

Silent Partners in Care: Examining Care Transitions for Caregivers of Hip Fracture and Stroke

Patients

by

Justine Toscan

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AUTHOR'S DECLARATION

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

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

ABSTRACT

Background: Quality of care and patient safety have been demonstrated to be at increased risk during care transitions; making older adults with complex medical issues especially vulnerable due to the multifaceted care they require (Coleman, 2003; Cook et al., 2000; Forster et al., 2003; Murtaugh & Litke, 2002; Picker Institute, 1999; van Walraven et al., 2004). While a strong focus on patient issues during care transitions exists in current literature, there is a dearth of knowledge surrounding the role of informal caregivers in this process. As the senior population continues to grow in Canada, it is inevitable that the health system will be increasingly reliant upon informal caregivers to meet the demanding and complex care needs of older adults. This research explored informal caregiver experiences following an older patient's medical crisis in order to foster a deeper understanding of caregiver needs during transitional care. This work will support efforts to develop viable interventions within formal care settings to better support and prepare individuals for informal care responsibilities (Canadian Caregiver Coalition, 2008; National Centre for Social and Economic Modelling, 2004).

Methods: A qualitative, post-positivist grounded theory study was employed to acquire an understanding of the role and needs of informal caregivers during transitional care. Semi-structured interviews were conducted with six community and resource case managers, and informal caregivers of eight hip fracture and two stroke caregivers. Two additional interviews were conducted with hip replacement caregivers. Questions explored individual experiences interacting with and/or providing informal care, and honed in on observed and experienced challenges, support received, and recommendations for future efforts to support care. NVivo8 software facilitated qualitative data analysis through hierarchical coding (Glaser & Strauss, 1967).

Results: Six properties of caregiver needs arose from the data, each consisting of several important ideas fostering its understanding. The core concept threading across all properties was *building capacity to care*. Combined, thematic interpretations were integrated into a comprehensive *theory of caregiver needs to support a successful care transition from hospital to home*, consisting of three layers: 1) Timeline of caregiver needs; 2) Instrumental needs; and 3) Emotional needs. A member-checking process of the theory consisting of both a focus group and individual interviews indicated high face and content validity, and highlighted priority areas for future interventions.

Discussion: The developed substantive theory is a valuable tool for which to understand the instrumental and emotional needs of hip fracture and stroke caregivers along a timeline of transitional care between hospital and home. Focus group and individual feedback indicate strong endorsement for theory adoption as a guiding framework for an intervention strategy to support informal caregivers within formal care settings and throughout the transition home. Results suggest the potential to broaden the conceptualization of the substantive theory to a formal explanation of transitional care needs for other medical crises across numerous types of transitions between formal hospital settings and the community.

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DEDICATION

I would like to dedicate this thesis to my parents, Frank and Dayle Toscan and my siblings Jordan, Dylan and Julia Toscan, as well as my best friend and biggest fan Andrew Giosa.

To my family—thank you for always believing in me and for supporting me in everything that I do. Without your love and support I could not achieve my goals.

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OVERVIEW

Health care for older adults in Canada exists in a variety of settings including, but not limited to, acute hospital care, in-patient rehabilitation, outpatient clinics, and long-term care homes. The most appropriate setting, or level of care within a setting, dynamically changes as both the level and the intensity of care required by a care recipient varies. Care transitions are defined as those periods in time when individuals shift within or between care settings according to changes in their health and functional status (Covinsky, Palmer, & Fortinsky, 2003). Although it seems logical that individuals move between settings in order to target the appropriate level of care they require, it is during periods of transition when the quality of care and patient safety have been demonstrated to be at increased risk, making older adults with complex medical issues especially vulnerable (Murtaugh & Litke, 2002). To date, a focus on patient issues during care transitions is most prominent in the literature, particularly in community-based transitions. For example, patients often experience medication errors (Moore, Wisnivesky, Williams, & McGinn, 2005), a return to higher intensity care settings (Coleman & Berenson, 2004), and/or inadequate discharge summaries (Kripalani et al., 2007), as a result of poorly executed care transitions. Alone, patient transitional care issues are substantial. However, it should be recognized that multiple stakeholders involved in the care transition process face significant challenges, which have the potential to exacerbate patient-specific difficulties. Therefore, these various perspectives should be incorporated into the research and subsequent literature in this field in order to uncover all potential challenging aspects of transitional care (Coleman & Borenson, 2004).

Specifically, there is a lack of knowledge surrounding the role of the informal caregiver during patient transitions from a formal hospital care setting to more informal care at home in the community. To illustrate the severity of this knowledge gap, caregivers have even been referred to in the literature as “silent victims in a silent system” (Canada’s Association for the Fifty-plus, 1999). Care transitions between hospital and home often involve a sudden shift in care provision from the formal health care team to an informal caregiver, who, many times, is without the necessary skills, knowledge, and tools to manage the care situation confidently or effectively (Covinsky et al., 2003). As family members are often the only common persons a patient encounters during a move between a formal care setting and informal care in the community, the lack of research and practical focus on caregiver needs is worrisome due to the high level of responsibility they often acquire following emergency medical situations (Graham, Ivey, & Neuhauser, 2009).

Further, this gap in knowledge is particularly concerning in light of the current health system reform from largely institutional-based care to more self-directed, informal, home-based care and aging at home strategies, which are often facilitated by an informal caregiver. For example, several Community Care Access Centres (CCACs) in Ontario, including Waterloo-Wellington, have recently adopted a “*Home First*” philosophy for discharge planning in hospital settings. The philosophy is meant to encourage health care providers to investigate the home as the first option for patients who might otherwise experience a lengthy hospital stay, enter long term care, or become designated as Alternative Level of Care (ALC) within an acute care setting (Lanteigne, 2011). This transformation in health care is largely due to the pressure of the aging population on the formal care system, and is leading to an increasing number of individuals being thrust into the caregiving role unexpectedly. Informal caregivers are thus left to navigate the

health care system for a loved one with little formal support and guidance. For example, focus groups conducted as part of *The Caregiver Needs Project* (Dupuis & Smale, 2004; Smale & Dupuis, 2004), with caregivers of dementia patients, uncovered feelings of frustration with having to navigate both within and between a variety of programs and agencies to access the services and support needed. Research focusing on the role and needs of informal caregivers during a medical crisis is therefore crucial to sustain the level of informal care that will be necessary in the coming years.

CHAPTER 1: BACKGROUND & LITERATURE REVIEW

1.1 THE AGING POPULATION: COMPLEX HEALTH NEEDS, HIGH USAGE PATTERNS OF HEALTH SERVICES, AND EXPENSIVE CARE

The Canadian population is undergoing a major demographic transformation, with the percentage of the population aged 65 and older expected to increase to 21% by the year 2027 (Health Canada, 2002; Hébert, 2002). While low fertility rates and increasing life expectancy have been documented by Statistics Canada (2006) as major contributing factors to population aging, much of this demographic shift has been attributed to the aging of Canadians born between 1946 and 1964; known as the baby boom population (Wister, 2005). This age cohort will begin to turn 65 in the year 2012, and by the year 2031 will consist entirely of older adults between 65 and 85 years of age (Wister, 2005). These radical changes in population composition will have major implications for health and disability in Canada, as the increasing representation of older adults is being met with corresponding high demands on the health care system. Over 50% of the highest users of health services in Canada are 60 years of age or older and experience multiple complex, chronic, physical, and mental conditions (Reid, Roos, MacWilliam, Frohlich, & Black, 2002). Freeborn and colleagues (1990) discovered that high users of the health care system report higher numbers of medical conditions and are more likely to indicate suffering from arthritis, high blood pressure, heart conditions and other comorbid chronic issues. The multiplicity and complexity of health concerns faced by the senior population contributes to an increase in challenging, time consuming, and expensive health care services (Reid et al., 2002). As reported by Ruggeri (2002), the average cost of health care in Canada per person aged 65 to 74 exceeds three times the average cost per person in the younger 25 to 44 year old age group.

