whereas in the qualitative method it was assessed through interview. Either method could result in under or over-reporting of caregiver distress.

The qualitative interview data highlighted the interconnection between client's level of therapeutic self-care ability and the occurrence of caregiver distress. The results indicated that the informal caregivers reported a high level of caregiver distress when they were looking after individuals with cognitive impairment and behavioral problems, such as resistive to care and disruptive behaviors. Furthermore, the interview data revealed that 40% of the informal caregivers rated their perceived physical health status as poor. Those caregivers who rated their health as poor were the individuals who looked after the clients with low therapeutic self-care scores (score \leq 3). These qualitative findings are consistent with the report from the Health Council of Canada (2012) in which it was noted that informal caregivers who experienced caregiver distress were at greater risk for injury or for aggravating pre-existing health issues. Specifically, the level of distress was higher for those caregivers who provided care to individuals with low therapeutic self-care ability and for those who were caring for clients with cognitive deficits or behavioral problems. The Canadian Institute of Health Information (2010) reported similar findings in which the level of distress was higher for informal caregivers who provided more than 21 hours per week of care and for those who were caring for clients with

mental illness, such as depression, as well as cognitive impairment including dementia and Alzheimer's Disease.

The qualitative descriptions did not reveal unintended weight loss as a safety concern in relation to therapeutic self-care ability among the home care clients. However, the quantitative analysis indicated that home care clients with low therapeutic self-care ability had increased odds of experiencing unintended weight loss. Previous research found that unintended weight loss (9%) was one of the most prevalent adverse events among the home care clients (Doran et al., 2009). In particular, Blais et al. (2013) found that individuals' risk of having an adverse event increased by 54% for those who were functionally vulnerable as indicated by each increase in level of the four-point IADL score. The ability to carry out IADL is an important functional aspect of therapeutic self-care, which includes the ability to prepare one's own meals. As home care clients become more dependent in IADL, they may experience more difficulty in meal preparation. Therefore, unintended weight loss could be a result of difficulty with meal preparation and poor management of nutritional intake among individuals with low therapeutic self-care ability. The quantitative finding underscores the importance of ensuring home care clients have IADL support in the areas of meal preparation and nutritional management in order to prevent unintended weight loss.

5.4. Contribution of Quantitative Methods

To my knowledge, this quantitative research is the first study that investigated the relationship between therapeutic self-care and adverse events in home care. In particular, my study was able to provide a detailed description about the differences in the characteristics of low self-care and high self-care home care clients. The low self-care clients were characterized as

older individuals having more complexity in clinical status such as having recent hospitalizations; multiple chronic diseases, polypharmacy; and health instability as indicated by higher CHESS scores. They also demonstrated poor functional status with impaired self-reliance and difficulties with ADL activities such as mobility, as well as difficulties with IADL activities such as medication management. Further, the low self-care individuals were found to be more cognitively impaired with depressive symptoms and behavioral symptoms including wandering, verbal abuse and resistive to care. This detailed description about the characteristics of clients with low therapeutic self-care ability is important to help identify the baseline characteristics of those individuals who are at risk for adverse events at home.

There have been other studies that examined adverse events in the context of home care safety (Doran et al., 2009; Blais et al, 2013; Doran et al., 2013). However, my quantitative research provides an added dimension to the examination of whether therapeutic self-care ability predicts the types and frequency of adverse events experienced by home care clients. It also points to some solutions. The findings underscore the importance of supporting the development of therapeutic self-care ability in the prevention of adverse events in home care. The study findings revealed that high therapeutic self-care ability could be a protective factor against safety problems, while low self-care ability could be a risk factor in the occurrence of adverse events. These findings are consistent with the literature on patient activation. Previous research indicated that being an engaged and active participant in one's own care was related to better health outcomes (Hibbard, Stockard Mahoney & Tusler, 2004). For instance, those with a higher level of patient activation reported significantly better health as measured by SF 8 ($r=0.38$, $p<.001$), were more likely to comply with drug regimen and had significantly lower rates of hospitalizations ($r= -0.07$, $p<0.01$).

Another important contribution of the quantitative study is the focus on examining the relationship between therapeutic self-care ability and the utilization of health care resources. With regards to the use of health care resources, the study findings revealed that the prevalence rate for ER visits was 56.9% and the prevalence rate for hospital visits was 48.8%. These rates are consistent with the findings of recent home care studies in which researchers determined that unplanned visits to ER (60.5%) and unplanned admission to hospital (38.3%) were among the most frequent adverse events for home care clients (Blais et al., 2013; Doran et al., 2013). My study found that home care clients with high therapeutic self-care ability had lower odds of experiencing new hospital visit than clients with low therapeutic self-care ability. Specifically, the results indicated that there was interaction between polypharmacy and therapeutic self-care ability in the occurrence of unplanned hospital visits. In particular, high polypharmacy was associated with the increased odds of experiencing new hospital visit among the individuals with low therapeutic self-care ability.

In the literature on Patient Activation, it was noted that individuals who were less engaged in self-care were found to be less compliant with drug regimens (Hibbard & Tusler, 2007). For instance, lack of knowledge regarding one's medication was found to be a contributing factor for the occurrence of medication non-compliance (Kahn & Angus, 2011). A possible explanation for the present study findings is that home care clients with higher level of therapeutic self-care ability were more likely to become activated to engage in self-care practices. With a higher level of therapeutic self-care ability, clients may have the knowledge and skills needed to comply with medication regimens, and therefore may be more able to manage their polypharmacy. On the other hand, clients with a low therapeutic self-care level may lack the ability or knowledge to manage multiple medications, or access appropriate care to

prevent health declines. These study findings suggest there is a conditional relationship between therapeutic self-care ability, polypharmacy and unplanned hospitalizations.

5.5. Contribution of Qualitative Methods

The qualitative method has advanced the understanding of therapeutic self-care in home care. Therapeutic self-care is defined as the client's knowledge and ability to manage their health condition, such as knowledge of the prescribed medications and treatment; ability to recognize signs and symptoms; skills to carry out treatments as prescribed; and knowledge of what to do in case of an emergency (Sidani, 2011). When clients were asked to describe the types of activities in relation to therapeutic self-care, they described the disease-specific self-care activities that are consistent with the definition of therapeutic self-care. For example, home care clients described their experiences with medication management, and the need for increased medication knowledge in order to reduce medication errors and enhance medication compliance. Home care clients also indicated the need for symptoms management that was related to their illness, such as managing the signs and symptoms of urinary tract infections. ADL and IADL adjustments were evident in home care clients who described carrying out treatments and making lifestyle changes as a result of their disease management. One such example was clients with chronic obstructive pulmonary diseases (COPD) who needed to make adjustment in their daily activities as a result of their use of oxygen therapy. Further, clients explained the importance of health monitoring in determining when and how to access appropriate care to prevent further health declines, such as monitoring the worsening of pressure ulcers.

The qualitative data revealed that clients and informal caregivers struggled through the multiple aspects of safety challenges in relation to self-care and informal caregiving. There were

safety challenges in the following nine aspects: (1) physical; (2) emotional; (3) cognitive; (4) instrumental; (5) financial; (6) social; (7) environmental; (8) technological; (9) cultural. While other studies provided general definitions for the different types of safety issues in home care (Lang et al, 2013; Craven et al, 2008), my study has revealed the multiple aspects of safety challenges that are rooted in self-care and informal caregiving experiences. Specifically, the interviews focused on exploring the safety challenges experienced by home care clients in relation to therapeutic self-care. I expanded an understanding of the domains of therapeutic self-care activities in which the clients engage, such as medication management, symptoms management, ADL and IADL adjustment, and health maintenance.

My interview data was able to reveal the substantive differences between the home care clients and their informal caregivers in regards to their struggles with safety challenges. For example, home care clients struggled with maintaining their independence in self-care as a result of physical frailty, while their informal caregivers struggled with the balance between promoting clients' independence and maintaining their safety at the same time. Informal caregivers expressed the need to provide safe and supportive care related to giving medications, monitoring signs and symptoms, and managing meal preparation and the finances. At the same time, the informal caregivers struggled with "finding a balance" between providing self-care to their loved ones and providing self-care to themselves. My study data pointed out the different vulnerabilities and needs that exist in therapeutic self-care and informal caregiving at home.

I explored the nature of the relationship between client's therapeutic self-care ability and informal care-giving at home in the context of the client and caregiver dyad. My study data revealed that there was inter-dependent relationship between the home care client and informal caregiver in supporting therapeutic self-care at home. Previous qualitative studies related to

home care safety have highlighted the inter-relationship between home care professionals' experiences of safety and those of their clients (Craven, Byrne, Sims-Gould & Martin-Matthews, 2010; Stevenson, McRae & Mughal, 2008). My study provided an added dimension to the examination of safety concerns by highlighting the inter-dependent relationship between the clients and informal caregiver dyads. For example, clients with decline in activities of daily living were at risk for falls, which in turn put informal caregiver at risk for back injuries due to client falls. Similarly, informal caregivers experienced increased fatigue as a result of clients' increasing frailty, which in turn put clients at increased health risks, such as medication errors. Lang et al. (2013) describe this situation as "the shared decay of health at home" in which the caregiver's own health began to deteriorate as a result of their loved one's declining health status and increasing reliance on them. My study provided further insight into this inter-dependent relationship by exploring how safety concerns of both clients and informal caregivers are deeply rooted in therapeutic self-care at home.

5.6. Impact of Mixed Methods Study

My research study used a complementary mixed methods design, where different but complementary data were collected on the same topic. The reason for collecting complementary data was to bring together the strengths of both forms of research with the aim of more fully explaining the results of analyses. First, the mixed methods approach achieved complementarity by using results from one method to clarify the understanding of results from another method. For instance, my quantitative analysis found that home care clients with low therapeutic self-care ability had higher odds of experiencing adverse events, including unplanned hospitalizations, ADL decline, unintended weight loss, falls and medication non-compliance than clients with high therapeutic self-care ability. The understanding of these quantitative findings was clarified

by the results of the qualitative analysis. The essential element added by the qualitative descriptions was my ability to explain the relationship between therapeutic self-care and adverse events. The analyses of the qualitative data revealed that home care clients managed therapeutic self-care by developing knowledge, competence and self-confidence. Home care clients indicated the importance of knowledge, sense of competence and self-confidence to help them comply with treatment regimens and maintain health functioning. On the other hand, clients reported that low therapeutic self-care ability was related to the inability to know how to manage their condition, access appropriate care and prevent health decline. As a result, clients with low measured therapeutic self-care were more likely to experience adverse events in home care, such as higher rates of acute care utilization and adverse events including falls and medication non-compliance.

This mixed methods study has illuminated different aspects of safety challenges and concerns related to therapeutic self-care in the home care context. The quantitative analysis provided a detailed description about the prevalence rates for different types of adverse events in home care, with a particular focus on the physical aspects of therapeutic self-care practices. On the other hand, qualitative descriptions provided an enhanced understanding of the multiple dimensions of therapeutic self-care that represented client's vulnerabilities and needs. These areas included physical, emotional, cognitive, instrumental, financial, social, environmental, technological and cultural. Specifically, qualitative analysis demonstrated the interconnecting patterns between the multiple dimensions of safety concerns. For example, clients reported that challenges in their cognitive ability may lead to problems in other areas of therapeutic self-care, such as medication management, financial management and social engagement. My study

findings point to the need for an increased understanding about the multi-faceted aspects of therapeutic self-care at home.

This mixed methods study achieved the goal of complementarity to reveal an enriched, elaborated understanding of therapeutic self-care and informal caregiving in the context of home care. For example, the quantitative results advanced the knowledge of the risk factors that were associated with the increased likelihood of adverse events, such as polypharmacy and its conditional relationship with therapeutic self-care and hospitalizations. On the other hand, the qualitative analysis demonstrated an enriched understanding of the reciprocal nature of therapeutic self-care and informal caregiving. For example, the interview data revealed the complexity of informal caregiving where mutual caregivers occurred when both clients and caregivers were taking turns to function as a caregiver for the other. This process of mutual caregiving involved a form of reciprocal care in which the care dyads compensated for one another's deficits in therapeutic self-care. The results of my study point to the complex dynamics of mutual caregiving in which client's self-care experiences are intertwined with informal caregiving. In particular, my study highlights the relational aspects of therapeutic self-care in the context of home care.

Finally, the results obtained through mixed methods were more comprehensive than what would have been achieved through quantitative or qualitative assessment alone. My quantitative analysis was able to reveal that safety in home care was dependent upon client's therapeutic self-care ability, while the qualitative descriptions helped to create a deeper understanding of the contribution of informal caregivers and home care professionals that support therapeutic self-care. The qualitative data underscored the importance of knowledge, sense of competence and self-confidence in empowering the development of therapeutic self-care ability. Specifically,

developing care routines, setting goals and receiving positive feedback were examples of the factors that enabled clients to better manage their therapeutic self-care activities. The interview data also provided insight into how informal caregivers coped with supporting client's therapeutic self-care practices. For example, possessing problem-solving ability, developing stress management strategies and receiving adequate caregiver relief were the factors that increased their self-efficacy in informal caregiving.

Furthermore, my qualitative data revealed that both clients and informal caregivers seek education, support and collaboration from the health care professionals. Clients and caregivers indicated the need for education about the development of therapeutic self-care ability; increased respite and funding support; as well as the need to establish continuity of care. This mixed methods study revealed that safety in therapeutic self-care at home not only dependent upon the clients, but also the contribution of informal caregivers and home care professionals. The results obtained through complementarity not only revealed the nature of the relationship between therapeutic self-care and adverse events, but also offered a comprehensive picture of the underlying factors that influenced therapeutic self-care and informal caregiving at home. Clients identified the need for health care professionals to move away from “doing everything for them” to “enabling them to reclaim self-care and independence”. This can be achieved by having home care professionals to play the roles as the educator, supporter and collaborator. In summary, the purpose of the mixed methods study was to investigate the enablement perspective of therapeutic self-care in the context of home care safety. The enablement perspective of therapeutic self-care is viewed as the knowledge and skill of self-care that could influence the processes (i.e. decision-making processes) and outcomes of disease management.

5.7. Strengths and Limitations of Mixed Methods Study

5.7.1. Quantitative Study

To my knowledge, my quantitative research is the first study that investigated the relationship between therapeutic self-care and adverse events in home care, and thus it makes an important contribution to the field. My research advances the understanding of the relationship between therapeutic self-care ability and the types and frequency of adverse events experienced by home care clients. The findings highlight the importance of therapeutic self-care ability in influencing the occurrence of safety outcomes in the management of disease conditions at home. An added strength is the complementary use of multiple methods incorporating the qualitative and quantitative approaches while using multiple data sources that are well-established, such as HOBIC-HC for Therapeutic Self-Care Scale; RAI-HC instrument; NACRS and DAD. My research is the first study that utilizes HOBIC-HC database to address the research on home care safety with a focus on therapeutic self-care ability.

Internal and external validity were addressed through a number of strategies. For example, the data in this study were obtained from well-established secondary databases housed at the Institute of Clinical and Evaluative Sciences (ICES). Threats to internal validity were minimized by using risk adjustment strategies to control for individual differences in the risk factors associated with adverse events. To further ensure the internal validity of the study results, the statistical techniques developed by Xu and Kubilius (2010) were used to build each of the logistic regression models. This process involved the use of rigorous statistical techniques by preparing study variables; screening client risk factors; model building and assessing model fit. Polit (2010) recommended that examining interactions is an important step towards

investigating confounding variables. Therefore, interaction terms were added to control for confounding and collinearity that existed during the modelling process. The above strategies contributed to enhancing the validity of the statistical conclusions in this study.

The quantitative part of this study has a number of limitations. First, the study cohort of 1470 individuals is considered a small sample in secondary data research. The sample was small because there were a limited number of home care organizations submitting HOBIC-HC data to ICES at the time of the research. The sample size was further limited by including only long-stay clients who qualified for a RAI-HC assessment. Therefore, the study findings are only generalizable to the long-stay clients. Future research, involving more home care agencies across different geographical areas could further validate the evidence generated from the present study.

Another limitation was the different age-related sample inclusions between the quantitative and qualitative approaches. The quantitative approach included home care clients who were younger than 65 years of age, and they were found to have higher therapeutic self-care ability when compared to the qualitative sample that comprised of older home care clients with lower therapeutic self-care ability. These differences hold implications for the study results, such as the differences in the quantitative and qualitative findings regarding the relationship between therapeutic self-care and the occurrence of caregiver distress. Despite this limitation, the different age-related sampling inclusion was necessary to achieve the study purpose and address the research questions. Specifically, the quantitative approach addressed the broader question about the nature of relationship between therapeutic self-care and adverse events, whereas the qualitative approach provided greater depth into the contextual details of home care safety among the older adults who were at greater risk of experiencing challenges in therapeutic self-care.

Another limitation of the quantitative method was the amount of missing data in the HOBIC-HC database. Multiple imputation was conducted because this approach is currently considered the most acceptable method for addressing missing data (Tabachnick & Fidell, 2007). Sensitivity analyses were conducted to test the adequacy of multiple imputation approach. The results of the sensitivity analyses revealed that multiple imputation procedure resulted in unbiased estimates of important statistical parameters, such as magnitude and direction of the relationship of study variables. Another limitation of the quantitative component is the under-reporting or over-reporting of the actual experience. For example, the frequency distribution of the HOBIC-HC therapeutic self-care scores was skewed with a high number of scores 5 among the study cohort. This situation may be due to the possibility that home care clients, informal or formal caregivers have over-reported or over-estimated the self-care ability of the individuals. Client's perceived ability to perform self-care behaviors is a subjective phenomenon (Sidani, 2011). Therefore, a response bias such as social desirability bias is a potential limitation when self-care is measured through the survey methods (Horsburgh, 1999). This situation was addressed in the analysis by dichotomizing the HOBIC therapeutic self-care scores into low self-care group (score 0 to 4) and high self-care group (score 5).

Similar to other home care safety studies, there is no reliable way to determine with certainty whether the adverse events observed were due to the care delivered in the home or due to client's underlying diseases (Blais et al., 2013). This limitation was addressed through the use of risk adjustment strategies to control for individual differences in the risk factors such as client characteristics or clinical status. Finally, there is the possibility that some adverse events were missed by the RAI-HC assessment because the periodical assessments are completed on average every 6 months. It is possible that not all adverse events could be detected at the time of follow-

up RAI-HC assessment, and therefore my study results likely underreported the occurrence of adverse events. Doran et al. (2013) highlighted some examples of adverse events in home care that are likely to be under-reported in RAI-HC assessment, including non-recognition or non-reporting of medication-related problems; fall injuries that do not leave visible marks; or pressure ulcers and urinary tract infections that require clinical examination.

5.7.2. Qualitative Study

Qualitative description was the appropriate choice because a comprehensive summary of straight descriptions of the phenomena of interest was the goal of this study. The benefit of conducting qualitative descriptive analysis was to allow me to stay close to the data and to the surface of words and events using an interpretive lens. My qualitative descriptions advanced the understanding of therapeutic self-care in the context of home care. For example, the qualitative data revealed the multi-dimensionality of safety challenges in relation to therapeutic self-care and informal caregiving at home. There have been other studies that provided general definitions for the different types of safety issues in home care (Lang et al, 2013; Craven et al, 2008). My study provided an added dimension to the existing home care safety literature by revealing the multiple aspects of safety challenges for both clients and informal caregivers that are deeply rooted in therapeutic self-care at home.

There were a number of methodological strengths for this qualitative descriptive study. For example, I sought both descriptive validity and interpretive validity throughout the stages of the qualitative descriptive study, including sampling, data collection and data analysis. Specifically, I made efforts to enhance the descriptive validity by using maximum variation

sampling approach, and using peer debriefing techniques during data collection and analysis. I also ensured interpretive validity during the data analysis by moving back and forth throughout the six phases of thematic analysis as described by Braun and Clarke (2013). This process of data analysis is designed to provide a rigorous and standardized approach to thematic analysis. This process of thematic analysis helped contribute to interpretive validity as the researcher became reflexive and interactive by moving throughout the phases of data collection and data analysis, whereby both mutually shape each other to tell the story of the data. Also, I was faithful to the interview data by using data extracts to exemplify themes and sub-themes to illustrate interpretive validity of the data analysis. Finally, auditability was an example of a process to ensure trustworthiness of a qualitative study. Memos, field notes, and descriptive summaries were used to add to the validity of the study findings by describing the methodological decisions and the analytic insights made by me during qualitative data analysis.

This qualitative component of this study has a number of limitations. First, my qualitative study focused on the home care clients and informal caregiver dyads, and did not include home care professionals. Despite this limitation, this study has generated findings that have implications about home care professionals' roles in supporting the development of client's therapeutic self-care ability. Another limitation of my study was the focus on primary caregivers. The interview data revealed that the nature of informal caregiving often involved multiple caregivers who shared care and responsibilities in looking after their loved ones at home. Future research should include the perspectives about the dynamics of multiple caregivers who shared overlapping informal caregiving roles to support therapeutic self-care activities. Furthermore, my study sample did not include home care clients who were palliative care, and those who had severe dementia or Alzheimer's disease. The reason for not including these types

of clients was due to the difficulty in interviewing because of their health frailty and cognitive impairment. However, these special populations may have different types of needs with regards to therapeutic self-care, and therefore future research should investigate the perspectives of these special populations. As my study data were based on the recollections of participant's experiences, there may be recall limitations. Also, my qualitative data relied solely on the participant's verbal descriptions of their experiences. Future research may utilize observational or visual data to assess the complexity of therapeutic self-care within the context of home care.

5.7.3. Summary

The use of mixed methods can produce complementary results and increase the validity of the research study (Yauch & Steudel, 2003). A mixed methods approach was used to address the research objectives, and had a significant benefit by revealing the different aspects of safety in relation to therapeutic self-care and informal caregiving. In particular, the quantitative analyses provided evidence about the relationship between therapeutic self-care and the occurrence of adverse events. The qualitative analyses provided a rich and contextual understanding of the lived experiences of older home care clients and their informal caregivers.

First, my study data revealed that a low level of therapeutic self-care ability could be a risk factor associated with the occurrence of adverse events in home care. On the other hand, high therapeutic self-care ability is viewed as an enabling factor that could protect clients against safety problems in home care. Second, my study findings provided insight into the inter-dependent relationship of both clients and informal caregivers in which their safety concerns are deeply rooted in therapeutic self-care at home. Third, my work highlights the holistic view of the multi-faceted aspects of safety challenges in therapeutic self-care at home. Finally, the

results of my study point to the complex dynamics of mutual caregiving in which client's self-care experiences are intertwined with informal caregiving. My research reveals the relational aspects of therapeutic self-care in the context of home care. In summary, therapeutic self-care not only entails the individual capacity to manage their disease conditions, but it is also dependent on the availability of the resources and support provided by the informal caregivers and health care providers. This mixed methods approach helped me explain and compare results across different sources of data. This enhanced understanding would have been impossible to achieve if only one study method had been used.

Chapter Six

Study Implications and Conclusion

6.1. Study Implications

6.1.1. Implications for health care professionals

One of the recommendations from Masotti et al. (2009) about adverse events in community care was the need for an understanding of the factors associated with the occurrence of adverse events. My study advanced this understanding by examining the relationship between therapeutic self-care ability and adverse events among home care clients. The results of the quantitative approach revealed that home care client's therapeutic self-care ability was one of the factors associated with the occurrence of adverse events. Home care clients with low therapeutic self-care ability were found to have higher likelihood of experiencing adverse events when compared with high self-care individuals. One important implication is that low therapeutic self-care ability was found to be a risk factor, while high self-care ability was a protective factor against the occurrence of adverse events. Therefore, it is important for health care professionals to use assessment tools to identify those vulnerable individuals who are at greater risk of experiencing an adverse event due to their low therapeutic self-care ability. In particular, not all home care clients are physically or mentally capable of engaging in self-care. Increased support for informal caregivers may be needed in these situations.

The quantitative approach revealed the types of adverse events associated with low therapeutic self-care individuals, including ADL decline, unintended weight loss, client falls, and medication non-compliance. These findings underscore the need for health care professionals to

provide interventions targeted at preventing these adverse events. Health care professionals may provide clients with increased education to promote therapeutic self-care ability related to the following areas: (1) client's knowledge of prescribed medications and treatment; (2) ability to recognize signs and symptoms; (3) skills to carry out treatment as prescribed; and (4) knowledge of what to do in case of emergency (Sidani, 2008). Clients reported that health care professionals are often "overly task-oriented" and "doing everything for them". Therefore, they reported not having enough time to learn self-care skills, and thus feeling overwhelmed when they were left alone with the self-care tasks. Home care clients reported the need for health care professionals to empower them to reclaim their self-care ability, so that they are better able to manage their disease conditions independently at home. This notion of empowerment is needed for building client's capacity in therapeutic self-care.

This study revealed that home care clients with low therapeutic self-care ability had increased use of health care resources, including unplanned hospitalizations. If the needs of home care clients are not adequately addressed, clients are at risk for acute care hospitalizations at increased cost (Bryan, 2010). The Canadian Institute of Health Information (2012) reported that the first 30 to 60 days post-hospital discharge is a high risk period for home care client's admissions to hospital. Therefore, health care professionals should assess client's level of therapeutic self-care ability, and provide preventive home visits to reduce the risk of unnecessary hospitalizations during the transition of care from hospital to home care. For example, the Rapid Response Nurse provides preventive home visits offered by the Community Care Access Centre with the goal of providing support to vulnerable clients, and monitoring their risks for further health decline during post-acute period (OACCAC, 2014). Rapid Response Nurses help clients understand their illness and symptoms, their hospital discharge plan, and how to take prescribed

medications. A systematic review of home-based nursing health promotion found that preventive home visits worked best at early intervention in the continuum of health to disability (Markle-Reid et al., 2006). The results of my study point to the need for instituting early interventions, such as preventive home visits to reduce the risk of unnecessary hospitalizations among home care clients.

The findings from the qualitative approach revealed the importance of knowledge, sense of competence and self-confidence in developing client's therapeutic self-care ability. In particular, the interview data highlighted that knowledge of medication management, symptoms recognition and health maintenance is an important factor that affects client's ability to successfully engage in therapeutic self-care. My study points to the need for health care professionals to provide strategies to improve client's engagement in therapeutic self-care, such as establishing care routines, encouraging active participation, setting appropriate goals, and providing positive feedback. For example, health coaching can be an intervention that helps home care client to gain knowledge, skills and confidence to become an active participant in therapeutic self-care. Bennett, Coleman, Parry, Bodenheimer and Chen (2010) explained that health coaching involves health care professionals who provide teaching in disease-specific skills; imparting problem-solving skills; connecting the clients with resources; and promoting continuity of care. Research has shown that home care clients receiving post-discharge health coaching were significantly less likely to be re-hospitalized than clients in the control group (Coleman, Parry, Chalmers, & Min, 2006). My study underscores the importance of instituting intervention, such as health coaching, to support home care client's development of therapeutic self-care ability.

This mixed method study revealed that caregiver distress was a commonly reported concern for informal caregivers who provided assistance to support client's therapeutic self-care activities. In particular, informal caregivers reported high levels of caregiver distress when they were looking after individuals with cognitive impairment and behavioral problems, such as resistive to care and disruptive behaviors. There is a need to develop proactive strategies and meaningful interventions that support informal caregivers in their caregiving roles (Giosa, Stolee, Dupuis, Mock & Santi, 2014). Home care professionals need to teach informal caregivers the knowledge and skills for managing clients' behaviors, as well as providing the strategies for managing their own psychological distress.

The Next Step in Care (United Hospital Fund, 2006) is an example of an online intervention developed to assist family caregivers in recognizing their needs in providing effective informal caregiving. Enhanced Caregiver Training is another example of an educational intervention targeted at promoting informal caregiver's self-efficacy for caregiving, preparedness in caregiving, and psychological well-being (Hendrix & Tulsy, 2014). Informal caregivers who received Enhanced Caregiver Training had an increase in self-efficacy, certainty to cope with own stress, and preparation for caregiving at the post-training assessment (Hendrix & Tulsy, 2014). In their foundational report, Edwards and Lang (2006) recognized that the safety of the patient, caregiver and provider is inextricably linked. If the needs of the informal caregivers are not adequately addressed, home care clients may be at greater risk for adverse events. Therefore, informal caregivers need to be assessed for safety concerns along with the home care clients. Home care professionals not only need to provide educational intervention to promote client's therapeutic self-care ability, they also need to provide educational training to improve the self-efficacy of informal caregiver.

6.1.2. Implications for Health Care Leaders and Health Policy

Understanding home care client's risk profile is foundational to effective patient care management (Doran et al., 2009). My study was able to reveal the characteristics and risk factors associated with low therapeutic self-care individuals. My study also expanded the breadth of home care safety research by providing evidence regarding the types of adverse events that were associated with therapeutic self-care ability. For example, there was interaction between polypharmacy and therapeutic self-care in the occurrence of unplanned hospitalizations. Polypharmacy increased the incidence of potential drug-drug interaction which was found to be associated with medication-related hospitalizations in previous research (Delafuente, 2003; Hanlon et al., 1997). In particular, drug interactions may cause a decline in functional ability in home care clients which compounded the risk of adverse events such as fall-related hospitalizations (Blais et al., 2013). The Canadian Institute for Health Information (2011) found that those individuals with chronic conditions taking five or more prescription medications (13%) were more likely to experience a side effect requiring health care than the individuals taking only one or two prescription medications (6%). Therefore, policies need to be developed to support best practices related to the management of polypharmacy at a health system level. For example, home care organizations need to develop guidelines and protocols for home care professionals in regards to medication reconciliation and frequency of medication review associated with polypharmacy. Reducing complex medication regimens to those necessary and aligned with client health goals should be central to medication management (Mery, Wodchis, Bierman & Laberge, 2013).

Furthermore, my study points out that the adverse events associated with therapeutic self-care ability could be potentially preventable, such as the occurrence of further ADL decline,

client falls, unintended weight loss and medication non-compliance. An understanding of the adverse events associated with therapeutic self-care ability should enable health leaders to make informed decisions about service priorities in home care. For example, the occurrence of unintended weight loss and medication non-compliance points to the need for service priorities to support client's IADL ability, including nutritional and medication management. Health care leaders need to allocate appropriate resources to support client's development of therapeutic self-care ability, as well as implementing appropriate measures in place that monitor client's risks for adverse events at home. For example, home care organizations may adopt the use of HOBIC-HC therapeutic self-care scale as a tool to assess client's self-care ability and their risks for further ADL decline. Organizational policies need to be in place regarding modifications to home care environment to target the prevention of falls, as well as the implementation of Registered Nurses' Association of Ontario best practice guidelines into clinical practice to assess risk for falls and fall prevention strategies (RNAO, 2011). Markle-Reid et al. (2010) found that a six-month multi-factorial and interdisciplinary team approach to fall prevention in home care favorably reduced the incidence of falls which could have the potential for considerable cost-savings for the health care system.