1.2 THE RISE OF INFORMAL CARE

An aging population, high usage patterns of health services, the complexity of illnesses, and costs of medically treating older adults, are all contributing to a shortage in health resources and creating an unsustainable strain on the already sparse availability of frontline care providers with geriatric expertise (Blanchette & Flynn, 2001). This growing reality makes the role of informal caregivers essential to meet the health needs of the rising senior population (National Centre for Social and Economic Modelling, 2004). In contrast to common belief, 90% of Canadian older adults who require health care services live in private homes, and not in long-term nursing homes (National Advisory Council on Aging, 1999; Agency for Health Care Research and Quality, 2000). Furthermore, current literature suggests that among elders aged 65 and older living with disabilities, the use of formal, paid care has declined, while sole reliance on informal family caregivers has increased (Spillman & Black, 2005). In fact, The Canadian Caregiver Coalition (2008) estimated a prevalence of over four million informal caregivers in Canada. Specifically, these informal caregivers provide approximately 80% of all home care to community-dwelling older adults, and as much as 30% of services to older adults who are institutionalized (National Advisory Council on Aging, 1999). In fact, these statistics may be underestimates of the actual amounts of care provided, as they do not account for the emotional and social aspects of care that caregivers are responsible for. For example, it was found that the average caregiver in Canada spends 13 hours per week providing physical, hands-on care, and just over eight hours per week performing support activities (Duxbury, Higgins, & Schroder, 2009). It is therefore not surprising that, economically speaking, caregivers have been reported to contribute over five billion dollars of unpaid labour annually to Canadian health care (Pollara, 2006). Overall, it is evident that the role of informal care is rising within Canada.

1.3 CAREGIVERS: A HETEROGENEOUS POPULATION

The Family Caregiver Alliance (2006) released a consensual working definition of an informal caregiver, developed by a team of experts with a wide range of health expertise. A caregiver was described as: “any relative, partner, friend or neighbour who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (Family Caregiver Alliance (FCA), 2006). Although there is no one defining caregiver profile, several trends in the caring role have been recognized. A National Caregiver Survey (US) reported that the majority of caregivers are women. Specifically, 71.5% of caregivers are adult daughters and wives (Pinquart & Sorensen, 2006). Further, the majority of informal caregivers are middle-aged, with the mean age reported in North America as 51 years old (FCA, 2010). However, over time, these trends may also be changing. An increased number of males have reported taking on the caregiver role. In fact, a 50% increase in men becoming caregivers since 1994 has been reported (Spillman & Pezzin, 2000). The population of caregivers themselves is also aging alongside care recipients. According to Australian research evidence, the number of caregivers aged 65 and older will increase by 110% by the year 2031 (NATSEM, 2004).

1.4 CAREGIVER STRESS: HEALTH AND FAMILY

The diversity of the caregiver population makes it extremely challenging to predict which caregiver profile is the most vulnerable. However, evidence suggests that health and family stress are of major concern, and have age-specific impacts (Bull, Bowers, Kirschling, & Neufeld, 1990). Compared to non-caregivers, informal caregivers are themselves at increased risk for health problems due to the complexity, physical, and emotional strain of the caring role (Levine, Reinhard, Feinberg, Albert, & Hart, 2004). The majority of literature to date has focused mainly

on the decline of caregivers' mental health as a result of the increased stress and pressure of providing care (Pinquart & Sorensen, 2003). Caregivers have also reported feeling frustrated, angry, drained, guilty or helpless as a result of their caring role (Center on Aging Society, 2005). Not surprisingly then, between 40 to 70% of caregivers have clinically significant symptoms of depression (Zarit, 2006). Recent evidence also suggests that caregiving takes a significant toll on an individual's physical health. In 2005, three-fifths of caregivers reported fair or poor health status, one or more chronic conditions, or a disability, compared with one-third of non-caregivers (Ho, Collins, Davis, & Doty, 2005).

More specifically, the mental and physical health impacts of providing care are often exacerbated with age. Compared to their younger counterparts, older caregivers (aged 65 and older) report lower perceived health, increased use of psychotropic drugs, and higher prevalence of emotional and mental health issues, especially depression (Vitaliano, Zhang, & Scanlan, 2003). Physically, older caregivers are more likely to be dealing with their own chronic health issues in relation to the normal aging process (NATSEM, 2004). In 2005, older caregivers reported chronic conditions including heart attack, heart disease, cancer, diabetes and arthritis at nearly twice the rate of non-caregivers (45% versus 24%) (FCA, 2006). Based on these statistics, it is clear that in addition to concerns with patient health care quality, maintaining caregiver health during transitional care should be a priority.

Family dynamics can also contribute to the vulnerability of informal caregivers. The nuclear family of the 20th century consisting of a mother, father, and children all living within the same household, has evolved over time. The current and growing trend is that of a "blended" family, which usually increases the number of individuals considered to be members of a family. Most often, within blended families, stepparents and children living in multiple dwellings

become connected through divorce and re-marriage. While it may seem advantageous to be part of a larger family, with more individuals available to assist with the care of older family members, several aspects of this situation can be considerably challenging and stressful. First, larger families increase the possibility of more individuals requiring care, perhaps even simultaneously (Bengtson, 2001). Coordinating care responsibilities when multiple siblings are involved in the care of a parent or grandparent can be difficult. Relationship quality between generations, care recipient expectations, socioeconomic factors, available financial resources, and geographic dispersion are major stressors discussed in the literature (Suitor & Pillemer, 1988). For example, geographic distance between family members can cause unequal sharing of care tasks. The typical family pattern found to date is that one sibling, usually a daughter who lives close to their elderly parent, assumes the majority of the care responsibilities (Willyard, Miller, Shoemaker, & Addison, 2008).

Further, middle-aged individuals often experience a confusing shift in familial roles as a result of becoming an informal caregiver. Having to care for their full grown parents can be both psychologically and emotionally draining for adult children due to the strange nature of the role reversal (Levine, Reinhard, Feinberg, Albert, & Hart, 2004). For example, it has been noted that role reversals create an increase in a parent's dependence on their adult children, which may result in a reduction of positive feelings between the generations, and often creates tension in the relationship (Suitor & Pillemer, 1988). Further, middle aged caregivers are more likely to suffer multiple role strain, often caring for both children under the age of 18 and adults over the age of 65, while also participating either full-time or part-time in the workforce (Cantor, 1983). This complex, multigenerational caring role is often referred to as "sandwich caregiving" (Fredriksen & Scharlach, 1999).

1.5 CAREGIVER WELLBEING: ADOPTING A FAMILY-CENTERED APPROACH

Overall, it is important to recognize the vulnerabilities of the informal caregiver(s) associated with a particular care situation, in order to protect the health and wellbeing of all individuals involved. As patient-centred care has largely become the gold standard for current formal care delivery (MacKean, Thurston, & Scott, 2005) efforts should be made to expand this concept to include the needs and interests of families as a whole. Family-centred care should support and nurture the mutually beneficial relationships between patients, families, and relevant health care providers, and recognize that families provide the context for which to enhance the planning and delivery of health care services (Institute of Family Centered Care, 2007). For example, within a dementia context, Smale & Dupuis (2004) developed an alternative, family-centered framework for Dementia care in Ontario, called the *Dementia Supportive Environment Framework*. This framework is based directly on guiding principles identified in focus groups including both professionals and dementia caregivers, and aims to support families as caregiver “units” in order to maintain their overall wellbeing. In order to protect and promote their ongoing care efforts, a key issue is recognizing that the unit of care during transitions between formal settings and the community includes both the patient and the caregiver. Adopting a family-centred, rather than patient centred approach to care, should be extended into transitional care priorities, in order to support both patients and their families as they work together to manage an illness across the care continuum (National Consensus Project for Quality Palliative Care, 2004).

1.6. FLUCTUATING LEVELS OF CARE

The spectrum of informal caregiving encompasses a broad range of tasks that vary in difficulty from relatively simple, to more complex responsibilities that more closely resemble long-term care, and quite often, even higher skill level tasks mirroring hospital care (Levine et

al., 2004). Informal caregiving may involve medical nursing tasks such as applying wound dressings, infusion therapies, and tube feeding often directed by health care professionals. Caregivers also attend to personal care needs such as bathing, dressing, eating, or toileting, as well as support activities such as preparing meals, assistance with household chores, managing medications, and balancing finances (Canadian Caregiver Coalition, 2008; Levine, 2000). This wide range of care responsibilities tends to vary according to the level of care required by a care recipient and typically fluctuates according to both changes in health and functional status, as well as movement between care settings with varying levels of formal care (Covinsky et al., 2003). Transitional care is the term used to indicate the formal care provided to patients as they move between care sites with a primary aim to coordinate and provide continuity in healthcare across the continuum (Coleman & Berenson, 2004; Coleman & Bolt 2003). However, it is more often that the informal care provider rather than the formal health care team is left to shoulder the immense responsibility of facilitating and coordinating information between settings including acute hospital, post-acute care, long-term care, and home (Coleman & Williams, 2007). Therefore, in addition to their hands-on care provision, informal caregivers are left to act as the single “point person” during a patient transition with little support and guidance. Complicating matters further, is the issue that care settings too often function in isolation of each other (Coleman, 2003; Coleman & Boulton, 2003; FCA, 2006).

1.7 CARE TRANSITIONS: PATIENT AND CAREGIVER CHALLENGES

According to the American Geriatrics Society, continuity and coordination of health care experienced by patients as they move between different care settings is essential to the quality of care transitions (Coleman, 2003). Transitions from formal care settings to care in the home, often involve shifts in responsibilities in care provision from healthcare providers to informal

caregivers, requiring the transfer of patient medical information, care planning documents, and training to ensure informational continuity to support care (Haggerty et al., 2003). Support in the form of information promotes positive caregiver self-esteem, self-worth, and confidence in care abilities. Further, enhancing caregiver involvement, training, and support during the transition process has the potential to reduce unnecessary re-hospitalizations and better patient outcomes (Levine, Halper, Peist, & Gould, 2010). However, this is not indicative of the current picture of transitional care, as research has shown that between a quarter and half of all adverse events post-transition leading to re-hospitalization may be prevented (Forster et al., 2003; Naylor, 2002).

Research has demonstrated that both patients and caregivers are vulnerable during care transitions, with patients' safety and care quality threatened, while caregivers suffer from anxiety due to lack of preparedness for the caring role (Coleman, 2003; Cook, Remder & Woods, 2000; Gandhi 2005; Levine, 2000; Naylor, 2000; 2002; Picker Institute 1999; van Walraven et al., 2004). It is well documented that informal caregivers often feel unprepared in regards to the care required for the complex needs of patients, post-transition. McWilliam and Sangster (1994) report that caregivers often feel insufficiently informed on patient medication regimens, treatment protocols and dietary needs. Further, interviews with caregivers by Weaver and colleagues (1998) revealed that caregiver stress was inversely related to receiving formal instruction about medications, equipment, supplies, and care instructions post-discharge from a hospital to home setting. However, another study reported that rather than relying on health care professionals, informal caregivers most often rely on family and friends as the most common source for information on how to provide care post-discharge from a hospital. It was found that any information provided by health care professionals was too broad and unspecific, according to

unique family situations and need (Cumbler, Carter & Kutner, 2008; Graham, Ivey & Neuhauser, 2009;). This lack of formal support is bound to result in suboptimal patient care from inexperienced and uninformed informal caregivers. This is clearly evidenced in a recent National US survey revealing that while two-thirds of Americans over the age of 18 expect to become a caregiver in the future, 56% report feeling unprepared for both basic caregiving tasks, such as bathing, dressing, and toileting, as well as nursing care including medication assistance (Opinion Research Corporation, 2005). This is cause for concern, as the anxiety of transitioning into caring role and assuming responsibility for assisting a loved one can cause caregiver stress and burnout.

There is clearly a growing need to recognize the integral role played by informal caregivers during the transitional care. Coleman and Williams (2007) address the importance of informal caregivers within transitional care, referring to them as “silent partners” whose role is often unrecognized and unsupported. Further, the Family Caregiver Alliance (2006) refers to informal caregivers as the backbone of the health care system. However, the significance of their role and the stress and health issues they face are far too often overlooked. For example, The New York Hospital Fund reviewed over 150 transition protocols from hospitals within the United States, and found that only a few referred specifically to the role of informal caregivers (The Next Step in Care, 2006). Clearly the unexpected caregiving experience demands more attention in the literature, with a particular focus on the onset phase of care activities.

1.8 THE MOVE FROM A FORMAL TO INFORMAL CARE SETTING: THE TRANSITION FROM HOSPITAL TO HOME

It is important to recognize that like patients, informal caregivers also experience transitions between stages in care. These stages correspond and change according to a loved one’s

illness trajectory and intensity level of assistance required, both during their formal hospital care experience, and especially upon return home to the community. Schulz and Sherwood (2008) identify four caregiver transitions crucial to understanding the adoption and enactment of the informal caregiving role. The first transition occurs when caregivers begin assisting a relative with instrumental activities of daily living (IADLs) including, household chores and finances, and may not self-identify as a caregiver. The second transition occurs when a caregiver begins assisting an individual with activities of daily living (ADLs) including bathing, dressing and toileting, and is more likely to recognize their role as a caregiver. The third caregiver transition occurs when a caregiver moves an individual into a long-term care home, and the fourth transition occurs when the individual passes away. It is the second transition, the transition into providing assistance with ADLs, which Schulz identifies as being the most stressful.

Similarly, Aneshensel and colleagues (1995) have described the concept of caregiving as a process that follows along a trajectory as a “career” with three distinctive stages: 1) role acquisition, where an individual recognizes the need for care assistance and assumes the tasks, obligations and responsibilities required of the role; 2) role enactment, where the caregiver performs the necessary care tasks within the home, or sometimes even within a formal setting; 3) role disengagement, the end of the caregiver career, usually following a death of the care recipient. As shown in Figure 1, the shift between role acquisition and role enactment occurs between the “career phases” of starting to provide care and care in the home. Interestingly, the single arrow depicting this process in Figure 1, suggests a relatively straightforward and direct transition between formal and informal settings of care, which does not adequately reflect the immensely stressful and multifaceted onset of care responsibilities described by Schulz. Further,

the idea that the transition between formal and informal settings of care is a challenging and complex process is further supported in the literature.

Figure 1: The caregiver career (Aneshensel et al., 1995)

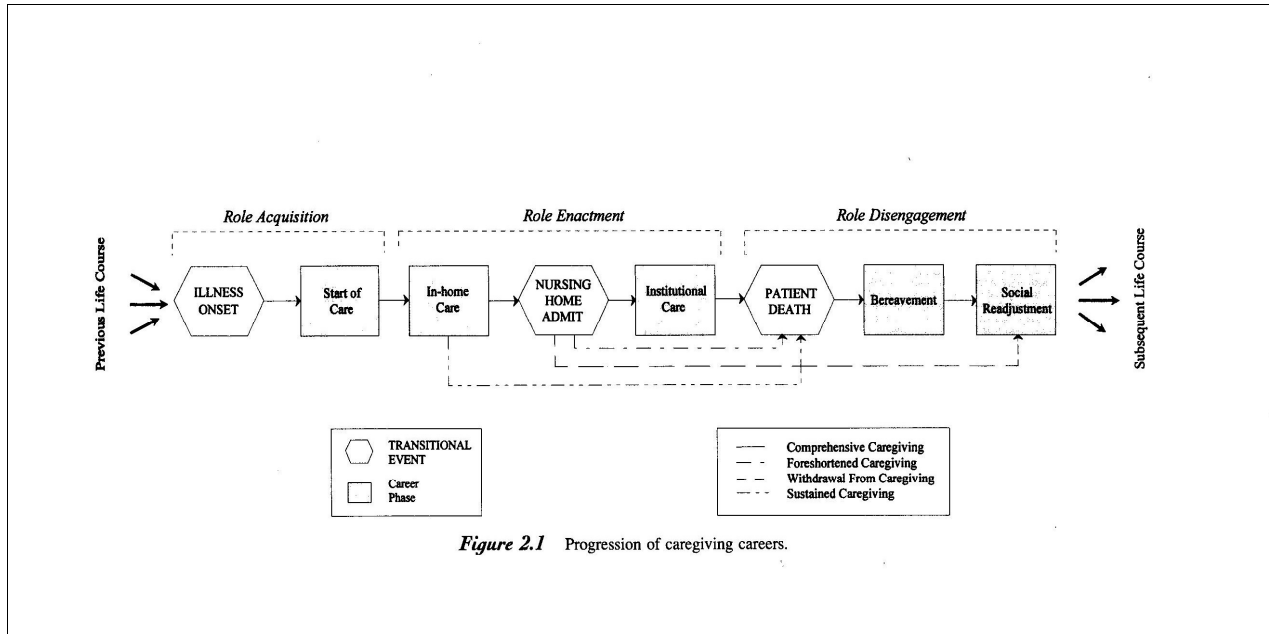


Figure 2.1 Progression of caregiving careers.