Edwards and Lang (2006) point to the need for expanding the definition of patient safety to include the four dimensions of safety (physical, emotional, social, and functional). This mixed methods study demonstrates the additional aspects of safety challenges in relation to therapeutic self-care and informal caregiving. These holistic aspects include physical, emotional, cognitive, instrumental, financial, social, environmental, technological and cultural. These findings highlight the need for health care leaders to understand the multi-faceted aspects of vulnerabilities and needs of home care clients and their informal caregivers. In addition to the

physical needs, clients indicated the need for increased emotional support, funding support for equipment, technical support for the use of technologies, and transportation support for traveling needs. Greater proportions of home care resources must be directed to support those home care clients who are experiencing multiple safety challenges, especially older adults who are at greater risk of losing independence in therapeutic self-care. Without the adequate home care support, clients and family caregivers' health status could deteriorate as a result of failure to manage at home, leading to a troubling trajectory back to the acute care settings (The Change Foundation, 2011).

This mixed methods study revealed that we need to do more to support the informal caregivers because they were the reasons why many home care clients were able to manage their care at home. The areas in which informal caregivers reported needing support were caregiver literacy, access to community resources, financial assistance and adequate caregiver relief. These areas of support could allow caregivers to be well-equipped and prepared for informal caregiving activities at home. The study findings underscore the importance of having a caregiver support policy that addresses the needs of informal caregivers in home care funding approaches. Lang et al. (2011) suggest that opportunities need to be embedded in service authorization and funding for caregivers to be the recipients of services and to be able to access respite care to promote caregiver health and well-being. Some Canadian home care programs are piloting a tool to assess the needs of caregivers called CARE (Caregiver's Aspirations Realities and Expectations) (Health Council of Canada, 2012). This tool is used to assess caregiver's needs, increase awareness of caregiver's role, and validate their challenges and concerns. My study points to the need to address caregiver burden through a systematic

approach by using validated assessment tools to pinpoint areas of needs, and offering both publicly-funded respite services and referrals to community support services to meet those needs.

This mixed methods study revealed that home care clients and informal caregivers reported their greatest needs were in relation to education, support and collaboration with health care professionals. Clients indicated that health care professional's role in supporting therapeutic self-care involved more than telling patients what to do. It involved acknowledging the client's central role in their care, delivering educational information, providing emotional support, promoting access to services and establishing continuity of care. This study underscores the importance for a model of practice that moves away from a directive approach to a collaborative approach. In a collaborative approach clients and home care professionals work together to identify problems, establish goals and develop care plans to support therapeutic self-care needs. Interdisciplinary collaboration can decrease fragmentation in services, and has been shown to improve the quality and safety of client care (Bender et al., 2013; Lainscak et al., 2013). Similarly, informal caregivers identified opportunities for improvement, such as consistency in scheduling of services, continuity of care providers, shorter wait time for services, and integrated care co-ordination, to better support their caregiving needs. Lang et al. (2013) proposed the need for a "home first" policy that includes service delivery to ensure seamless care, effective communication, and coordinated care for the clients and caregivers. My study points to the need for a model of practice that supports the collaboration of clients, informal caregivers and service providers to better support therapeutic self-care and informal caregiving at home.

6.2. Future Research

To my knowledge, my research is the first study that utilizes HOBIC-HC database to address the research on home care safety with a focus on therapeutic self-care ability. However, the sample size was small due to a limited number of home care organizations who submitted HOBIC-HC data to ICES at the time of the research study. Future research, involving more home care agencies across different geographical areas, could validate the evidence generated from this study. Researchers should make use of HOBIC-HC data to answer important questions about the safety and quality of home care services. The evidence could provide important feedback to health care providers and health care leaders to improve health outcomes, and support quality improvement in health care delivery (Wodchis et al., 2013). My study provided a beginning understanding of the conceptualization of therapeutic self-care in home care settings. Future work may further investigate the concept of therapeutic self-care in different contexts, such as other health care settings including acute care, rehabilitation or long-term care settings.

My study revealed that high therapeutic self-care ability was one important protective factor that could prevent the occurrence of adverse events. In particular, older home care clients with multiple chronic conditions reported an increased number of safety challenges in relation to their low therapeutic self-care abilities. The Canadian Institute for Health Information (2011) indicated that seniors with high comorbidities reported poorer health, took more prescriptions and had the highest rate of health care visits among seniors with chronic conditions. These findings raised the question whether therapeutic self-care ability has a role in moderating the effects of multi-morbidities in the occurrence of adverse events. Future research may further investigate the concept of multi-morbidities in relation to therapeutic self-care in the context of home care.

My study focused on exploring the experiences of primary caregivers. The interview data revealed that the nature of informal caregiving often involved multiple caregivers who shared care and responsibilities in looking after their loved ones at home. Future research should include the perspectives about the dynamics of multiple caregivers who shared overlapping informal caregiving roles to support therapeutic self-care activities. Furthermore, the qualitative study sample did not include home care clients who were palliative care, and those who had severe dementia or Alzheimer's disease. These special populations may have different types of needs with regards to therapeutic self-care, and therefore future research should investigate the perspectives of these special population groups. Future work may also focus on the therapeutic self-care needs of individuals with different chronic conditions, and may examine the differences in self-care behaviors associated with specific conditions, such as diabetes, arthritis or COPD. The interview data revealed that there were cultural considerations with regards to the safety needs of home care clients and informal caregivers. Future research would benefit from including a more culturally diverse sample to examine the cultural needs of therapeutic self-care and informal caregiving among different ethnic groups. Finally, the qualitative data relied solely on the participant's verbal descriptions of their experiences. Future research studies may benefit from collecting observational or visual data to capture the complexity of therapeutic self-care within the context of home care.

6.3. Conclusion

This mixed methods study advanced the understanding of the concept of therapeutic self-care in the context of home care. The quantitative method identified the nature of the relationship between client's therapeutic self-care ability and the occurrence of adverse events at home. The qualitative method generated knowledge about the clients and their informal caregiver's perspectives of home care safety in relation to therapeutic self-care and informal caregiving. This complementarity approach offered different strengths that enhanced the understanding of the concept of therapeutic self-care, and therefore contributed to the overall completeness of this research study. Therapeutic self-care is conceptualized as the medical management of disease conditions, and it entails the level of knowledge and skill needed to support self-care practice. Therapeutic self-care not only entails the individual capacity to manage disease conditions, but it is also dependent on the availability of the resources and support provided by the informal caregivers and health care providers.

My study findings demonstrated that therapeutic self-care is a relational concept in which there is inter-dependent relationship between the clients, informal caregivers and health care providers in the context of home care. In particular, there are multi-faceted aspects of safety challenges in home care in which the safety concerns of therapeutic self-care and informal caregiving are profoundly inter-connected. The study results revealed that home care clients with high measured therapeutic self-care ability were found to have lower likelihood of experiencing adverse events, such as unplanned hospitalizations, ADL decline, client fall, unintended weight loss and medication non-compliance. This finding points to the enablement perspective of therapeutic self-care. Specifically, my study suggests that high therapeutic self-care ability is one of the protective factors against the occurrence of adverse events. With higher level of

therapeutic self-care ability, clients may have the necessary knowledge to manage their health conditions and prevent health decline, as well as having the skills and confidence needed to maintain their health functioning and to access appropriate care. Therefore, home care professionals must focus on supporting the development of therapeutic self-care ability among home care clients, especially older adults who are at greater risk of losing independence as a result of their chronic conditions.

Furthermore, improving client's level of therapeutic self-care ability would benefit their informal caregivers by reducing caregiver burden and distress. Informal caregiver support is the key to enabling many seniors to remain in their communities safely and independently as they age. It is imperative that health care professionals take the time to understand the informal caregiver's unique and evolving challenges in order to address these needs. Creating a home care system with enhanced community and respite services would alleviate informal caregiver's care demands, as well as demonstrate continued support and appreciation for their contribution in informal caregiving (Canadian Caregiver Coalition, 2008). In the context of chronic disease management, shortened hospital stays, and increased complexity of home care clients, health care professionals will continue to have an important role in supporting clients in their development of self-care skills. A clear understanding of the nature of relationships between therapeutic self-care ability and adverse events helps to pinpoint the areas of home care service delivery required to improve clients' health and functioning. Such knowledge is vital for informing health care leaders about the effective strategies that promote therapeutic self-care and informal caregiving, as well as providing evidence for policy formulation in relation to risk mitigation that supports older adults and enables them to remain at home as long as possible.

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APPENDIX A: Operational Definitions of Adverse Events

Adverse Events	Operational Definitions	Coding	Sources of Data
New hospital visit	Any admission to hospital with an overnight stay within one year following HOBIC assessment	0 for none 1 for any	DAD
New emergency room visit	Any emergency room visit without an overnight stay within one year following HOBIC assessment	0 for none 1 for any	NACRS
Client Fall	Number of times fell in last 90 days or since last assessment if less than 90 days	If none, code “0”, if more than 9, code “9”	RAI-HC Variable name: K5
Unintended weight loss	Unintended weight loss of 5% or more in the last 30 days (or 10% or more in the last 180 days)	0 for No 1 for Yes	RAI-HC Variable name: L1a
Newly detected urinary tract infection	Urinary tract infection in last 30 days	0: not present 1 or 2: present	RAI-HC Variable name: J1W
New caregiver distress	A caregiver is unable to continue in caring activities (e.g. decline in the health of the caregiver makes it difficult to continue); primary caregiver expresses feelings of distress, anger or depression	0 for No 1 for Yes	RAI-HC Variable name: G2a and G2c
ADL decline	ADL status has become worse (ie. now more impairment in self-performance) as compared to status 90 days ago (or since last assessment if less than 90 days)	0 for No 1 for Yes	RAI-HC Variable name: H3

Adverse Events	Operational Definitions	Coding	Sources of Data
New pressure ulcer or Ulcer deterioration	Pressure ulcer appeared or stage increased at 2 nd assessment compared with previous assessment	0 for No 1 for Yes	RAI-HC Variable name: N2a
Non-Compliance/ Adherence with Medications	Compliant all or most of time with medication prescribed by physician in last 7 days	0 for Always compliant or compliant 80% of time or more 1 for compliant less than 80 % of time, including failure to purchase prescribed medications	RAI-HC Variable name: Q4

APPENDIX B

Home Care: THERAPEUTIC SELF-CARE SCALE (Sidani & Doran)

Instructions:

Each of the following statements is about an aspect of your care related to your present health condition. Indicate how much you are able to do each care related activity, by choosing the number between “0” and “5” that is most appropriate. “0” represents **Not at all** and “5” represents **Very much so**

Who responded to the questions?

☐ Patients ☐ Family ☐ Other, specify: _____

1. Do you know what medications you have to take?
2. Do you understand the purpose of the medications prescribed to you (that is, do you know what the medications do for your health condition)?
3. Do you take the medications as prescribed?
4. Can you recognize changes in your body (symptoms) that are related to your illness or health condition?
5. Do you know and understand why you experience some changes in your body (symptoms) related to your illness or health condition?
6. Do you know what to do (things or activities) to control these changes in your body (symptoms)?
7. Do you carry out the treatments or activities that you have been taught to manage these changes in your body (symptoms)?
8. Do you do things or activities to look after yourself and to maintain your health in general?
9. Do you know whom to contact to get help in carrying out your daily activities?
10. Do you know whom to contact in case of a medical emergency?
11. Do you perform your regular activities (such as bathing, shopping, preparing meals, visiting with friends)?
12. Do you adjust your regular activities when you experience body changes (symptoms) related to your illness or health condition?

Appendix C: Ethics Approval (University of Toronto)



UNIVERSITY OF
TORONTO

OFFICE OF THE VICE PRESIDENT, RESEARCH

PROTOCOL REFERENCE # 27223

March 13, 2012

Dr. Diane Doran
FACULTY OF NURSING

Mrs. Winnie Sun
FACULTY OF NURSING

Dear Dr. Doran and Mrs. Winnie Sun,

Re: Your research protocol entitled, "A mixed methods study: Examining the relationship between therapeutic self-care and adverse events for home care clients in Ontario"

ETHICS APPROVAL

Original Approval Date: March 13, 2012
Expiry Date: March 12, 2013
Continuing Review Level: 1

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol under the REB's delegated review process. Your protocol has been approved for a period of one year and ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Judith Friedland, Ph.D.
REB Chair

Daniel Gyewu
REB Manager

OFFICE OF RESEARCH ETHICS

McMurch Building, 12 Queen's Park Crescent West, 2nd Floor, Toronto, ON M5S 1S8 Canada

Tel: +1 416 946-3273 • Fax: +1 416 946-5763 • ethics.review@utoronto.ca • <http://www.research.utoronto.ca/for-researchers-administrators/ethics/>

Appendix D: Resident Assessment Instrument-Home Care (RAI-HC)

MINIMUM DATA SET - HOME CARE (MDS-HC)©

• Unless otherwise noted, score for last 3 days

• Examples of exceptions include IADLs/Continence/Services/Treatments where status scored over last 7 days

SECTION AA. NAME AND IDENTIFICATION NUMBERS

1. NAME OF CLIENT	a. (Last/Family Name)	b. (First Name)	c. (Middle Initial)
2. CASE RECORD NO.			
3. GOVERNMENT PENSION AND HEALTH INSURANCE NUMBERS	a. Pension (Social Security) Number b. Health insurance number (or other comparable insurance number)		

2. REASONS FOR ASSESSMENT	Type of assessment 1. Initial assessment 2. Follow-up assessment 3. Routine assessment at fixed intervals 4. Review within 30-day period prior to discharge from the program 5. Review at return from hospital 6. Change in status 7. Other
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SECTION BB. PERSONAL ITEMS (Complete at Intake Only)

1. GENDER	1. Male	2. Female
2. BIRTHDATE	Month Day Year	
3. RACE/ETHNICITY	(Check all that apply) RACE American Indian/Alaskan Native Asian Black or African American Native Hawaiian or other Pacific Islander White ETHNICITY Hispanic or Latino	
4. MARITAL STATUS	1. Never married 2. Married 3. Widowed 4. Separated 5. Divorced 6. Other	
5. LANGUAGE	Primary Language 0. English 1. Spanish 2. French 3. Other	
6. EDUCATION (Highest Level Completed)	1. No schooling 2. 8th grade/less 3. 9-11 grades 4. High school 5. Technical or trade school 6. Some college 7. Bachelor's degree 8. Graduate degree	
7. RESPONSIBILITY/ADVANCED DIRECTIVES	(Code for responsibility/advanced directives) 0. No 1. Yes a. Client has a legal guardian b. Client has advanced medical directives in place (for example, a do not hospitalize order)	

SECTION B. COGNITIVE PATTERNS

1. MEMORY RECALL ABILITY	(Code for recall of what was learned or known) 0. Memory OK 1. Memory problem a. Short-term memory OK — seems/appears to recall after 5 minutes b. Procedural memory OK — Can perform all or almost all steps in a multitask sequence without cues for initiation
2. COGNITIVE SKILLS FOR DAILY DECISION-MAKING	a. How well client made decisions about organizing the day (e.g., when to get up or have meals, which clothes to wear or activities to do) 0. INDEPENDENT—Decisions consistent/reasonable/safe 1. MODIFIED INDEPENDENCE—Some difficulty in new situations only 2. MINIMALLY IMPAIRED—In specific situations, decisions become poor or unsafe and cues/supervision necessary at those times 3. MODERATELY IMPAIRED—Decisions consistently poor or unsafe, cues/supervision required at all times 4. SEVERELY IMPAIRED—Never/rarely made decisions b. Worsening of decision making as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes
3. INDICATORS OF DELIRIUM	a. Sudden or new onset/change in mental function over LAST 7 DAYS (including ability to pay attention, awareness of surroundings, being coherent, unpredictable variation over course of day) 0. No 1. Yes b. In the LAST 90 DAYS (or since last assessment if less than 90 days), client has become agitated or disoriented such that his or her safety is endangered or client requires protection by others 0. No 1. Yes