The transition from hospital to home has been identified as a specific stage of intensified stress for family members, and can perpetuate negative implications on patient care (Bull, 1992; Bull, Maruyama, & Luo, 1995). For caregivers, issues of ensuring patient safety, assisting with activities of daily living (ADLs), as well as dealing with the behavioural and emotional changes of their loved ones are some of the most prominent issues arising during the transition from hospital to home (Grant et al., 2006). Correspondingly, it has been reported that seniors are at a heightened risk for medication errors, therapeutic errors, and infection, that often lead to hospital readmission following a transition between hospital and home (Coleman & Boulton, 2003; Coleman, Smith, Raha, & Min, 2005; Naylor, 2004).

1.9 THE NEED TO UNDERSTAND CAREGIVER NEEDS

Overall, these often unexpected and unanticipated challenges post-discharge from a hospital setting can create high levels of family stress, which then exacerbate patient challenges as they are trying to manage an illness within a home setting. Based on this evidence, it is clear that further research is needed which focuses specifically on uncovering the challenges and recognizing the needs of caregivers during the transition between hospital and home. A deeper understanding of the process between role acquisition and role enactment of the caregiving career, might contribute to an extension of this guiding theoretical concept, as well as ideas for novel interventions which might help to ameliorate the stress faced by both patients and their caregivers. The necessity to focus on the needs of informal caregivers assisting patients recovering from an acute medical crisis is further driven by current health policy shifts, the structure of hospital care, as well as significant gaps in the literature.

1.9.1 Aging At Home Strategy

A focus on the transition from acute hospital to home fits well within the context of the current Aging at Home Strategy in Ontario (Williams et al, 2009). This policy shift recognizes that most seniors wish to continue living at home as long as possible, and plans to implement community supports to match the needs of older adults and their caregivers in order to promote home as an optimal transitional care destination (Waterloo-Wellington Local Health Integration Network, 2007). Therefore, the needs and concerns of caregivers during hospital discharge to home should first be ascertained directly from those who have undergone the experience in order to target appropriate assessment and intervention strategies to dampen stress during emergency situations of care.

1.9.2 Discharge driven hospital care

Further exacerbating the stress of patients and caregivers, hospital care is discharge focused, resulting in shorter hospital stays that often require patients to transition home before their recovery is complete (Bull et al., 1990). Shorter hospital stays often lead to poor and limited discharge planning, inadequate training, and limited education, preparation and support for assuming active care responsibilities in the home (Donelan et al., 2002; Graham et al., 2009). All of these elements combined create a very challenging adjustment period for both patients and caregivers post- discharge; reports show that up to one quarter of discharged hospital patients face readmission due to this complex care situation (Murtaugh & Litke, 2002). Therefore, caregiver research focused specifically on the needs of caregivers during the transition from hospital to home is of particular importance in light of current care issues.

1.9.3 Managing Family Stress

Patterson (1988) developed the Family Adjustment and Adaptation Response (FAAR) model to describe how a family system is able to manage stress. The model focuses on the concept that families must maintain a balance between their capabilities (resources and coping strategies) and their demands (stressors) in order to adjust and adapt successfully when a crisis takes place. Research emphasis to date has been placed on issues related to chronic caregiver stress and impacts of stress on primary informal caregivers (Kahana, Kahana, Johnson, Hammond & Kirchner, 1994). These efforts have taken a largely reactive approach to caregiver stress management, with less of a focus on exploring proactive strategies to prevent long-term negative implications on caregiver health and lifestyle. As a result, the stressors that caregivers face are better understood than the resources and strategies they employ to overcome them. Researchers have recognized that short-term coping strategies for caregivers following a medical

crisis are different than long-term coping strategies, and therefore should have equal focus in the literature (Han & Haley, 1999).

Exploration into the needs and concerns of caregivers providing acute episodes of care following patient discharge from hospital to home is lacking, and there is an immense need to extend beyond caregiver stress literature (Bull et al., 1990). Specifically, there exists limited research addressing caregivers of hip fracture patients (Brown & Furstenberg, 1992; Williams, Oberst, Bjorklund & Hughes, 1996;), as well as other older adults who have experienced a medical crisis such as a stroke (Kinney, Stephens, Franks & Norris, 1995; Segal and Schall, 1997). It is following these unexpected medical crises, with periods of intense care during transitions, that family members and friends are often thrust into the caregiver role with little support or guidance.

CHAPTER 2: STUDY RATIONALE & OBJECTIVES

2.1 OVERALL PURPOSE

Caregiver needs during transitional care between formal hospital settings and informal settings in the community have not been actively researched. Therefore, an opportunity exists to address this knowledge gap in order to better support and guide caregivers during transitional care. While several efforts have been made by clinicians and researchers to develop strategies with this goal in mind, initiatives to date have largely failed to include caregiver experiences (i.e., knowledge, challenges, needs, recommendations) in their development and/or evaluation. Therefore, current support efforts are not adequately meeting the unique needs of informal caregivers, and, in fact, may be irrelevant to them. Prior to the development of additional caregiver-focused interventions, a more holistic understanding of the transition experience for family members, from their perspective, is needed. The ultimate goal of this research was to use direct caregiver input, in conjunction with health professional opinion, to develop a comprehensive theory of caregiver needs in order to inform the development of targeted interventions to most appropriately support families during transitional care.

2.2 LACK OF CAREGIVER INPUT INTO CURRENT INTERVENTION AND SUPPORT STRATEGIES

Despite several efforts that have been made in the literature to define the informal caregiver role, there is a lack of consensus on the components of this role. Recognizing this knowledge gap, Coleman and Williams (2007) suggested standardizing the definition, as well as the intensity of the roles of informal caregivers based on the “FACED” classification. Each letter of this proposed classification refers to a different task of caregiving: financial, advocacy, care coordination, emotional support, and direct care provision. Coleman and Williams (2007)

suggest that such a definition could inform health care providers about caregiver roles and capabilities to improve transitional care collaboration. However, informal caregivers were not included in the development of this classification, and further, it has yet to be widely adopted.

Additionally, The Family Caregiver Alliance (2006) has proposed the idea of incorporating family caregiver assessment into the spectrum of transitional care for older adults. This Alliance hosted The National Consensus Development Conference for Caregiver Assessment in 2005, which involved 54 recognized experts in caregiving. These experts deliberated on caregiver assessment in order to reach consensus on principles and guidelines for policy and practice. Seven guiding principles were agreed upon in order to foster a working definition of caregiver assessment:

“...a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver” (FCA,2006, p.5).

Further, it was discovered that systematic assessment occurs in medical settings typically for the patient only, therefore health professionals are unable to predict the support a caregiver may need distinctly separate from the patient (Baxter, 2000). In order to facilitate changes in practice, the “experts” proposed several domains and constructs to consider incorporating into caregiver assessments including: personal and environmental context, caregiver perception of health status of the patient, caregiver values and preferences, well-being of the caregiver, consequences of caregiving (challenges and benefits), and lastly potential resources that the caregiver could choose to use (FCA, 2006). Again, direct caregiver input was not incorporated into the development of priority items for caregiver assessment, and while consensus among experts regarding these items was reached, no specific tools have been developed based on the agreed upon domains and constructs.

The Canadian Caregiver Coalition (2008) also created a framework of guiding principles

for a Canadian Caregiver Strategy to ensure that the perspectives of caregivers are considered and represented in care decision-making. These principles include showing caregivers respect, allowing them to exercise choice, and giving them the opportunity for self-determination through providing information, assessing their needs, and through support interventions. Further, two national research priorities were identified in this strategy. Firstly, and most importantly, is the recognized need to invest in research on caregiving in order to make evidence-informed decisions. Additionally, the strategy places high priority on assessing caregivers for their own specific needs in order to sustain their contribution to care. Therefore, this study will integrate well within the context of current Canadian research frameworks.