SECTION CC. REFERRAL ITEMS (Complete at Intake Only)

1. DATE CASE OPENED/REOPENED	Month Day Year
2. REASON FOR REFERRAL	1. Post hospital care 2. Community chronic care 3. Home placement screen 4. Eligibility for home care 5. Day care 6. Other
3. GOALS OF CARE	(Code for client/family understanding of goals of care) 0. No 1. Yes a. Skilled nursing treatments b. Monitoring to avoid clinical complications c. Rehabilitation d. Client/family education e. Family respite f. Palliative care
4. TIME SINCE LAST HOSPITAL STAY	Time since discharge from last in-patient setting (Code for most recent instance in LAST 180 DAYS) 0. No hospitalization within 180 days 1. Within last week 2. Within 8 to 14 days 3. Within 15 to 30 days 4. More than 30 days ago
5. WHERE LIVED AT TIME OF REFERRAL	1. Private home/appt. with no home care services 2. Private home/appt. with home care services 3. Board and care/assisted living/group home 4. Nursing home 5. Other
6. WHO LIVED WITH AT REFERRAL	1. Lived alone 2. Lived with spouse only 3. Lived with spouse and other(s) 4. Lived with child (not spouse) 5. Lived with other(s) (not spouse or children) 6. Lived in group setting with non-relative(s)
7. PRIOR NH PLACEMENT	Resided in a nursing home at anytime during 5 YEARS prior to case opening 0. No 1. Yes
8. RESIDENTIAL HISTORY	Moved to current residence within last two years 0. No 1. Yes

SECTION C. COMMUNICATION/HEARING PATTERNS

1. HEARING	(With hearing appliance if used) 0. HEARS ADEQUATELY—Normal talk, TV, phone, doorbell 1. MINIMAL DIFFICULTY—When not in quiet setting 2. HEARS IN SPECIAL SITUATIONS ONLY—Speaker has to adjust tonal quality and speak distinctly 3. HIGHLY IMPAIRED—Absence of useful hearing
2. MAKING SELF UNDERSTOOD (Expression)	(Expressing information content—however able) 0. UNDERSTOOD—Expresses ideas without difficulty 1. USUALLY UNDERSTOOD—Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required 2. OFTEN UNDERSTOOD—Difficulty finding words or finishing thoughts, prompting usually required 3. SOMETIMES UNDERSTOOD—Ability is limited to making concrete requests 4. RARELY/NEVER UNDERSTOOD
3. ABILITY TO UNDERSTAND OTHERS (Comprehension)	(Understands verbal information—however able) 0. UNDERSTANDS—Clear comprehension 1. USUALLY UNDERSTANDS—Misses some part/intent of message, BUT comprehends most conversation with little or no prompting 2. OFTEN UNDERSTANDS—Misses some part/intent of message, with prompting can often comprehend conversation 3. SOMETIMES UNDERSTANDS—Responds adequately to simple, direct communication 4. RARELY/NEVER UNDERSTANDS
4. COMMUNICATION DECLINE	Worsening in communication (making self understood or understanding others) as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes

SECTION D. VISION PATTERNS

1. VISION	(Ability to see in adequate light and with glasses if used) 0. ADEQUATE—Sees fine detail, including regular print in newspapers/books 1. IMPAIRED—Sees large print, but not regular print in newspapers/books 2. MODERATELY IMPAIRED—Limited vision; not able to see newspaper headlines, but can identify objects 3. HIGHLY IMPAIRED—Object identification in question, but eyes appear to follow objects 4. SEVERELY IMPAIRED—No vision or sees only light, colors, or shapes; eyes do not appear to follow objects
2. VISUAL LIMITATION/DIFFICULTIES	Saw halos or rings around lights, curtains over eyes, or flashes of lights 0. No 1. Yes
3. VISION DECLINE	Worsening of vision as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes

SECTION A. ASSESSMENT INFORMATION

1. ASSESSMENT REFERENCE DATE	Date of assessment Month Day Year
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SECTION E. MOOD AND BEHAVIOR PATTERNS

1. INDICATORS OF DEPRESSION, ANXIETY, SAD MOOD		(Code for observed indicators irrespective of the assumed cause)	
0. Indicator not exhibited in last 3 days			
1. Exhibited 1-2 of last 3 days			
2. Exhibited on each of last 3 days			
a. A FEELING OF SADNESS OR BEING DEPRESSED, that life is not worth living, that nothing matters, that he or she is of no use to anyone or would rather be dead	e. REPETITIVE ANXIOUS COMPLAINTS, CONCERNS—e.g., persistently seeks attention/reassurance regarding schedules, meals, laundry, clothing, relationship issues		
b. PERSISTENT ANGER WITH SELF OR OTHERS—e.g., easily annoyed, anger at care received	f. SAD, PAINED, WORRIED FACIAL EXPRESSIONS—e.g., furrowed brows		
c. EXPRESSIONS OF WHAT APPEAR TO BE UNREALISTIC FEARS—e.g., fear of being abandoned, left alone, being with others	g. RECURRENT CRYING, TEARFULNESS		
d. REPETITIVE HEALTH COMPLAINTS—e.g., persistently seeks medical attention, obsessive concern with body functions	h. WITHDRAWAL FROM ACTIVITIES OF INTEREST—e.g., no interest in long standing activities or being with family/friends		
	i. REDUCED SOCIAL INTERACTION		
2. MOOD DECLINE		Mood indicators have become worse as compared to status of 90 days ago (or since last assessment if less than 90 days)	
		0. No 1. Yes	
3. BEHAVIORAL SYMPTOMS		Instances when client exhibited behavioral symptoms. If EXHIBITED, ease of altering the symptom when it occurred.	
		0. Did not occur in last 3 days 1. Occurred, easily altered 2. Occurred, not easily altered	
a. WANDERING—Moved with no rational purpose, seemingly oblivious to needs or safety			
b. VERBALLY ABUSIVE BEHAVIORAL SYMPTOMS—Threatened, screamed at, cursed at others			
c. PHYSICALLY ABUSIVE BEHAVIORAL SYMPTOMS—Hit, shoved, scratched, sexually abused others			
d. SOCIALLY INAPPROPRIATE/DISRUPTIVE BEHAVIORAL SYMPTOMS—Disruptive sounds, noisiness, screaming, self-abusive acts, sexual behavior or disrobing in public, smears/throws food/feeces, rummaging, repetitive behavior, rises early and causes disruption			
e. RESISTS CARE—Resisted taking medications/injections, ADL assistance, eating, or changes in position			
4. CHANGES IN BEHAVIOR SYMPTOMS		Behavioral symptoms have become worse or are less well tolerated by family as compared to 90 DAYS AGO (or since last assessment if less than 90 days)	
		0. No, or no change in behavioral symptoms 1. Yes	

SECTION F. SOCIAL FUNCTIONING

1. INVOLVEMENT	a. At ease interacting with others (e.g., likes to spend time with others) 0. At ease 1. Not at ease b. Openly expresses conflict or anger with family/friends 0. No 1. Yes		
2. CHANGE IN SOCIAL ACTIVITIES	As compared to 90 DAYS AGO (or since last assessment if less than 90 days ago), decline in the client's level of participation in social, religious, occupational or other preferred activities. IF THERE WAS A DECLINE, client distressed by this fact 0. No decline 1. Decline, not distressed 2. Decline, distressed		
3. ISOLATION	a. Length of time client is alone during the day (morning and afternoon) 0. Never or hardly ever 1. About one hour 2. Long periods of time—e.g., all morning 3. All of the time b. Client says or indicates that he/she feels lonely 0. No 1. Yes		

SECTION G. INFORMAL SUPPORT SERVICES

1. TWO KEY INFORMAL HELPERS		NAME OF PRIMARY AND SECONDARY HELPERS	
Primary (A) and Secondary (B)	a. (Last/Family Name)	b. (First)	
	c. (Last/Family Name)	d. (First)	
		(A) Prim	(B) Sec
	e. Lives with client 0. Yes 1. No 2. No such helper (skip other items in the appropriate column)		
	f. Relationship to client 0. Child or child-in-law 1. Spouse 2. Other Relative 3. Friend/neighbor		
	Areas of help: g. — Advice or emotional support h. — IADL care i. — ADL care	0. Yes 1. No	

1. TWO KEY INFORMAL HELPERS	if needed, willingness (with ability) to increase help: 0. More than 2 hours 1. 1-2 hours per day 2. No j. — Advice or emotional support k. — IADL care l. — ADL care	(A) Prim	(B) Sec
2. CAREGIVER STATUS	(Check all that apply) A caregiver is unable to continue in caring activities—e.g., decline in the health of the caregiver makes it difficult to continue Primary caregiver is not satisfied with support received from family and friends (e.g., other children of client) Primary caregiver expresses feelings of distress, anger or depression NONE OF ABOVE	a.	b.
3. EXTENT OF INFORMAL HELP (HOURS OF CARE, ROUNDED)	For instrumental and personal activities of daily living received over the LAST 7 DAYS, indicate extent of help from family, friends, and neighbors a. Sum of time across five weekdays b. Sum of time across two weekend days		HOURS

SECTION H. PHYSICAL FUNCTIONING:

- IADL PERFORMANCE IN 7 DAYS
- ADL PERFORMANCE IN 3 DAYS

1. IADL SELF PERFORMANCE—Code for functioning in routine activities around the home or in the community during the LAST 7 DAYS.		(A)	(B)
(A) IADL SELF PERFORMANCE CODE (Code for client's performance during LAST 7 DAYS)			
0. INDEPENDENT—do on own 1. SOME HELP—help some of the time 2. FULL HELP—performed with help all of the time 3. BY OTHERS—performed by others 4. ACTIVITY DID NOT OCCUR			
(B) IADL DIFFICULTY CODE How difficult it is (or would it be) for client to do activity on own			
0. NO DIFFICULTY 1. SOME DIFFICULTY—e.g., needs some help, is very slow, or fatigues 2. GREAT DIFFICULTY—e.g., little or no involvement in the activity is possible			
a. MEAL PREPARATION—How meals are prepared (e.g., planning meals, cooking, assembling ingredients, setting out food and utensils)			
b. ORDINARY HOUSEWORK—How ordinary work around the house is performed (e.g., doing dishes, dusting, making bed, tidying up, laundry)			
c. MANAGING FINANCE—How bills are paid, checkbook is balanced, household expenses are balanced			
d. MANAGING MEDICATIONS—How medications are managed (e.g., remembering to take medicines, opening bottles, taking correct drug dosages, giving injections, applying ointments)			
e. PHONE USE—How telephone calls are made or received (with assistive devices such as large numbers on telephone, amplification as needed)			
f. SHOPPING—How shopping is performed for food and household items (e.g., selecting items, managing money)			
g. TRANSPORTATION—How client travels by vehicle (e.g., gets to places beyond walking distance)			
2. ADL SELF PERFORMANCE—The following address the client's physical functioning in routine personal activities of daily life, for example, dressing, eating, etc. during the LAST 3 DAYS, considering all episodes of these activities. For clients who performed an activity independently, be sure to determine and record whether others encouraged the activity or were present to supervise or oversee the activity (Note—For bathing, code for most dependent single episode in LAST 7 DAYS)			
0. INDEPENDENT—No help, setup, or oversight —OR— Help, setup, oversight provided only 1 or 2 times (with any task or subtask)			
1. SETUP HELP ONLY—Article or device provided within reach of client 3 or more times			
2. SUPERVISION—Oversight, encouragement or cueing provided 3 or more times during last 3 days —OR— Supervision (1 or more times) plus physical assistance provided only 1 or 2 times (for a total of 3 or more episodes of help or supervision)			
3. LIMITED ASSISTANCE—Client highly involved in activity; received physical help in guided maneuvering of limbs or other non-weight bearing assistance 3 or more times —OR— Combination of non-weight bearing help with more help provided only 1 or 2 times during period (for a total of 3 or more episodes of physical help)			
4. EXTENSIVE ASSISTANCE—Client performed part of activity on own (50% or more of subtasks), but help of following type(s) were provided 3 or more times: —Weight-bearing support —OR— — Full performance by another during part (but not all) of last 3 days			
5. MAXIMAL ASSISTANCE—Client involved and completed less than 50% of subtasks on own (includes 2+ person assist), received weight bearing help or full performance of certain subtasks 3 or more times			
6. TOTAL DEPENDENCE—Full performance of activity by another			
8. ACTIVITY DID NOT OCCUR (regardless of ability)			

2. ADL SELF-PERFORMANCE (cont)	
a. MOBILITY IN BED —Including moving to and from lying position, turning side to side, and positioning body while in bed.	
b. TRANSFER —Including moving to and between surfaces—to/from bed, chair, wheelchair, standing position. [Note—Excludes to/from bath/toilet]	
c. LOCOMOTION IN HOME —[Note—If in wheelchair, self-sufficiency once in chair]	
d. LOCOMOTION OUTSIDE OF HOME —[Note—If in wheelchair, self-sufficiency once in chair]	
e. DRESSING UPPER BODY —How client dresses and undresses (street clothes, underwear) above the waist, includes prostheses, orthotics, fasteners, pullovers, etc.	
f. DRESSING LOWER BODY —How client dresses and undresses (street clothes, underwear) from the waist down, includes prostheses, orthotics, belts, pants, skirts, shoes, and fasteners	
g. EATING —Including taking in food by any method, including tube feedings.	
h. TOILET USE —Including using the toilet room or commode, bedpan, urinal, transferring on/off toilet, cleaning self after toilet use or incontinent episode, changing pad, managing any special devices required (ostomy or catheter), and adjusting clothes.	
i. PERSONAL HYGIENE —Including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands (EXCLUDE baths and showers)	
j. BATHING —How client takes full-body bath/shower or sponge bath (EXCLUDE washing of back and hair). Includes how each part of body is bathed: arms, upper and lower legs, chest, abdomen, perineal area. <i>Code for most dependent episode in LAST 7 DAYS</i>	
3. ADL DECLINE	ADL status has become worse (i.e., now more impaired in self performance) as compared to status 90 days ago (or since last assessment if less than 90 days) 0. No 1. Yes
4. PRIMARY MODES OF LOCOMOTION	0. No assistive device 3. Scooter (e.g., Amigo) 1. Cane 4. Wheelchair 2. Walker/crutch 8. ACTIVITY DID NOT OCCUR a. Indoors b. Outdoors
5. STAIR CLIMBING	In the last 3 days, how client went up and down stairs (e.g., single or multiple steps, using handrail as needed) 0. Up and down stairs without help 1. Up and down stairs with help 2. Not go up and down stairs
6. STAMINA	a. In a typical week, during the LAST 30 DAYS (or since last assessment), code the number of days client usually went out of the house or building in which client lives (no matter how short a time period) 0. Every day 2. 1 day a week 1. 2-6 days a week 3. No days b. Hours of physical activities in the last 3 days (e.g., walking, cleaning house, exercise) 0. Two or more hours 1. Less than two hours
7. FUNCTIONAL POTENTIAL	Client believes he/she capable of increased functional independence (ADL, IADL, mobility) Caregivers believe client is capable of increased functional independence (ADL, IADL, mobility) Good prospects of recovery from current disease or conditions, improved health status expected NONE OF ABOVE

SECTION I. CONTINENCE IN LAST 7 DAYS

1. BLADDER CONTINENCE	a. In LAST 7 DAYS, control of urinary bladder function (with appliances such as catheters or incontinence program employed) [Note—if dribbles, volume insufficient to soak through underpants] 0. CONTINENT—Complete control; DOES NOT USE any type of catheter or other urinary collection device 1. CONTINENT WITH CATHETER—Complete control with use of any type of catheter or urinary collection device that does not leak urine 2. USUALLY CONTINENT—Incontinent episodes once a week or less 3. OCCASIONALLY INCONTINENT—Incontinent episodes 2 or more times a week but not daily 4. FREQUENTLY INCONTINENT—Tends to be incontinent daily, but some control present 5. INCONTINENT—Inadequate control, multiple daily episodes 6. DID NOT OCCUR—No urine output from bladder b. Worsening of bladder incontinence as compared to status 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes
2. BLADDER DEVICES	(Check all that apply in LAST 7 DAYS) Use of pads or briefs to protect against wetness Use of an indwelling urinary catheter NONE OF ABOVE

3. BOWEL CONTINENCE	In LAST 7 DAYS, control of bowel movement (with appliance or bowel continence program if employed) 0. CONTINENT—Complete control; DOES NOT USE ostomy device 1. CONTINENT WITH OSTOMY—Complete control with use of ostomy device that does not leak stool 2. USUALLY CONTINENT—Bowel incontinent episodes less than weekly 3. OCCASIONALLY INCONTINENT—Bowel incontinent episode once a week 4. FREQUENTLY INCONTINENT—Bowel incontinent episodes 2-3 times a week 5. INCONTINENT—Bowel incontinent all (or almost all) of the time 6. DID NOT OCCUR—No bowel movement during entire 7 day assessment period
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SECTION J. DISEASE DIAGNOSES

Disease/Infection that doctor has indicated is present and affects client's status, requires treatment, or symptom management. Also include if disease is monitored by a home care professional or is the reason for a hospitalization in LAST 90 DAYS (or since last assessment if less than 90 days)

[blank]. Not present 1. Present—not subject to focused treatment or monitoring by home care professional 2. Present—monitored or treated by home care professional [If no disease in list, check J1ac, None of Above]																																									
1. DISEASES	<table border="1"> <tr> <td>HEART/CIRCULATION</td> <td>p. Osteoporosis</td> </tr> <tr> <td>a. Cerebrovascular accident (stroke)</td> <td>SENSES</td> </tr> <tr> <td>b. Congestive heart failure</td> <td>q. Cataract</td> </tr> <tr> <td>c. Coronary artery disease</td> <td>r. Glaucoma</td> </tr> <tr> <td>d. Hypertension</td> <td>PSYCHIATRIC MOOD</td> </tr> <tr> <td>e. Irregularly irregular pulse</td> <td>s. Any psychiatric diagnosis</td> </tr> <tr> <td>f. Peripheral vascular disease</td> <td>INFECTIONS</td> </tr> <tr> <td>NEUROLOGICAL</td> <td>t. HIV infection</td> </tr> <tr> <td>g. Alzheimer's</td> <td>u. Pneumonia</td> </tr> <tr> <td>h. Dementia other than Alzheimer's disease</td> <td>v. Tuberculosis</td> </tr> <tr> <td>i. Head trauma</td> <td>w. Urinary tract infection (in LAST 30 DAYS)</td> </tr> <tr> <td>j. Hemiplegia/hemiparesis</td> <td>OTHER DISEASES</td> </tr> <tr> <td>k. Multiple sclerosis</td> <td>x. Cancer—(in past 5 years) not including skin cancer</td> </tr> <tr> <td>l. Parkinsonism</td> <td>y. Diabetes</td> </tr> <tr> <td>MUSCULO-SKELETAL</td> <td>z. Emphysema/COPD/asthma</td> </tr> <tr> <td>m. Arthritis</td> <td>aa. Renal Failure</td> </tr> <tr> <td>n. Hip fracture</td> <td>ab. Thyroid disease (hyper or hypo)</td> </tr> <tr> <td>o. Other fractures (e.g., wrist, vertebral)</td> <td>ac. NONE OF ABOVE</td> </tr> </table>	HEART/CIRCULATION	p. Osteoporosis	a. Cerebrovascular accident (stroke)	SENSES	b. Congestive heart failure	q. Cataract	c. Coronary artery disease	r. Glaucoma	d. Hypertension	PSYCHIATRIC MOOD	e. Irregularly irregular pulse	s. Any psychiatric diagnosis	f. Peripheral vascular disease	INFECTIONS	NEUROLOGICAL	t. HIV infection	g. Alzheimer's	u. Pneumonia	h. Dementia other than Alzheimer's disease	v. Tuberculosis	i. Head trauma	w. Urinary tract infection (in LAST 30 DAYS)	j. Hemiplegia/hemiparesis	OTHER DISEASES	k. Multiple sclerosis	x. Cancer—(in past 5 years) not including skin cancer	l. Parkinsonism	y. Diabetes	MUSCULO-SKELETAL	z. Emphysema/COPD/asthma	m. Arthritis	aa. Renal Failure	n. Hip fracture	ab. Thyroid disease (hyper or hypo)	o. Other fractures (e.g., wrist, vertebral)	ac. NONE OF ABOVE				
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h. Dementia other than Alzheimer's disease	v. Tuberculosis																																								
i. Head trauma	w. Urinary tract infection (in LAST 30 DAYS)																																								
j. Hemiplegia/hemiparesis	OTHER DISEASES																																								
k. Multiple sclerosis	x. Cancer—(in past 5 years) not including skin cancer																																								
l. Parkinsonism	y. Diabetes																																								
MUSCULO-SKELETAL	z. Emphysema/COPD/asthma																																								
m. Arthritis	aa. Renal Failure																																								
n. Hip fracture	ab. Thyroid disease (hyper or hypo)																																								
o. Other fractures (e.g., wrist, vertebral)	ac. NONE OF ABOVE																																								
2. OTHER CURRENT OR MORE DETAILED DIAGNOSES AND ICD-9 CODES	<table border="1"> <tr> <td>a.</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>b.</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>c.</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>d.</td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>	a.										b.										c.										d.									
a.																																									
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c.																																									
d.																																									

SECTION K. HEALTH CONDITIONS AND PREVENTIVE HEALTH MEASURES

1. PREVENTIVE HEALTH (PAST TWO YEARS)	(Check all that apply—in PAST 2 YEARS) Blood pressure measured Received influenza vaccination Test for blood in stool or screening endoscopy IF FEMALE: Received breast examination or mammography NONE OF ABOVE
2. PROBLEM CONDITIONS PRESENT ON 2 OR MORE DAYS	(Check all that were present on at least 2 of the last 3 days) Diarrhea Difficulty urinating or urinating 3 or more times at night Fever a. Loss of appetite b. Vomiting c. NONE OF ABOVE
3. PROBLEM CONDITIONS	(Check all present at any point during last 3 days) PHYSICAL HEALTH Chest pain/pressure at rest or on exertion No bowel movement in 3 days Dizziness or lightheadedness Edema Shortness of breath MENTAL HEALTH Delusions Hallucinations NONE OF ABOVE

4. PAIN	<p>a. Frequency with which client complains or shows evidence of pain 0. No pain (score b-e as 0) 2. Daily - one period 1. Less than daily 3. Daily - multiple periods (e.g., morning and evening)</p> <p>b. Intensity of pain 0. No pain 1. Mild 2. Moderate 3. Severe 4. Times when pain is horrible or excruciating</p> <p>c. From client's point of view, pain intensity disrupts usual activities 0. No 1. Yes</p> <p>d. Character of pain 0. No pain 1. Localized - single site 2. Multiple sites</p> <p>e. From client's point of view, medications adequately control pain 0. Yes or no pain 1. Medications do not adequately control pain 2. Pain present, medication not taken</p>	
5. FALLS FREQUENCY	Number of times fell in LAST 30 DAYS (or since last assessment if less than 30 days) if none, code "0"; if more than 9, code "9"	
6. DANGER OF FALL	(Code for danger of falling) 0. No 1. Yes	
	a. Unsteady gait	
	b. Client limits going outdoors due to fear of falling (e.g., stopped using bus, goes out only with others)	
7. LIFE STYLE (Drinking/Smoking)	(Code for drinking or smoking) 0. No 1. Yes	
	a. In the LAST 90 DAYS (or since last assessment if less than 90 days), client felt the need or was told by others to cut down on drinking, or others were concerned with client's drinking	
	b. In the LAST 90 DAYS (or since last assessment if less than 90 days), client had to have a drink first thing in the morning to steady nerves (i.e., an "eye opener") or has been in trouble because of drinking	
	c. Smoked or chewed tobacco daily	
8. HEALTH STATUS INDICATORS	(Check all that apply) Client feels he/she has poor health (when asked) Has conditions or diseases that make cognition, ADL, mood, or behavior patterns unstable (fluctuations, precarious, or deteriorating) Experiencing a flare-up of a recurrent or chronic problem Treatments changed in LAST 30 DAYS (or since last assessment if less than 30 days) because of a new acute episode or condition Prognosis of less than six months to live—e.g., physician has told client or client's family that client has end-stage disease NONE OF ABOVE	a. b. c. d. e. f.
9. OTHER STATUS INDICATORS	(Check all that apply) Fearful of a family member or caregiver Unusually poor hygiene Unexplained injuries, broken bones, or burns Neglected, abused, or mistreated Physically restrained (e.g., limbs restrained, used bed rails, constrained to chair when sitting) NONE OF ABOVE	a. b. c. d. e. f.

SECTION L. NUTRITION/HYDRATION STATUS

1. WEIGHT	(Code for weight items) 0. No 1. Yes	
	a. Unintended weight loss of 5% or more in the LAST 30 DAYS [or 10% or more in the LAST 180 DAYS]	
	b. Severe malnutrition (cachexia)	
	c. Morbid obesity	
2. CONSUMPTION	(Code for consumption) 0. No 1. Yes	
	a. In at least 2 of the last 3 days, ate one or fewer meals a day	
	b. In last 3 days, noticeable decrease in the amount of food client usually eats or fluids usually consumes	
	c. Insufficient fluid—did not consume all/almost all fluids during last 3 days	
	d. Enteral tube feeding	
3. SWALLOWING	0. NORMAL—Safe and efficient swallowing of all diet consistencies 1. REQUIRES DIET MODIFICATION TO SWALLOW SOLID FOODS (mechanical diet or able to ingest specific foods only) 2. REQUIRES MODIFICATION TO SWALLOW SOLID FOODS AND LIQUIDS (puree, thickened liquids) 3. COMBINED ORAL AND TUBE FEEDING 4. NO ORAL INTAKE (NPO)	

SECTION M. DENTAL STATUS (ORAL HEALTH)

1. ORAL STATUS	(Check all that apply) Problem chewing (e.g., poor mastication, immobile jaw, surgical resection, decreased sensation/motor control, pain while eating) Mouth is "dry" when eating a meal Problem brushing teeth or dentures NONE OF ABOVE	a. b. c. d.
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SECTION N. SKIN CONDITION

1. SKIN PROBLEMS	Any troubling skin conditions or changes in skin condition (e.g., burns, bruises, rashes, itchiness, body lice, scabies) 0. No 1. Yes										
2. ULCERS (Pressure/Stroke)	<p>Presence of an ulcer anywhere on the body. Ulcers include any area of persistent skin redness (Stage 1); partial loss of skin layers (Stage 2); deep crater in the skin (Stage 3); breaks in skin exposing muscle or bone (Stage 4). [Code 0 if no ulcer, otherwise record the highest ulcer stage (Stage 1-4).]</p> <p>a. Pressure ulcer—any lesion caused by pressure, shear forces, resulting in damage of underlying tissues</p> <p>b. Stasis ulcer—open lesion caused by poor circulation in the lower extremities</p>										
3. OTHER SKIN PROBLEMS REQUIRING TREATMENT	(Check all that apply) Burns (second or third degree) Open lesions other than ulcers, rashes, cuts (e.g., cancer) Skin tears or cuts	<table border="1"> <tr> <td>a.</td> <td>Surgical wound</td> <td>d.</td> </tr> <tr> <td>b.</td> <td>Corns, calluses, structural problems, infections, fungi</td> <td>e.</td> </tr> <tr> <td>c.</td> <td>NONE OF ABOVE</td> <td>f.</td> </tr> </table>	a.	Surgical wound	d.	b.	Corns, calluses, structural problems, infections, fungi	e.	c.	NONE OF ABOVE	f.
a.	Surgical wound	d.									
b.	Corns, calluses, structural problems, infections, fungi	e.									
c.	NONE OF ABOVE	f.									
4. HISTORY OF RESOLVED PRESSURE ULCERS	Client previously had (at any time) or has an ulcer anywhere on the body 0. No 1. Yes										
5. WOUND/ULCER CARE	(Check for formal care in LAST 7 DAYS) Antibiotics, systemic or topical Dressings Surgical wound care Other wound/ulcer care (e.g., pressure relieving device, nutrition, turning, debridement) NONE OF ABOVE	a. b. c. d. e.									

SECTION O. ENVIRONMENTAL ASSESSMENT

1. HOME ENVIRONMENT (Check any of following that make home environment hazardous or uninhabitable (if none apply, check NONE OF ABOVE. If temporarily in institution, base assessment on home visit))	Lighting in evening (including inadequate or no lighting in living room, sleeping room, kitchen, toilet, corridors) Flooring and carpeting (e.g., holes in floor, electric wires where client walks, scatter rugs) Bathroom and toiletroom (e.g., non-operating toilet, leaking pipes, no rails though needed, slippery bathmat, outside toilet) Kitchen (e.g., dangerous stove, inoperative refrigerator, infestation by rats or bugs) Heating and cooling (e.g., too hot in summer, too cold in winter, wood stove in a home with an asthmatic) Personal safety (e.g., fear of violence, safety problem in going to mailbox or visiting neighbors, heavy traffic in street) Access to home (e.g., difficulty entering/leaving home) Access to rooms in house (e.g., unable to climb stairs) NONE OF ABOVE	a. b. c. d. e. f. g. h. i.
2. LIVING ARRANGEMENT	<p>a. As compared to 90 DAYS AGO (or since last assessment), client now lives with other persons—e.g., moved in with another person, now moved in with client 0. No 1. Yes</p> <p>b. Client or primary caregiver feels that client would be better off in another living environment 0. No 1. Client only 2. Caregiver only 3. Client and caregiver</p>	

SECTION P. SERVICE UTILIZATION (IN LAST 7 DAYS)