Finally, there exists one particular caregiver intervention specifically targeted to caregivers of patients undergoing a transition from hospital to home. *The Next Step in Care* was developed in 2006 by a multidisciplinary team of health care professionals involved with the United Hospital Fund in New York. This online intervention strategy provides 20 free downloadable guides and checklists in English, Spanish, and Chinese to assist caregivers in recognizing their needs to provide care during this transition (<http://www.nextstepincare.org/>). However, while this intervention appears to be innovative, there continues to be a lack of monitoring to track its effectiveness. Further, while the guides and checklists seem appropriate given the population, an expert panel consisting solely of health care professionals created them. Therefore, input from caregivers themselves, regarding their own needs and experiences during care transitions was not included in the development of the intervention.

Overall, it is evident that a substantial gap exists in current efforts to support informal caregivers, as these definitions, frameworks, and intervention strategies have failed to directly investigate or incorporate their self-identified specific needs. To date, these efforts have been

largely guided by clinical expertise only, and therefore may not be entirely representative of a true picture of informal caregiver needs during transitional care. This study will provide a more complete and comprehensive understanding of the transition process through incorporating the experiences of both professionals, and informal caregivers into a theory of their transitional care needs that might lead to more well informed and targeted support interventions (Penrod & Dellasega, 1998).

2.3 STUDY OBJECTIVES

Given the importance of theory in guiding practice, and the lack of caregiver voices in existing theory, the primary objective of this study was to develop a substantive theory of informal caregiver needs to support a successful care transition from hospital to home for hip fracture and stroke patients. Specifically, the researcher set out:

- a) To identify caregiver needs and their roles during the transition from hospital to home, both from the perspectives of family members and health care professionals.
- b) To understand caregiver challenges associated with the transition from hospital to home both from the perspectives of family members and health care professionals.
- c) To explore family member and health care professional recommendations for future transitional care support and intervention strategies.

CHAPTER 3: METHODS

3.1 EPISTEMOLOGY

Broadly speaking, epistemology refers to the beliefs surrounding the structure, source, conditions, and limits of knowledge and reality with which a researcher approaches a research situation (Carter & Little, 2007). There are several major epistemological paradigms including: positivism, post-positivism, interpretivism, critical theory, and constructivism (Guba & Lincoln, 2005). It is important to define one's epistemological stance at the beginning of a qualitative study, as it allows the researcher to understand their own views on the topic of interest, and will influence how the methodology is approached and data are interpreted (Carter & Little, 2007).

The present study was conducted from a post-positivist epistemological standpoint. This approach required the researcher to remain as objective as possible in both data collection and analysis, in order for the developed theory to be truly representative of the data (Glaser & Strauss, 1967; Lazarsfeld, 1958). Although subjectivity in qualitative research can never be completely avoided, the researcher attempted to manage the subjectivity carefully in the present study. By constantly stepping away from the data and asking, "what is going on here?", within a post-positivist approach, the researcher recognized that knowledge is discovered, rather than produced, and therefore mutually exclusive from the individual who reports it (Ryan, 2006).

To help narrow the gap in existing caregiver research by adding the caregiver voice to clinically developed frameworks, recommendations, and interventions to support their transitional care efforts, it was extremely important for the researcher to represent caregiver views in thematic interpretations using language that was close to the data (Denzin & Lincoln, 2005). Specifically, the intent of the researcher was to not force the data into a theory, but rather to allow the theory to emerge directly from the data (Glaser & Strauss, 1967). It has been

suggested that theories derived directly from the data are more likely to represent reality than through speculation and interpretation (Lincoln & Guba, 2000).

3.2 METHODOLOGICAL APPROACH

The present study employed a Grounded Theory methodology, which has a longstanding and widespread use within health care research. According to Rice and Ezzy (2000), qualitative research methods are valuable for interpreting meanings that people attach to the experience of health and illness. Grounded Theory originated in the early 1960s and evolved during the research process of examining dying patients in hospitals. Grounded Theory has been successfully used for research on sensitive issues within palliative care (Steil et al., 2010). Furthermore, Grounded Theory has been used to make valuable contributions to medical education research (Tavakol, Torabi, & Zeinaloo, 2006), and has also been instrumental in the development of ‘best practices’ within nursing (Elliot & Laznbatt, 2004). The major benefit to this approach across all of these health care fields is that Grounded Theory allows researchers to develop theories, which are “grounded in the realities of everyday clinical practice” (Streubert-Speziale & Carpenter, 2003).

Grounded Theory is a qualitative research method used to examine a research situation to understand how key players manage their roles (Glaser & Strauss, 1967). Emphasis is placed on developing an understanding of human behaviour and interactions through a process of discovery and inductive reasoning, rather than deduction and hypothesis testing (Elliot & Laznbatt, 2004). The intended outcome of this approach is to develop a theory or framework to convey an understanding about a research situation (Glaser & Strauss, 1967). Given the primary objective in this study of developing a substantive theory explaining how family members manage the informal caregiver role across a formal to informal care transition, grounded theory seemed to be

the most appropriate methodological choice. Similar to palliative care research, studies surrounding medical crises situations can be incredibly stressful and emotional for patients and families (Funk & Stajduhar, 2009). Therefore, it was important to choose a methodology, which allowed researchers to be sensitive to this issue, and place priority in understanding the individual experience of transitional care.

3.2.1 Constant Comparative Method

One of the most important concepts for conducting an effective grounded theory study is a cyclical method. Glaser (1998) refers to this process as the “constant comparative method”; a cyclical method requires a researcher to collect and analyze data concurrently. In order to accomplish this approach, a suite of research methods was required to carry out the present study, including theoretical sampling, interviewing, focus groups, coding, and memoing. Dye and colleagues (2000) refer to this process as collecting a “kaleidoscope of data”. These methods were not viewed as separate steps in the research process, but rather as continuous procedures, which were recurring until the theory of caregiver needs was developed (Glaser & Strauss, 1967). It is important to understand how each of these methods were incorporated into the present work, in order to understand the research process which ultimately led to theory development.

3.2.2 Theoretical Sampling and Saturation

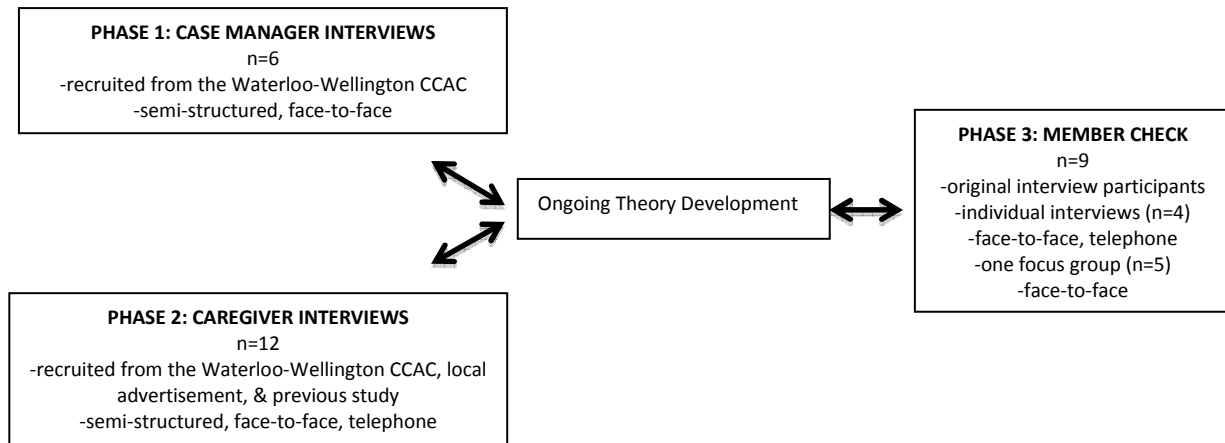
Theoretical sampling is the iterative process of choosing new research cases throughout the study, in order to confirm, further develop and elaborate upon emerging themes in the data. Additionally, using this method, researchers might also source extreme or deviant cases, in order to explore limits in the applicability of the developing theory (Glaser & Strauss, 1967). As the goal of theoretical sampling is different from other research sampling methods, it is not

necessary to capture all possible variations of a population, or ‘outliers’, but rather to continuously build and gain a deeper understanding of the analyzed cases and themes (Marshall, 1996). Further, within Grounded Theory studies, the sample size is not readily determined prior to the commencement of data collection. Following guidelines for qualitative research, sampling should continue until theoretical saturation is reached. This is the point when sufficient data is obtained where additional data will no longer contribute to new theoretical insights properties, or categories (Strauss & Corbin, 1998; Glaser, 2001). Therefore, within the present study, the variety and size of the case manager and caregiver sample was not predetermined prior to the commencement of data collection.