1. FORMAL CARE (Minutes rounded to even 10 minutes)	Extent of care or care management in LAST 7 DAYS (or since last assessment if less than 7 days) involving a. Home health aides b. Visiting nurses c. Homemaking services d. Meals e. Volunteer services f. Physical therapy g. Occupational therapy h. Speech therapy i. Day care or day hospital j. Social worker in home	<table border="1"> <thead> <tr> <th rowspan="2"></th> <th colspan="3">(A) # of Days</th> <th colspan="3">(B) Hours</th> <th colspan="3">(C) Mins</th> </tr> <tr> <th>1</th> <th>2</th> <th>3</th> <th>1</th> <th>2</th> <th>3</th> <th>1</th> <th>2</th> <th>3</th> </tr> </thead> <tbody> <tr><td>a.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>b.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>c.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>d.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>e.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>f.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>g.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>h.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>i.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> <tr><td>j.</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr> </tbody> </table>		(A) # of Days			(B) Hours			(C) Mins			1	2	3	1	2	3	1	2	3	a.										b.										c.										d.										e.										f.										g.										h.										i.										j.									
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2. SPECIAL TREATMENTS, THERAPIES, PROGRAMS	<p>Special treatments, therapies, and programs received or scheduled during the LAST 7 DAYS (or since last assessment if less than 7 days) and adherence to the required schedule. Includes services received in the home or on an outpatient basis.</p> <p>(Blank). Not applicable 1. Scheduled, full adherence as prescribed 2. Scheduled, partial adherence 3. Scheduled, not received (If no treatments provided, check NONE OF ABOVE P2aa)</p> <p>RESPIRATORY TREATMENTS</p> <p>a. Oxygen</p> <p>b. Respirator for assistive breathing</p> <p>c. All other respiratory treatments</p> <p>OTHER TREATMENTS</p> <p>d. Alcohol/drug treatment program</p> <p>e. Blood transfusion(s)</p> <p>f. Chemotherapy</p> <p>g. Dialysis</p> <p>h. IV infusion - central</p> <p>i. IV infusion - peripheral</p> <p>j. Medication by injection</p> <p>k. Ostomy care</p> <p>l. Radiation</p> <p>m. Tracheostomy care</p> <p>THERAPIES</p> <p>n. Exercise therapy</p> <p>o. Occupational therapy</p> <p>p. Physical therapy</p> <p>PROGRAMS</p> <p>q. Day center</p> <p>r. Day hospital</p> <p>s. Hospice care</p> <p>t. Physician or clinic visit</p> <p>u. Respite care</p> <p>SPECIAL PROCEDURES DONE IN HOME</p> <p>v. Daily nurse monitoring (e.g., EKG, urinary output)</p> <p>w. Nurse monitoring less than daily</p> <p>x. Medical alert bracelet or electronic security alert</p> <p>y. Skin treatment</p> <p>z. Special diet</p> <p>aa. NONE OF ABOVE</p>
3. MANAGEMENT OF EQUIPMENT (in last 3 days)	<p>Management codes:</p> <p>0. Not used</p> <p>1. Managed on own</p> <p>2. Managed on own if laid out or with verbal reminders</p> <p>3. Partially performed by others</p> <p>4. Fully performed by others</p> <p>a. Oxygen</p> <p>b. IV</p> <p>c. Catheter</p> <p>d. Ostomy</p>
4. VISITS IN LAST 90 DAYS OR SINCE LAST ASSESSMENT	<p>Enter 0 if none, if more than 9, code "9"</p> <p>a. Number of times ADMITTED TO HOSPITAL with an overnight stay</p> <p>b. Number of times VISITED EMERGENCY ROOM without an overnight stay</p> <p>c. EMERGENCY CARE—including unscheduled nursing, physician, or therapeutic visits to office or home</p>
5. TREATMENT GOALS	<p>Any treatment goals that have been met in the LAST 90 DAYS (or since last assessment if less than 90 days)</p> <p>0. No</p> <p>1. Yes</p>
6. OVERALL CHANGE IN CARE NEEDS	<p>Overall self sufficiency has changed significantly as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days)</p> <p>0. No change</p> <p>1. Improved—receives fewer supports</p> <p>2. Deteriorated—receives more support</p>
7. TRADE OFFS	<p>Because of limited funds, during the last month, client made trade-offs among purchasing any of the following: prescribed medications, sufficient home heat, necessary physician care, adequate food, home care</p> <p>0. No</p> <p>1. Yes</p>

SECTION Q. MEDICATIONS

1. NUMBER OF MEDICATIONS	<p>Record the number of different medicines (prescriptions and over the counter), including eye drops, taken regularly or on an occasional basis in the LAST 7 DAYS (or since last assessment) (If none, code "0", if more than 9, code "9")</p>
2. RECEIPT OF PSYCHOTROPIC MEDICATION	<p>Psychotropic medications taken in the LAST 7 DAYS (or since last assessment) (Note—Review client's medications with the list that applies to the following categories)</p> <p>0. No</p> <p>1. Yes</p> <p>a. Antipsychotic/neuroleptic</p> <p>b. Anxiolytic</p> <p>c. Antidepressant</p> <p>d. Hypnotic</p>
3. MEDICAL OVERSIGHT	<p>Physician reviewed client's medications as a whole in LAST 180 DAYS (or since last assessment)</p> <p>0. Discussed with at least one physician (or no medication taken)</p> <p>1. No single physician reviewed all medications</p>
4. COMPLIANCE/ADHERENCE WITH MEDICATIONS	<p>Compliant all or most of time with medications prescribed by physician (both during and between therapy visits) in LAST 7 DAYS</p> <p>0. Always compliant</p> <p>1. Compliant 80% of time or more</p> <p>2. Compliant less than 80% of time, including failure to purchase prescribed medications</p> <p>3. NO MEDICATIONS PRESCRIBED</p>

☐ - When box blank, must enter number or letter ☐ - When letter in box, check if condition applies

5. LIST OF ALL MEDICATIONS	<p>List prescribed and nonprescribed medications taken in LAST 7 DAYS (or since last assessment)</p> <p>a. Name and Dose—Record the name of the medication and dose ordered.</p> <p>b. Form: Code the route of Administration using the following list:</p> <p>1. By mouth (PO) 5. Subcutaneous (SQ) 9. Enteral tube 2. Sublingual (SL) 6. Rectal (R) 10. Other 3. Intramuscular (IM) 7. Topical 4. Intravenous (IV) 8. Inhalation</p> <p>c. Number taken—Record the amount of medication administered each time the medication is given</p> <p>d. Freq: Code the number of times per day, week, or month the medication is administered using the following list:</p> <p>PRN: As necessary SQ: Five times daily QH: Every hour QOD: Every other day Q2H: Every two hours QW: Once each wk Q3H: Every three hours 2W: Two times every week Q4H: Every four hours 3W: Three times every week Q6H: Every six hours 4W: Four times each week Q8H: Every eight hours 5W: Five times each week QD: Once daily 6W: Six times each week BID: Two times daily (includes every 12 hrs) 1M: Once every month TID: Three times daily 2M: Twice every month QID: Four times daily C: Continuous O: Other</p>
a. Name and Dose	<p>b. Form c. Number Taken d. Freq.</p> <p>a. _____</p> <p>b. _____</p> <p>c. _____</p> <p>d. _____</p> <p>e. _____</p> <p>f. _____</p> <p>g. _____</p> <p>h. _____</p> <p>i. _____</p> <p>j. _____</p> <p>k. _____</p>

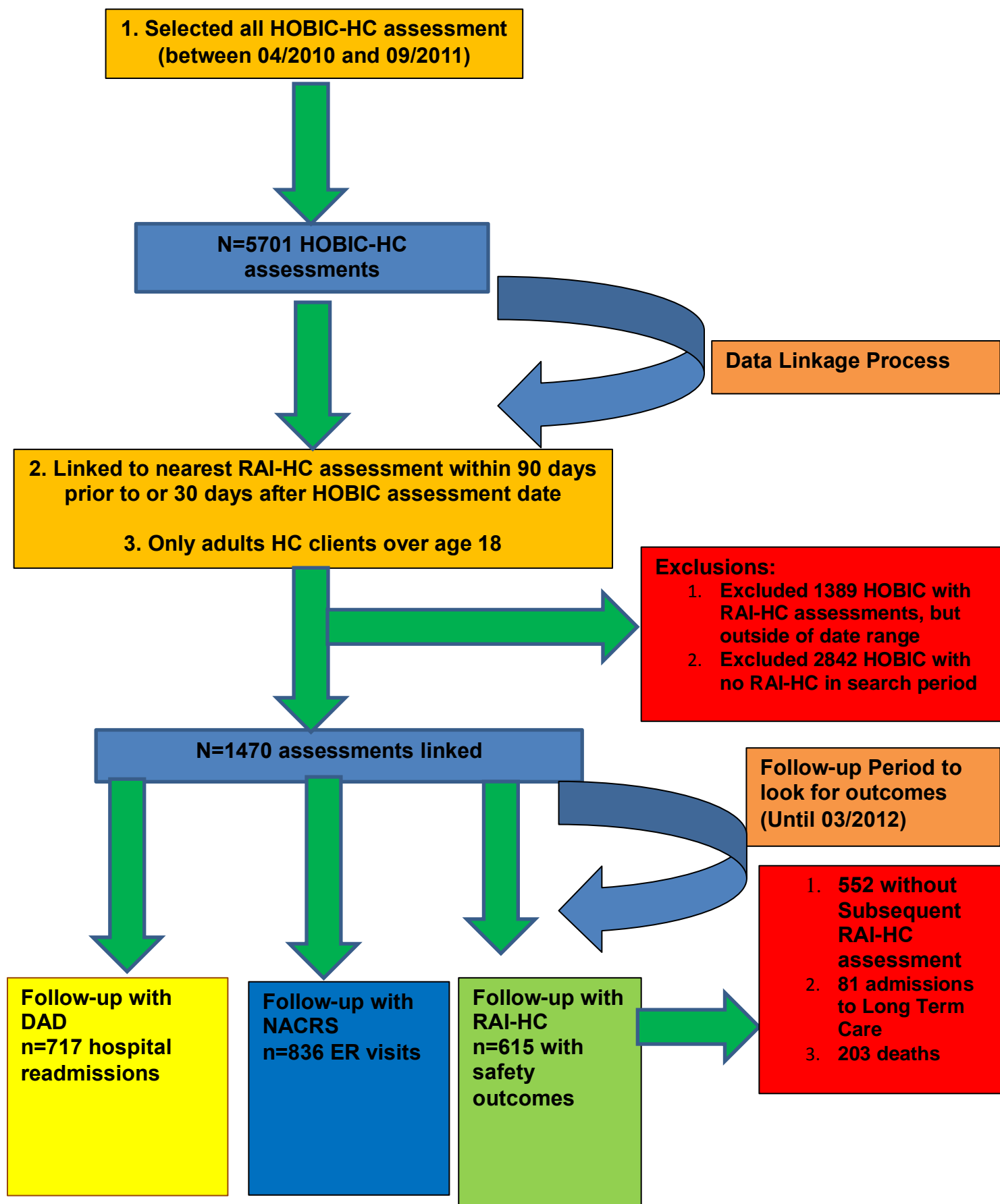
SECTION R. ASSESSMENT INFORMATION

1. SIGNATURES OF PERSONS COMPLETING THE ASSESSMENT:
a. Signature of Assessment Coordinator
b. Title of Assessment Coordinator
c. Date Assessment Coordinator signed as complete
d. Other Signatures
e. _____
f. _____
g. _____
h. _____
i. _____

Although reproduction of the blank forms included herein is not permitted, blank and completed forms may be photocopied for patient clinical assessment purposes related to the administration of the MassHealth program. All other uses are not permitted.

APPENDIX E

Data Linkage Process



Appendix F: Results of Sensivity Analyses

Table 1.1 Logistic Regression Model with Non-Imputed Data: Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to ER Visit

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	1.25	1.01, 1.58	0.05
Over age 75	0.63	0.50, 0.87	0.01
Female	0.77	0.61, 0.97	0.03
Diabetes	1.32	1.03, 1.70	0.03
Education	0.78	0.58, 0.11	0.05
History of ADL Decline	0.75	0.59, 0.96	0.02
Locomotion Outside of Home	0.80	0.62, 1.03	0.08
Any Psychiatry Illness	1.37	0.98,1.89	0.06
Parkinson's	0.40	0.20, 0.79	0.01
Emphysema/COPD/Asthma	1.29	1.00, 1.71	0.05
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	55.54	10	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.62		

Table 1.2 Interaction Model with Non-Imputed Data: Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Hospital Visit

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.63	0.41, 0.96	0.03
Over age 75	1.01	0.79, 1.44	0.66
Female	0.75	0.60, 0.94	0.01
Polypharmacy	0.89	0.54, 1.46	0.64
Polypharmacy*Therapeutic Self-Care	1.67	0.96, 2.92	0.07
CHESS Scores	1.44	1.15, 1.81	<0.00
Congestive Heart Failure	1.75	1.24, 2.46	<0.00
Alzheimer's Disease	1.30	1.00, 1.71	0.02
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	56.58	9	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.62		

Table 1.3. Logistic Regression Model with Non-Imputed Data: Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to New ADL Decline

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.60	0.41, 0.80	0.02
Over age 75	1.76	1.15, 2.70	0.05
Female	1.43	0.98, 2.08	0.06
Chess	2.11	1.44, 3.08	<0.00
History of falls	1.64	1.11, 2.43	0.01
Unsteady gait	1.85	1.19, 2.85	<0.00
Polypharmacy	1.20	1.10, 2.67	<0.00
Anxiolytic medications	1.55	1.01, 2.39	0.05
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	67.49	10	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-index	0.71		

Table 1.4. Logistic Regression Model with Non-Imputed Data: Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to New Client Fall

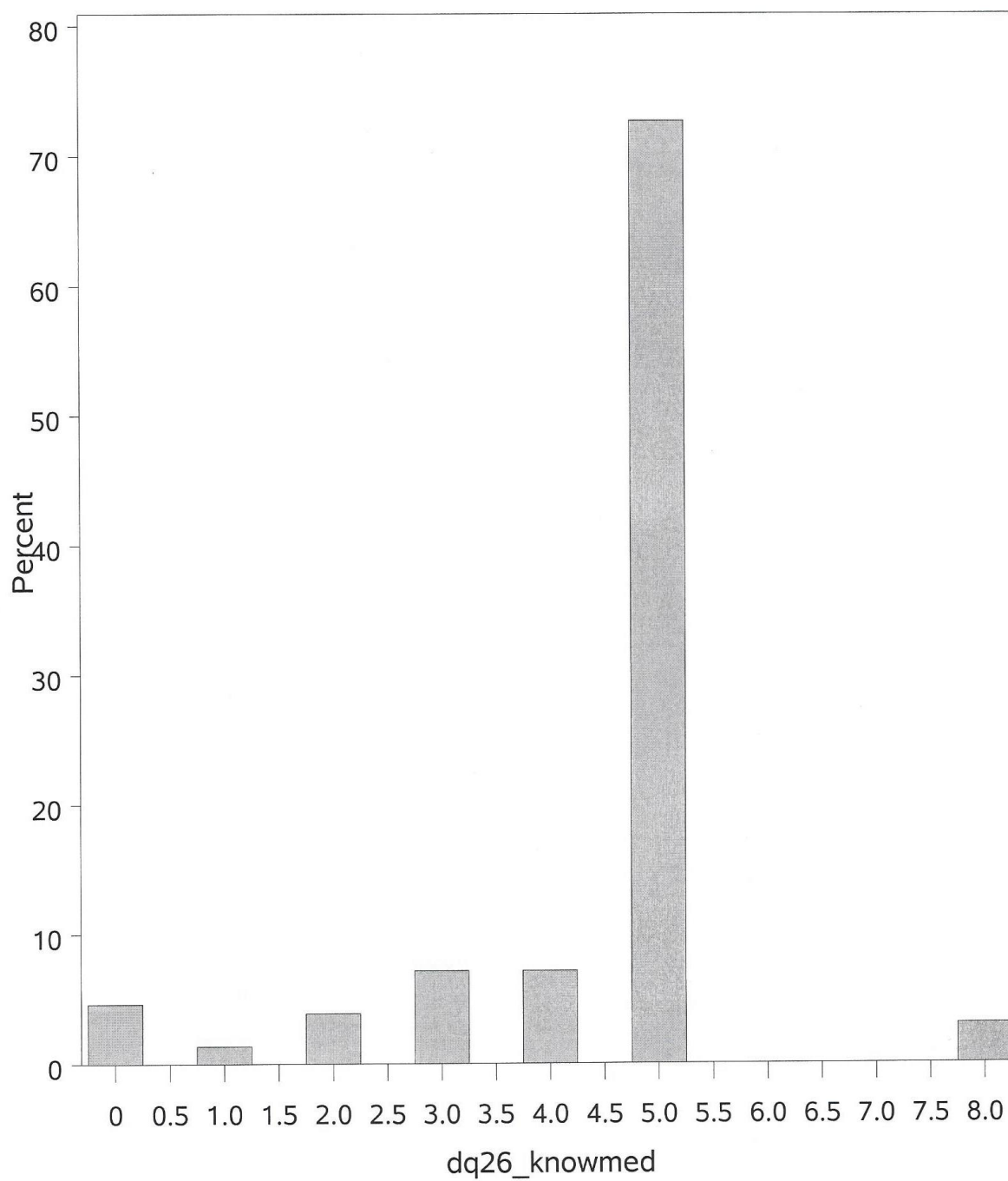
Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.63	0.40, 0.98	0.05
Over age 65	0.93	0.55, 1.58	0.79
Female	0.96	0.65, 1.47	0.91
Anti-depressant medications	1.60	1.05, 2.48	0.03
History of falls	5.82	3.94, 8.61	<0.00
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	98.56	6	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.74		