Due to time and resource constraints, however, the researcher explored the literature to gain an idea of the range in number of individuals that have been included in studies of similar nature. This was completed in order to determine how many cases might be necessary to recruit, as an approximation only. In the first methodological review of 50 grounded theory studies from various disciplines, the average sample size was 24 (Thompson, 2005). Further, Riley (1996) suggests that many grounded theory studies reach theoretical saturation in the range of eight to 24 interviews. More specifically, in a study conducted with family caregivers of older adults transitioning to long-term care homes, 21 interviews were completed in order to reach saturation (Reuss, Dupuis, & Whitfield, 2005). Overall, the researcher was prepared to include a broad range of individuals within the present study based on grounded theory literature to date.

3.3 RESEARCH STUDY PHASES

Figure 2. Flowchart of study procedures



3.3.1 Phase One

Using grounded theory methodology, phase one involved the researcher expanding a theoretical sensitivity surrounding formal to informal care transitions. Glaser (1998) describes the process of theoretical sensitivity as “developing the insight with which a researcher comes to the research situation”. Further, theoretical sensitivity is often described as a creative process by which the researcher obtains experience and expertise in a particular field (Glaser & Strauss, 1967). More specifically, it was important to understand the context within which transitions occur before exploring the experience for individual caregivers. In order to achieve this goal in the present study, the researcher conducted face-to face semi-structured interviews with resource and community case managers in order to elicit health professional opinion regarding caregiver involvement during the hospital to home care transition. These individuals were chosen based on their role in assisting patients in navigating the complex health care services available to them when they return home into the community. Their goal is to help find balance between each family’s unique needs, concerns and preferences, and also to assist with solving service delivery problems (www.ccac-ont.ca). Therefore, case managers have extensive experience collaborating

with family members to manage patient care situations in the home and have an understanding of the transition process that help to illuminate the care experience during transitional care.

The case manager interview process contributed to a deeper understanding of the context of transitional care between formal and informal settings. These interviews allowed the researcher the opportunity to relate, recognize and understand the meaning of the subsequent collected data by informing the development of a semi-structured interview guide for caregiver interviews (see phase two below). Targeted, specific, and clinically relevant caregiver research questions were imperative in order to formulate a rich and conceptually dense theory of caregiver needs during transitional care (Fielding, 1994).

3.3.2 Phase Two

Phase two of this study involved face-to-face semi-structured interviews with informal caregivers. This phase employed a theoretical sampling methodology whereby the researcher chooses an initial interview “case” and contemporaneously collects, codes and analyzes data to make decisions about subsequent interview cases (Glaser & Strauss, 1967). According to LaForest (2009), the initial interview case should be someone:

“...who, because of their position, activities or responsibilities have a good understanding of the problem to be explored” (p.2)

Rationale for this decision is usually based on a researcher’s theoretical sensitivity, expertise in the field through experience, and an understanding of relevant current literature. Therefore, in order to gain an understanding of caregiver experiences, and to elicit their needs during the hospital to home care transition, the initial interview “case” was recruited from a sample of hip fracture and stroke caregivers.

Hip fracture and stroke patients were chosen for investigating transitional care needs for several reasons. Hip fracture and stroke patients are prominent and relevant examples of complex

care situations typically faced by older adults and their informal caregivers. Hip fractures are the most commonly cited injury requiring hospitalization of older adults, and 50-60% of these individuals are discharged home to the community post-surgery (Pickett, Hartling, & Brison, 1997; Lyons, 1997). Similarly, stroke is a medical crisis that is widely faced by the aging population and a leading cause of adult disability in the United States. Approximately four million stroke survivors are alive in the United States today (American Heart Association, 2001). Further, 68-74% of stroke victims are discharged home from hospital under the care of family members (Han & Haley, 1999). Therefore, hip fracture and stroke patients serve as a relevant population for which to focus on the hospital to home care transition.

Further, hip fracture patients tend to have a health profile that is reflective of the frailty and complexity of issues faced by large proportions of the aging population as a whole. In a recent study, it was found that 44 percent of individuals over the age of 65 report, at least one medical co-morbidity (Hewitt, Rowland, and Yancik, 2003). Similarly, the presence of three or more comorbid conditions has been found to be the strongest preoperative risk factor for hip fracture in older adults (Roche, Wenn, Sahota, & Moran, 2005), and comorbid health conditions such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), dementia, tumour, and malignancy were found to produce a three-fold risk of death one year post-fracture compared to matched controls (de Luise, 2008). Therefore, hip fractures often serve as the tipping point for frail individuals and can result in an emergency situation of deteriorating health (Martin, 2010). Although large numbers of the aging population are facing the harsh reality of complex, comorbid health issues, many older adults live quite independently with minimal external, visible, or symptomatic health issues. It is often in these situations where medical crises can create even more sudden and unexpected care situations. Stroke tends to be

exemplary of this situation, as unlike other chronic conditions, a stroke is a sudden event which can result in drastic changes in an individual's health status leading to emergency situations of need for informal care (Wright, Hickey, Buckwalter, & Clipp, 1995). Therefore, a focus on caregivers of hip fracture and stroke patients will shed light on how individuals must quickly adapt and manage a sudden and unexpected caring role.

3.3.3 Phase Three

One important way to improve the rigour of grounded theory studies is to employ a member-checking phase. This is a participant feedback technique employed by researchers as the final stage of a study, in order to improve its dependability, credibility, and completeness. Member-checking involves sharing the research findings with the participants who were involved in the study, and asking them to critically analyze the work in order to ensure it is congruent with their experiences, opinions, and feelings about the topic of study (Bradbury-Jones, 2007).

Phase three of the present study involved both individual caregiver feedback interviews, and a case manager focus group to ascertain the face and content validity of the developed working theory of caregiver needs to support a successful care transition from hospital to home.

3.4 DATA COLLECTION

3.4.1 Interviews

The primary data collection strategy within the present study was one-on-one, in-person, semi-structured interviewing. Interviews in grounded theory are seen as a way to collect facts regarding a particular topic (Charmaz, 2006), and served two purposes within the present study. The first purpose was to gain systematic insight into case manager and informal caregiver accounts of transitional care between hospital and home. The second purpose of interviews

within the present study was eliciting detailed feedback from informal caregivers on the developed theory of caregiver needs during the member-checking phase (phase 3). Therefore, it was imperative to choose a data collection strategy, which would uncover in-depth details of these unique experiences. Agar and MacDonald (1995) claim that the individual qualitative interview is a data collection strategy that tends to reveal the most detailed information, as these types of interviews encourage individuals to explain and elaborate on intimate information and allow researchers the opportunity to probe more deeply. Further, Kaplowitz and Hoehn (2000) recognized that individual interviews are most often used in situations dealing with sensitive topic matters, where the objective is to promote the sharing of emotions, motivations, and attitudes. Therefore, conducting individual interviews surrounding the experience of providing care following a medical crisis was an appropriate method for the present study, as this is often a delicate topic area to discuss with all parties involved in transitional care, including both health care professionals and informal caregivers.

Interviews were semi-structured in nature, meaning that the researcher used a combination of scripted and spontaneous probes in order to capture the complexity of participants' transitional care experiences (Lindlof & Taylor, 2002). Semi-structured interviews are flexible in the length and number of questions asked. It is this flexibility that allows questions to emerge throughout the process; often stemming from answers given by the interviewee (Lindlof & Taylor, 2002). A general framework of topics, known as an "interview guide", was used to ensure interviews were conducted as directed conversations rather than periods of formal questioning, and yet provided the basis for some standardization in the topic areas covered (Charmaz, 2006; Lofland & Lofland 1984).

3.4.2 Focus Groups

Focus groups were used in the present study to engage case manager participants in the member-checking phase of the research, where case managers provided feedback on the developed theory of caregiver needs to support a successful care transition from hospital to home. Focus groups are group interviews conducted with six to 10 individuals and are powerful in evaluating and testing new ideas (Krueger & Casey, 2000). The benefit of eliciting feedback in a group setting was that the researcher could ascertain the extent to which there was consensus within the professional group regarding opinions surrounding the theory of caregiver needs (Morgan & Krueger, 1993). A focus group protocol containing several general feedback discussion questions was developed by the researcher in order to guide and support this process.

3.5 DATA ANALYSIS: HIERARCHICAL CODING

Analysis of interview and focus group transcripts followed the Grounded Theory Hierarchical Coding method according to Glaser and Strauss (1967). This coding strategy allowed the researcher to move from initial descriptions of caregiver experiences of transitional care, towards a conceptualization of their needs and perceptions through abstracting key properties and concepts. Thematic interpretations were modified and extended throughout the entire course of the research process as the researcher continuously recruited additional research cases via theoretical sampling (Charmaz, 2006).

Primarily, following each interview, transcripts were read multiple times, in order for the researcher to become increasingly immersed in the data as they were being collected. Next, three levels of coding were used to complete hierarchical coding. Open coding describes the first phase, and was conducted primarily by hand, using printed copies of transcripts, along with highlighters and pens, to assess and assign codes to each line of the data in order to identify,

name and describe the phenomena that existed in the text. These codes were usually nouns and verbs, and often came directly from the text (Pandit, 1996). After conducting this process by hand, the researcher imported electronic copies of the transcripts into NVivo8, a qualitative data analysis software program, and transferred the written codes into electronic versions within the program, called “free nodes” (QSR International, 2008).

Next, the researcher carried out the axial coding phase, electronically, using NVivo8. Building upon initial “free nodes”, the researcher grouped codes into categories or themes, known as properties (Glaser & Strauss, 1967). This process occurs through discovering relationships between codes using a combination of both inductive and deductive reasoning (Pandit, 1996). Within Nvivo8, relationships are represented as “tree nodes” (QSR International, 2008). As grounded theorists emphasize causal relationships, theoretical sampling is especially useful within this phase, in order to confirm or negate discovered categorical relationships (Elliot & Lazenblatt, 2004), and to ensure all possible relationships are adequately explored until the point of theoretical saturation.

Finally, the researcher conducted selective coding as the final phase in Glaser and Strauss’ hierarchical strategy. Selective coding describes the process of choosing a single property to represent the “core concept” of the grounded theory, and then relating all other properties to the core concept. The core concept acts as the foundation of the theory; the overarching theme, which all other properties come together to explain.

3.6 MEMOING

As data collection and analysis occur concurrently within Grounded Theory studies, researchers often use a form of note-taking called memoing to integrate and track the research process. Within the present study, the researcher utilized two forms of memoing: 1) the field

note; and 2) the code note (Hallberg, 2006). Field notes were written by the researcher during the data collection process in order to provide the context necessary to analyze the textual transcripts. For example, during interviews, the researcher took notes on non-verbal cues, behaviours, and details about the interview setting and attached these notes to the interview transcript text files. On the other hand, code notes were written during the analytical process. As the researcher named, categorized and grouped the data into properties, an inventory of codes was generated to explain the meaning and purpose of each of the codes (Montgomery & Baily, 2007). Overall, memoing is useful in bridging the processes of data collection and analysis.

CHAPTER 4: CASE MANAGER INTERVIEWS

4.1 INTRODUCTION

The following chapter details the data collection and analysis procedures carried out by the researcher in an effort to become theoretically sensitive to the context of care transitions between a formal (hospital) setting to and informal (home) setting for family members of older hip fracture and stroke patients. This section also presents results from the interviews, and discusses salient transitional care issues for families, as described by case managers.

4.2 RECRUITMENT

In Ontario, The Ministry of Health and Long-Term Care funds 14 Community Care Access Centres (CCACs). The CCAC provides health services and advice through various professional staff including nurses, physiotherapist, social workers, dieticians, occupational therapists, speech therapists and personal support workers. Specifically, for home care, a resource or community case manager works with patients and their family members to build a customized care plan. The only difference between resource and community case managers is that resource case managers provide all of their services over the telephone, and community case managers make an initial home assessment. Typically, community case management is reserved for individuals with complex comorbidities who require a wide range of services (www.ccac-ont.ca).

The only inclusion criteria for case manager participants was that they were employed by the Waterloo-Wellington CCAC and had experience working in the community with informal caregivers of hip fracture and stroke patients. Based on these criteria, eligible resource case manager participants were identified by a location contact at the Waterloo-Wellington CCAC. Following receipt of University of Waterloo Research Ethics clearance (Appendix A), the CCAC

location contact electronically distributed a case manager information letter (Appendix B), and the researcher contacted interested resource case managers to provide them with additional information about the study and schedule in-person interviews (Appendix C). A written consent form was signed prior to each of the interviews. (Appendix D), and these interviews also informed the addition of several interview questions to the original interview guide, in order to target questions to clarify specific thematic interpretations during the final two interviews. Please refer to Appendix E for an example of a transformed interview question.

The researcher employed a 'theoretical snowball sampling technique' to then recruit two community case managers to participate in the study. Resource case manager participants were instrumental in identifying community case managers as key informants who would be knowledgeable about additional details of the hospital to home care transition (Rossi, Lipey, & Freeman, 2004). These recommendations were made based on community case manager unique experiences providing home visits to clients who have experienced hip fracture or stroke. Community case managers were contacted and interviewed in the same fashion as resource case managers.

4.3 DATA COLLECTION

A total of six in-depth semi-structured interviews, lasting an average of 38 minutes, were conducted with the resource case managers and community case managers. All interviews were carried out in private rooms within the Kitchener and Cambridge offices of the Waterloo-Wellington CCAC, and were audio-recorded. To facilitate the conversations, a semi-structured interview guide was developed based on the previously discussed Patterson's (1988) Family Adjustment and Adaptation Response (FAAR) framework. The researcher attempted to tap into individual case manager experiences working with informal caregivers. Specifically, the

researcher sought to ascertain their professional opinions regarding caregiver ability to balance stressors and resources, in order to manage transitions from hospital to home following a medical crisis for an older adult. Questions regarding caregiver needs, challenges and the use and availability of support resources were asked of the case managers. Additionally, the researcher documented observational notes regarding the location and time of day the interview took place, the interviewee's tone of voice, and any non-verbal cues that would help to understand the interview during the analysis. Please refer to Appendix F and G for a copy of the interview guide and an example field note entry.

4.4 DATA ANALYSIS

Data analysis took place in an integrated fashion with the above data collection procedure. Following each interview, audio files were numerically coded in order to protect the identity of interview participants, and subsequently transcribed verbatim by an external transcription company. In total, case manager interviews resulted in 74 one and a half-spaced pages of transcribed text for analysis. Each transcript was analyzed individually and emerging themes became increasingly detailed with each consecutive interview described above.

4.5 FINDINGS AND INTERPRETATIONS

4.5.1 Sample Characteristics

Six case managers were interviewed in total. Four of these individuals were resource case managers, and two of these individuals were community case managers. The average age of case manager participants was 43 years, and all participants had been working in their current position for at least one year, and up to eight years prior to their interview. All case managers practiced nursing previous to their current role, with an average of 16 years of total clinical experience.