Table 1.5. Logistic Regression Model with Non-Imputed Data: Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Unintended Weight Loss

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.52	0.30, 0.90	0.02
Over age 75	0.97	0.49, 1.91	0.92
Female	0.74	0.44, 1.24	0.25
Chess	2.18	1.26, 3.77	<0.00
Locomotion Outside of Home	2.83	1.47, 5.44	<0.00
Cancer	2.17	1.24, 3.80	<0.00
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	44.41	11	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-Index	0.72		

Table 1.6. Logistic Regression Model with Non-Imputed Data: Adjusted Odds Ratio Estimates for Therapeutic Self-Care in Relation to Medication Non-Compliance

Variables	Adjusted Odds Ratio	95% Confidence Interval	p-value
Therapeutic Self-Care	0.46	0.26, 0.81	<0.00
Over age 75	1.76	1.13, 2.60	0.55
Female	1.39	0.78, 2.48	0.27
ADL Self-Performance	0.30	0.15, 0.59	<0.00
History of falls	1.82	1.01, 3.28	0.05
Difficulty in Managing Medications	2.93	1.51, 5.69	<0.00
Skin Problems	2.96	1.65, 5.31	<0.00
Model Fit Assessment	Chi-Square	DF	p-value
Likelihood Ratio	40.93	8	<0.00
Model Fit Assessment	Association of Predicted Probabilities and Observed Responses		
C-index	0.73		

Appendix G: Distribution of Therapeutic Self-Care Scores

Appendix H: Potential Risk Adjustment Variables from RAI-HC

Variable Name	Variable Code	Operational Definition
Edema	K3a	Problem condition
Diabetes	J1y	Disease diagnosis
Polypharmacy	Q1	Taking more than 9 medications
Depression Rating Scale	DRS	Scale to measure depressive symptoms
Changes in Health, End-Stage Disease, Signs and Symptoms Scale	Chess	Composite measure of change in health status, end-stage disease and symptoms and signs (e.g. vomiting, dehydration, weight loss and shortness of breath)
Anti-depressant	Q2c	Receipt of psychotropic medication
Cognitive Performance Scale	CPS	Scale to measure level of cognitive impairment
Activity of Daily Living Self-Performance	ADL	Scale to address client's physical functioning in routine personal activities of daily life, for example, dressing, eating etc.
Education	BB6	Education(Highest level completed)
Instrumental Activity of Daily Living Self-Performance	IADL	Scale to measure level of difficulty when performing IADL tasks: meal prep, telephone use, ordinary housework, managing finances, managing medications, shopping and transportation
Transfer	H2b	Including moving to and between surfaces, to/from bed, chair, wheelchair, standing position
Wandering	E3a	Moved with no rational purpose, seemingly oblivious to needs or safety
Arthritis	J1m	Disease diagnosis: Musculoskeletal
Hip fracture	J1n	Disease diagnosis: Musculoskeletal
Cognitive skills for daily decision making	B2a	Cognitive Patterns: how well client made decisions about organizing the day
Other fractures	J1o	Other fractures (e.g. wrist, vertebral)
ADL decline	H3	ADL status has become worse (i.e. now more impaired in self-performance)

Variable Name	Variable Code	Operational Definition
Osteoporosis	J1p	Disease diagnosis: Musculoskeletal
Locomotion in home	H2c	Physical functioning in home
Locomotion outside of home	H2d	Physical functioning outside of home
Cancer	J1x	Disease diagnosis
History of falls frequency	K5	History of number of times fell
Managing Medications	H1d	How medications are managed (e.g. remembering to take medicines, opening bottles, taking correct drug dosages, giving injections, applying ointments)
Self-Reliance Index	SRI	The SRI categorizes clients as being either self-reliant or impaired. Self-reliance is based on being independent or requiring set-up help only on bathing, personal hygiene and walking, and being independent in cognitive skills for daily decision making.
Anxiolytic	Q2b	Receipt of psychotropic medication
Unsteady gait	K6a	Danger of falling
Informal helper lives with client	G1e	Informal support services
Verbally abusive behavioral symptoms	E3b	Threatened, screamed at, cursed at others
Physically abusive behavioral symptoms	E3c	Hit, shoved, scratched, sexually abused others
Socially inappropriate or Disruptive behavioral symptoms	E3d	Disruptive sounds, noisiness, screaming, self-abusive acts, sexual behavior or disrobing in public, smears/throws food/feces, rummaging, repetitive behavior, rises early and causes disruption
Resists care	E3e	Resisted taking medications/injections, ADL assistance, eating, or changes in position
Morbid obesity	L1c	Nutrition/hydration status: weight
Severe malnutrition	L1b	Nutrition/hydration status: weight
Skin problems	N1	Any troubling conditions or changes in skin condition (e.g. burns, bruises, rashes, itchiness, body lice, scabies)
History of pressure ulcers	N2a	Any lesion caused by pressure, shear forces, resulting in damage of underlying tissues
Stroke	J1a	Disease diagnosis: heart/circulation

Variable Name	Variable Code	Operational Definition
Congestive heart failure	J1b	Disease diagnosis: heart/circulation
Coronary artery disease	J1c	Disease diagnosis: heart/circulation
Hypertension	J1d	Disease diagnosis: heart/circulation
Alzheimer's	J1g	Disease diagnosis: Neurological
Dementia other than Alzheimer's disease	J1h	Disease diagnosis: Neurological
Any psychiatric diagnosis	J1s	Disease Diagnosis: Psychiatric/Mood
Parkinsonism	J1l	Disease Diagnosis: Neurological
Emphysema/COPD/Asthma	J1z	Disease Diagnoses

Appendix I

Model Building for Each Outcome:

Client Risk Factors for Inclusion with Therapeutic Self-Care

1. New ER Visits:

- **Risk factors entered in initial model**
 - Age, Gender, Education, Diabetes, CHES, Cognitive Performance Scale, IADL Performance, ADL Performance, Wandering, Cognitive Skill for Daily Decision-Making, History of ADL Decline, Osteoporosis, Locomotion Outside of Home, Locomotion in Home, Managing Medications, Self-Reliance Index, Verbal Abuse, Malnutrition, Skin problems, Parkinson's, any Psychiatry Diagnosis, Emphysema/COPD/Asthma, Coronary Artery Disease
- **Risk factors entered as interaction terms in final model:**
 - Age, Gender, IADL Performance, ADL Performance, CHES, Cognitive Performance Scale, Wandering, Cognitive Skill for Daily Decision-Making, History of ADL Decline, Osteoporosis, Locomotion Outside of Home, Locomotion in Home, Managing Medications, Self-Reliance Index, Verbal Abuse, Coronary Artery Disease

2. New Hospital Visits:

- **Risk factors entered in initial model**
 - Age, Gender, Diabetes, Polypharmacy, CHES, ADL Performance, IADL Performance, History of ADL Decline, History of Falls, Managing Medications, Self-Reliance Index, Anxiolytic, Unsteady Gait, Physical Abuse, Post-Acute, Edema, Anti-Depressant, Congestive Heart Failure, Alzheimer's Disease
- **Risk factors entered as interaction terms in final model:**
 - Age, Gender, Polypharmacy, ADL Performance, CHES, History of Falls, Managing Medications, Congestive Heart Failure, Alzheimer's Disease

3. New Falls:

- Age, Gender, Diabetes, Depression Rating Scale, CHES, Anti-Depressant, ADL Performance, IADL Performance, Transfer, History of ADL Decline, Locomotion in Home, Locomotion Outside of Home, Cancer, History of Falls, Managing Medications, Self-Reliance Index, Unsteady Gait, Skin problems, History of Pressure Ulcer

4. Unintended Weight Loss:

- Age, Gender, Polypharmacy, CHESS, Cognitive Performance Scale, Arthritis, Other Fractures, Osteoporosis, Locomotion Outside of Home, Cancer, Self-Reliance Index, Morbid Obesity, Malnutrition, Skin problem

5. ADL Decline:

- Age, Gender, Edema, Polypharmacy, CHESS, Cognitive Performance Scale, ADL Performance, Wandering, Hip Fracture, Other Fractures, Cognitive Skill for Daily Decision-Making, Locomotion Outside of Home, History of Falls, Managing Medications, Anxiolytic, Unsteady Gait, Physical Abuse, Morbid Obesity, History of Pressure Ulcer

6. Compliance/Adherence of Medication:

- Age, Gender, Polypharmacy, Depression Rating Scale, Anti-Depressant, ADL Performance, Transfer, Other Fractures, Locomotion in Home, Cancer, Managing Medication, Morbid Obesity, Skin Problem

7. Newly Detected Urinary Tract Infection:

- Age, Gender, Diabetes, Polypharmacy, Depression Rating Scale, CHESS, cancer, Self-Reliance Index, Anxiolytic, Verbal Abuse, Malnutrition

8. New Caregiver Distress:

- Age, Gender, Depression Rating Scale, CHESS, Anti-depressant, Cognitive Performance Scale, ADL Performance, IADL Performance, Transfer, Wandering, Arthritis, Cognitive Skill for Daily Decision-Making, History of ADL Decline, Locomotion in Home, Locomotion Outside of Home, Cancer, History of Falls, Verbal Abuse, Physical Abuse, Skin Problem

9. New Pressure Ulcer or Ulcer deterioration:

- Age, Gender, Diabetes, CHESS, ADL Performance, Education, Transfer, Hip Fracture, Locomotion in Home, Cancer, History of Pressure Ulcer, Disruptive Behavioral Symptoms, Resists Care



APPENDIX J

LETTER OF INFORMATION AND CLIENT CONSENT

Study Title: A Mixed Methods Study: Examining the Relationship between Therapeutic Self-Care and Adverse Events For Home Care Clients in Ontario

Request for Participation:

This letter of information and client consent form is intended to give you a basic idea of the research project itself, and the expectations of you as a participant. Please take the time to read this information carefully and to understand what is involved. Specific details such as consent and scheduling will be reviewed with you by phone once you have agreed to participate.

If you would like to participate, or if you have more questions, please contact the researcher, Winnie Sun, via phone call or email using the contact information below:

Principal Investigator: Winnie Sun, RN, MN, PhD candidate
 Lawrence S. Bloomberg Faculty of Nursing,
 University of Toronto
 155 College Street, Suite 130
 Toronto, ON M5T 1P8
 Phone: 416-978-7139
 Fax number: 416-946-7142
 E-mail: winnie.sun@utoronto.ca

Supervisor: Dr. Diane Doran, RN, PhD, Professor
 Lawrence S. Bloomberg Faculty of Nursing, University of Toronto
 Phone: 416-978-2866
 E-mail: diane.doran@utoronto.ca

Purpose:

This study is partial requirement of the PhD thesis requirements of the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto

Clients and informal caregivers (unpaid caregivers) are central to the success of home care. Therefore, it is important that the decisions regarding client services in home care must take into account what the informal caregivers need to help them care for the client, as well as what the clients need to maintain and manage their own health and well-being.

The purpose of this study is to describe what safety challenges clients and their informal caregivers experience related to self-care, and the support needed from home care services.

Invitation:

You are being invited to participate in an interview with the researcher to discuss the types of safety challenges and concerns in relation to managing self-care, and to suggest ways for home care services to improve support for self-care.

Eligibility:

To be eligible to participate, you must be:

- 1) Able to speak and understand English
- 2) Mentally capable of participating
- 3) A client in home care for more than 60 days
- 4) 65 years of age and over
- 5) Having a unpaid, primary caregiver who may or may not live with you, such as family member, friend, relative or neighbor (**Paid caregivers are not eligible**)

Note: You may choose to participate in this study with or without your caregiver.

Procedures

If you decide to take part in this study, an interview will take place in your home, and will be scheduled at a time agreeable to you and your caregiver. However, you may choose to have your caregiver present during the interview, or alternatively, to be interviewed by the researcher alone in a private space. If you prefer, you may be given an alternative option for location to be interviewed. This location could be a suitable public location that is safe and accessible for you and the researcher. The duration of the interview will be approximately 60 minutes and the content of the interview will be audio-taped.

During the interview, you will be asked to provide information concerning yourself and your health status. You will also be asked to answer questions about your experience of managing self-care in the home; the types of safety issues that concern you; your experience with home care services in relation to managing self-care; and making suggestions and recommendations for improving self-care experience in the home.

Conditions For Participation:

Your participation in this study is completely voluntary. You may refuse to participate, withdraw at any time, and decline to answer any question without negative consequences. You may notify the researcher that you wish to withdraw from the study at any point. When you decide to withdraw, you may choose to have any data collected from you not be used in the study and deleted from our databases within 3 months of data collection.

Risk/ Benefits:

You will benefit by participating in this project from knowing that you are contributing to helpful research. Also having the opportunity to discuss your issues and concerns may be an emotional/psychological benefit to you. Although involvement in this study will not result in additional treatment services for you as a client, study findings may provide useful information to home care services with an increased understanding of what client and informal caregiver need to manage self-care and care-giving safely at home. Additionally, you will receive \$20 from the research team as a thank you for your time and cooperation at the end of the interview.

There are no known risks to participating in the study. However, there may be a possibility that you may become emotional when you discuss your self-care experiences. The researcher will be aware of how you are feeling as the interview progresses, and will ask if you would like to stop or have a break at any time to compose yourself. If you need further care and support, you may be referred to the Home Care Hot Line at 1-866-876-7658.

Confidentiality:

All information obtained during the study will be treated in a confidential manner by the research team. Your name will not be linked with any of your health information for this study. You will be identified with a code number so that we can keep track of who is participating. A master code list will be kept in safekeeping in a separate locked filing cabinet from where the data are stored. The data collected during this study will be analyzed and presented in summary form in a way that does not identify any individual. You will never be named in any presentation or report that might be prepared about this study. Your name and contact information will be stored in a file, away from the interview data. All interview data will be kept in a password-protected computer. All information obtained in this study will be used for research purposes only.

Rights of Participants:

You may choose not to participate, refuse to answer any questions, and refuse to give permission for the use of your health information. You waive no legal rights by participating in this study.

Dissemination of Findings:

You may request a copy of the study results at the end of the study by contacting the researchers.

Contact Persons:

If you would like to discuss any aspects the study please feel free to contact the researcher, Winnie Sun at (416) 978-7139 or email: winnie.sun@utoronto.ca

If you have questions about your rights as a research participant, please contact Office of Research Ethics, University of Toronto, at telephone 416-946-3273 or by e-mail at ethics.review@utoronto.ca

Consent to Participate for Client:

I had an opportunity to discuss this study, and any questions that I have asked have been answered to my satisfaction. I voluntarily consent to participate in the study “A Mixed Methods Study: Examining the Relationship Between Therapeutic Self-Care and Adverse Outcomes For Home Care Clients in Ontario.”

_____	_____	_____
Participant's Name (Print)	Participant's Signature	Date
_____	_____	_____
Investigator's Name	Investigator's Signature	Date

Please fax the signed consent form to the researcher, Winnie Sun, Lawrence S. Bloomberg Faculty of Nursing at fax number (416) 946-7142

Thank you very much for taking the time to consider this request!

APPENDIX K

LETTER OF INFORMATION AND INFORMAL CAREGIVER CONSENT

Study Title: A Mixed Methods Study: Examining the Relationship between Therapeutic Self-Care and Adverse Events For Home Care Clients in Ontario

Request for Participation:

This letter of information and client consent form is intended to give you a basic idea of the research project itself, and the expectations of you as a participant. Please take the time to read this information carefully and to understand what is involved. Specific details such as consent and scheduling will be reviewed with you by phone once you have agreed to participate.

If you would like to participate, or if you have more questions, please contact the researcher, Winnie Sun, via phone call or email using the contact information below:

Principal Investigator: Winnie Sun, RN, MN, PhD Student
Lawrence S. Bloomberg Faculty of Nursing,
University of Toronto
155 College Street, Suite 130
Toronto, ON M5T 1P8
Phone: 416-978-7139
Fax: 416-946-7142
E-mail: winnie.sun@utoronto.ca

Supervisor: Dr. Diane Doran, RN, PhD, Professor
Lawrence S. Bloomberg Faculty of Nursing, University of Toronto
Phone: 416-978-2866
E-mail: diane.doran@utoronto.ca

Purpose:

This study is partial requirement of the PhD thesis requirements of the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto

Clients and informal caregivers (unpaid caregivers) are central to the success of home care. Therefore, it is important that the decisions regarding client services in home care must take into account what the informal caregivers need to help them care for the client, as well as what the clients need to maintain and manage their own health and well-being.

The purpose of this study is to describe what safety challenges clients and their informal caregivers experience related to self-care, and the support needed from home care services.

Invitation:

You are being invited to participate in an interview with the researcher to discuss the types of safety challenges and concerns in relation to care-giving, and to suggest ways for home care services to improve support for informal caregivers.

Eligibility:

To be eligible to participate, you must be:

- 1) Able to speak and understand English
- 2) Providing care to your loved one who is currently receiving home care services, and is expected to receive services for more than 60 days
- 3) A unpaid, primary caregiver who may or may not live with your loved one, such as a family member, friend, relative or neighbor (**Paid caregivers are not eligible to participate**)

NOTE: You may choose to participate in this study with or without your loved one.

Procedures

If you decide to take part in this study, an interview will take place in your home, and will be scheduled at a time agreeable to you and your loved one. However, you may choose to have your loved one present during the interview, or alternatively, to be interviewed by the researcher alone in a private space. If you prefer, you may be given an alternative option for location to be interviewed. This location could be a suitable public location that is safe and accessible for you and the researcher. The duration of the interview will be approximately 60 minutes and the content of the interview will be audio-taped.

During the interview, you will be asked to provide information concerning yourself and your health status. You will also be asked to answer questions about your experience of providing care-giving in the home; the types of safety issues that concern you as a caregiver; your experience with home care services in relation to support for care-giving; and making suggestions and recommendations for improving care-giving experience in the home.

Conditions For Participation:

Your participation in this study is completely voluntary. You may refuse to participate, withdraw at any time, and decline to answer any question without negative consequences. You may notify the researcher that you wish to withdraw from the study at any point. When you decide to withdraw, you may choose to have any data collected from you not be used in the study and deleted from our databases within 3 months of data collection.

Risk/ Benefits:

You will benefit by participating in this project from knowing that you are contributing to helpful research. Also having the opportunity to discuss your issues and concerns may be an emotional/psychological benefit to you. Although involvement in this study will not result in additional treatment services for your loved one as a client, study findings may provide useful information to home care services with an increased understanding of what client and informal caregiver need to manage self-care and care-giving safely at home. Additionally, you will receive \$20 from the research team as a thank you for your time and cooperation at the end of the interview.

There are no known risks to participating in the study. However, there may be a possibility that you may become emotional when you discuss your care-giving experiences. The researcher will be aware of how you are feeling as the interview progresses, and will ask if you would like to stop or have a break at any time to compose yourself. If you need further care and support, you may be referred to the Home Care Hot Line at 1-866-876-7658.

Confidentiality:

All information obtained during the study will be treated in a confidential manner by the research team. Your name will not be linked with any of your health information for this study. You will be identified with a code number so that we can keep track of who is participating. A master code list will be kept in safekeeping in a separate locked filing cabinet from where the data are stored. The data collected during this study will be analyzed and presented in summary form in a way that does not identify any individual. You will never be named in any presentation or report that might be prepared about this study. Your name and contact information will be stored in a file, away from the interview data. All interview data will be kept in a password-protected computer. All information obtained in this study will be used for research purposes only.

Rights of Participants:

You may choose not to participate, refuse to answer any questions, and refuse to give permission for the use of your health information. You waive no legal rights by participating in this study.

Dissemination of Findings:

You may request a copy of the study results at the end of the study by contacting the researchers.

Contact Persons:

If you would like to discuss any aspects the study please feel free to contact the researcher, Winnie Sun at (416) 978-7139 or email: winnie.sun@utoronto.ca

If you have questions about your rights as a research participant, please contact Office of Research Ethics, University of Toronto, at telephone 416-946-3273 or by e-mail at ethics.review@utoronto.ca

Consent to Participate for Informal Caregiver:

I had an opportunity to discuss this study, and any questions that I have asked have been answered to my satisfaction. I voluntarily consent to participate in the study “A Mixed Methods Study: Examining the Relationship Between Therapeutic Self-Care and Adverse Outcomes For Home Care Clients in Ontario.”

_____	_____	_____
Participant's Name (Print)	Participant's Signature	Date

_____	_____	_____
Investigator's Name	Investigator's Signature	Date

Please fax the signed consent form to the researcher, Winnie Sun, Lawrence S. Bloomberg Faculty of Nursing at fax number (416) 946-7142

Thank you very much for considering our request!

APPENDIX L:

LETTER OF INFORMATION FOR HOME CARE SUPERVISOR

Study Title: A Mixed Methods Study: Examining the Relationship between Therapeutic Self-Care and Adverse Events For Home Care Clients in Ontario

Request for Assistance with Participant Recruitment:

This letter of information is intended to give you a basic idea of the research project itself, and the expectations of you to help with the participant recruitment. Please take the time to read this information carefully and to understand what is involved. Thank you for your participation!

Purpose:

This study is partial requirement of the PhD thesis requirements of the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto

Clients and informal caregivers (unpaid caregivers) are central to the success of home care. Therefore, it is important that the decisions regarding client services in home care must take into account what the informal caregivers need to help them care for the client, as well as what the clients need to maintain and manage their own health and well-being.

The purpose of this study is to describe what safety challenges clients and their informal caregivers experience related to self-care, and the support needed from home care services.

Assistance with Participant Recruitment:

You are being invited to assist with identifying eligible clients and their informal caregivers who are willing to participate in one-on-one, semi-structured interview. The following are eligibility criteria for clients and their informal caregivers:

To be eligible to participate, clients and their informal caregivers must be:

- 1) Able to speak and understand English
- 2) Mentally capable of participating
- 3) A client in home care for more than 60 days
- 4) A client who is 65 years of age and over
- 5) A primary caregiver who may or may not live with the client, such as family member, friend, relative or neighbor (**Paid caregivers are not eligible**)

Note: Clients may choose to participate in this study with or without their informal caregivers.

Sampling:

To achieve maximum variation sampling, you are asked to seek variation in the study sample by identifying diverse groups of clients and their informal caregivers. The following are examples of variation in study sample:

1. Age
2. Gender
3. Variations in types of informal caregivers (ie. spouse, siblings, daughter, son, relatives, friends or neighbors)
4. Length of time receiving home care services
5. Different types of medical diagnoses or chronic diseases
6. Receiving different types of home care services
7. Diversity in ethnic background
8. Variations in geographical locations (ie. urban or rural areas)

Procedures

Once you are able to identify eligible participants, you are asked to obtain client's permission to release their names and contact information to the researcher. Eligible clients and their caregivers will be contacted by the researcher by phone to obtain informed consent.

If you have more questions, please contact the researcher, Winnie Sun, via phone call or email using the contact information below:

Principal Investigator:

Winnie Sun, RN, MN, PhD candidate
 Lawrence S. Bloomberg Faculty of Nursing,
 University of Toronto
 155 College Street, Suite 130
 Toronto, ON M5T 1P8
 Phone: 416-978-7139
 Fax number: 416-946-7142
 E-mail: winnie.sun@utoronto.ca

Supervisor:

Dr. Diane Doran, RN, PhD, Professor
 Lawrence S. Bloomberg Faculty of Nursing, University of Toronto
 Phone: 416-978-2866
 E-mail: diane.doran@utoronto.ca



APPENDIX M: Demographic and Descriptive Data for Client

The following information is being collected strictly for background description only. This description will provide a general profile of client characteristics. Filling out this form is completely voluntary. You may choose not to share this information.

1. Code number of client participant: _____
2. Sex: Male _____ Female _____
3. Age: _____
4. Marital status: Single _____ Married _____ Divorced _____ Widowed _____
5. Who is the primary caregiver at home? _____
6. Living arrangement (i.e. living alone or with spouse): _____
7. Type of dwelling (i.e. house, apartment, stair-climbing etc): _____
8. Date of last hospital stay (if applicable): _____
9. Date of admission to home care services: _____
10. What types of medications are you receiving?

11. What types of health conditions are you having?

12. What types of services are you currently receiving from home care agencies? (i.e. nursing, personal support, physiotherapy , occupational therapy etc)

13. What aspects of care can you perform on your own (i.e. housework, personal care, shopping, meal preparation, managing medications etc)

14. What aspects of care do you have difficulty managing at home? Who provide assistance with managing these aspects of care (ie. family members, friends, neighbours, home care workers etc)

APPENDIX N: Demographic and Descriptive Data for Informal Caregiver

The following information is being collected strictly for background description only. This description will provide a general profile of caregiver characteristics. Filling out this form is completely voluntary. You may choose not to share this information.

1. Code number of caregiver participant: _____
2. Sex: Male _____ Female _____
3. Age: _____
4. Marital status: Single _____ Married _____ Divorced _____ Widowed _____
5. Number of dependents: _____
6. Living arrangement (i.e. living alone or with client): _____
7. Occupation and employment status: _____
8. How long have you been a caregiver for the client? _____
9. Average number of hours of care giving provided to client per week: _____
10. Aspects of care provided to client at home (i.e. housework, personal care, shopping, meal preparation, managing medications, managing finance etc)

11. If you become ill, do you have secondary helper (s) to provide care for the client?

12. Do you have any types of health conditions? If so, what are these conditions?

**13. Are you currently receiving any caregiver respite services from home care agencies?
If so, are you paying for these services or are they publicly funded? How many
hours and what type of respite services**

APPENDIX O: Interview Guide for Client

1. On a typical day, what do you need to do to look after yourself in relation to your (name of health condition)?

- Are there particular tasks you have to do every day/week/periodically?
- Have you had to develop a routine? (ie. personal care, daily activities, exercise program etc)
- Are there things you need to keep track of? (ie. blood pressure, blood glucose levels, dietary intake, urinary output, pain level, medication dosages, exercise and activity levels etc)

[participant will likely indicate things they are doing well and/or challenges]. Let them talk about these but come back to them in more detail later.

2. What was it like establishing your care routine?

- Was there a period of adjustment? (ie. lifestyle changes, learning medical treatments, coping with signs and symptoms, understanding disease conditions, getting help from others etc)
- How did you figure out what you had to do?
- Did you have any help/support? Who from? Was this helpful?
- How long was it before you had to take over and manage on your own?

3. What are the things you feel like you're managing well?

- Why do you think you're managing well with [task]?
- What have been the things that make it possible for you to do this successfully? (ie. support from care providers, knowledge and confidence, social support, community resources etc)

4. Have there been any challenges for you in terms of looking after yourself?

- What are the things that have made it hard for you? (ie. physical limitations, financial issues, inadequate social support, lack of knowledge and confidence, cutbacks on services etc)
- What would you need to do better/feel more confident with this? (ie. compliance with medications, follow-up on exercises, teaching from care provider, changes in home environment, emotional support, financial support, assistive devices/equipment etc)

5. I understand that you're also receiving home care. Tell me about what they do for you.

- What's the home care like?
- What do they do that you can't do for yourself? (ie. nursing care, personal care support, homemaking help, physiotherapy, dietary counseling, social work etc)
- Do they support you in ways that make it easier to look after yourself?
- How does homecare fit with your own self-care? Is it a good fit?

6. Has anything ever happened in relation to your (health condition) that made you feel unsafe?

- Any specific incidents. What happened? What did you do?
- Any ongoing concerns e.g. medication management; blood glucose levels, falls etc.
- Were you prepared for the possibility of these things happening?
- Did you (or anyone else) put anything in place to prevent this from happening again? (ie. modifications to home environment, education and training, referral to resources etc)
- Is there anything that continues to worry you in relation to safety? (ie. risks for falls, decline in activities of daily living, medication errors, being forgetful, knowing when to seek help etc)

7. So given everything we've been talking about, how important is it to you to be actively involved in your own care?

- Dignity
- Independence
- Confidence in your own health
- Quality of Life
- Empowerment
- Self-worth
- Connectedness

APPENDIX P:

Interview Guide for Informal Caregiver

1. On a typical day, what do you need to do to look after your loved one in relation to his/her (name of health condition)?

- Are there particular tasks you have to do for him/her every day/week/periodically?
- Have you had to develop a care routine? (ie. personal care, daily activities etc)
- Are there things you need to keep track of? (ie. blood pressure, blood glucose levels, dietary intake, urinary output, pain level, medication dosages, exercise and activity levels etc)
- [participant will likely indicate things they are doing well and/or challenges]. Let them talk about these but come back to them in more detail later.

2. What was it like establishing your care-giving routine?

- Was there a period of adjustment? (ie. lifestyle changes, learning medical treatments, work scheduling, family adjustment, making care decisions, modifications to social activities etc)
- How did you figure out what you had to do?
- Did you have any help/support? Who from? Was this helpful?

3. What are the things you feel like you're managing well?

- Why do you think you're managing well with [caring task]?
- What have been the things that make it possible for you to do this successfully? (ie. support from care providers, knowledge and confidence, community resources, stress management etc)

4. Have there been any challenges for you in terms of looking after your loved one?

- What are the things that have made it hard for you? (ie. physical limitations, financial issues, inadequate social support, lack of knowledge and confidence, multiple demands)
- What would you need to do better/feel more confident with this? (ie. teaching from care provider, changes in home environment, emotional support, knowing when to get help etc)

5. I understand that your loved one is also receiving home care. Tell me about what they do for your loved one and you as a caregiver.

- What's the home care like?
- What do they do that you can't do for your loved one? (ie. nursing care, personal care support, homemaking help, physiotherapy, dietary counseling, social work etc)
- Do they support you in ways that make it easier to look after your loved one?
- How does homecare fit with your care-giving experience? Is it a good fit?

6. Has anything ever happened in relation to looking after your loved one that made you feel unsafe?

- Any specific incidents. What happened? What did you do?
- Any ongoing concerns eg. fatigue, stress and burnout, multiple responsibilities
- Were you prepared for the possibility of these things happening?
- Did you (or anyone else) put anything in place to prevent this from happening again? (ie. modifications to home environment, education and training, referral to resources etc)
- Is there anything that continues to worry you in relation to safety? (ie. feeling unprepared, medication error, lack of sleep and rest, multiple demands, back injury, emotional needs etc)

7. So given everything we've been talking about, how important is it to you to look after your loved one at home

- Responsibility
- Obligation
- Empowerment
- Self-worth
- Connectedness
- Satisfaction from giving
- Societal expectations
- Rewarding vs. stressful