Case Manager Type	Clinical Background	Year of Birth	Total Years of Clinical Experience	Years in Current Position
Resource	Nurse	1981	5	1.5
Resource	Nurse	1965	14	2
Resource	Nurse	1961	26	1.5
Resource	Nurse	1967	20	8
Community	Nurse	1961	15	6
Community	Nurse	1973	16	4

Table 1. Case manager sample characteristics

4.5.2 *The Context of the Formal to Informal Care Transition: Key Factors*

Four themes were identified from case manager interviews, which explain the context of formal to informal care transitions for caregivers of older hip fracture and stroke patients from health professional perspectives. The following themes will be discussed in detail below: 1) Each family has a unique situation; 2) Caregivers face time restrictions in formal care; 3) Care transitions inflict challenging emotions; 4) Caregivers receive limited practical education and information from formal care providers. In addition to these themes, the researcher noted that all case managers expressed the need for a more family-focused approach to managing care transitions between hospital and home. Further, case managers were very interested in participating in future efforts to improve the caregiver experience of transitional care.

Each family has a unique situation

During the course of the interviews, case managers repeatedly stressed the importance of formal health care providers being cognizant that each medical crisis situation is unique to the family who is experiencing it. In fact, familial circumstances can influence an informal caregiver's ability or willingness to care for their older family member. Therefore, how a family

member reacts and adjusts to assuming responsibility for the care of a loved one can be quite variable. To illustrate this, one case manager stated:

Well it depends on the family a lot too. Some families are really extremely supportive and very strong advocates for their loved ones; other times it can be maybe like another frail elderly person with their spouse who maybe they're just ok, he has to come home I guess, well I wasn't quite ready but ok, I guess that's what we have to do, you know. So it really depends on the family [CM4]

Further complicating a family's ability to adjust and cope during a medical crisis, case managers pointed out that families often have more than one informal caregiver involved in coordinating care for a loved one, and sometimes these individuals are separated by great physical distance. This can be quite challenging, and as a result, care responsibilities are often not equally shared between family members. Specifically, several case managers discussed managing finances as a care task causing major tension when multiple family members are involved during the hospital to home care transition:

We see lots of family conflict yup, you know just because I live in town and my sister lives in you know Oakville why am I the one, you know maybe she needs to come and then we get the financial piece you know, like that's a biggie, lots of problems there when someone has to take over the banking and you know seen lots of issues, we see that all the time. So yeah it becomes very tense. When we have a big family group especially if it's one family member that's been doing everything and suddenly she's thought you know what I can't do this, I need the rest of my, bring the siblings in and it can be quite a meeting you know. [CM5]

While resource and community case managers both recognized the variety of important issues families typically deal with during transitions between hospital and home, they also expressed concern that these issues are not dealt with in a proactive fashion prior to the transition taking place. A failure to recognize unique family situations during care planning efforts was described as a barrier to developing individualized care plans for older adults experiencing medical crises. Several case managers suggested that more effort be made by staff in the hospital setting to

understand the unique family dynamics which might influence an older patient's journey home to the community:

Again I think it comes right from the hospital. You know the hospital they have made some, like they have the GEM nurses, geriatric emergency medicine nurses, and we work with them quite well but they're only through the emergency department. Again social workers on the floor as well—their kind of the role should be with our hospital case manager together to look at the family dynamics before they come home.[CM5]

A major emphasis during case manager interviews was on maintaining a family-centered focus during care transitions from formal hospital care to informal care in the home. Case managers discussed a domino effect; supporting family caregivers is necessary in order to protect their efforts and ability to provide care for their loved one. One case manager specifically discussed the need to consider patients and caregivers together as a unit of care:

Well I think they need to feel supported by not only, like I think sometimes they feel like the client is only supported and not the whole family is supported in the process which you know a lot of the calls that will come through will be in regards to not the client but the wife doesn't feel supported. They don't feel supported but I think that's more of the direct focus is on the ill spouse or the ill child or you know that sort of thing and it's just the adjustment. They need to feel supported to make it all work you know so they don't realize that sometimes the background of it is supporting both of them to support the ill or you know.[CM2]

Overall, there was a general consensus between case managers that an investment of time by health professionals in tailoring care-planning efforts according to unique family situations is worthwhile. These efforts were described as having the potential to empower and equip families with the confidence and skills necessary to facilitate manageable and productive care transitions for older adults who have experienced a medical crisis.

Caregivers face time restrictions when adjusting to the caring role

All case manager interviews were thematically laden with time limitations affecting informal caregivers. Case managers frequently discussed the difficulty families face when they

are thrust into the caregiving role abruptly, resulting from the combined effect of shortened hospital stays, and lack of involvement in planning their loved one's care trajectory.

Unfortunately, older adults are returning home more acutely ill and requiring higher levels of medical care in the home due to the heavy demand for the limited beds available within formal hospital settings. However, in many instances, family members do not have a realistic picture of the level of care required of their loved one when they assume the informal caregiver role. One case manager discussed this issue:

I think some of the other transition problems might be that people are being more acutely ill now and then that goes again with being released more at an acute level than they used to be as well. So part of it is the education of the community to know the expectation isn't any longer that you are taken care of until you can take care of yourself perfectly. The other expectation now is drawn towards the fact that we are expecting that the family and friends will assist in the care of the client and I don't know if that's fully communicated either. [CM3]

One reason proposed by case managers, to explain the mismatch between caregiver expectations and patient needs at discharge, was that health care providers do not involve families at an early enough stage in care planning discussions in the hospital. It would seem that the discharge process ends too quickly, in an almost unexpected manner, with little time to process and develop a plan of action for managing care in the community:

You know far ahead, like I think to sometimes they seem a little bit surprised when the person is getting discharged on this day, it seems to soon. So I think if like if that has started to be talked about right from the start then maybe that would lessen that anxiety and they would feel they were a bit more in on the planning process right from the start not just getting oh guess what they're coming home tomorrow and you have to be here to pick them up and the toilet's being delivered at 10:00 so be there for it and then come and get them. [CM 2]

Although case managers noted that health care providers could be more inclusive of families in decision-making throughout the hospital stay, they also recognized that the health system is not well designed to accommodate the busy schedules of working informal caregivers. Case

managers suggested that health care providers often have good intentions to engage family members, however, daytime appointments are often barriers to family-centered care:

For caregiver's I think too, especially when its like a child of someone, they don't live with that person and they're working or doing things and it's like well sometimes like the therapist wants them to be there for the visit but they can't always leave work to go and make this visit in the middle of the day. I think maybe sometimes the hours when professionals want to meet with the family but it's always inconvenient for people that have children or they're working, things like that. There's no chance for, like we're nursing visits in the evening, therapies don't do that. Maybe it might be a little bit more stressful. I know for me if I had to go and leave work to go to an, like that would be a challenge, like and especially too for people that have jobs, a lot of people's jobs are not flexible to let them leave to attend medical appointments for their parents. [CM4]

Overall, case managers empathized with informal caregivers regarding the time pressure that is experienced during transitional care between hospital and home. Case managers expressed the need for a greater consideration of the time family members require in preparing to shoulder the responsibility of care, and to factor this need into each stage of the hospital stay; not only on the day of discharge.

Care transitions inflict challenging emotions

According to both resource and community case managers, the experience of a medical crisis is incredibly overwhelming for both a patient and their family members. As an older adult copes with their physical pain and puts effort into rehabilitation across the continuum of care, family members are often the only consistent support system present between settings. Case managers described the level of effort and length of time a family member is advocating and providing for a loved one as often very physically and mentally taxing, and that it can result in the experience of a variety of difficult emotions.

Initially, case managers described caregivers feeling stressed during the transition between hospital and home. Not only is a family member often trying to attend medical appointments and

stay informed within the hospital setting, they are attempting to prepare a suitable home environment for their loved one to return to, in tandem with their own busy schedules. The stress of transitional care often results in countless worries and anxiety until the patient is settled at home. Case managers describe this emotional journey as follows:

I think most people they want to do, like sometimes like could care less but most people want to do what's, like they want to help their family member right, it's your family, but I think that it also puts stress on them about trying to be there, to go to every appointment and get them home from the hospital and be there, someone's going to be there when we deliver them. I can definitely see that people feel stressed about that trying to coordinate everything, especially when they don't live with the person. [CM2]

A lot of them are worried. A lot of them are worried because they're taking the responsibility often and they aren't necessarily content with that role. So they are worried that they will miss something. [CM6]

Until they get home and realize that they can manage I think there's just that high level of anxiety until things start to fall into place like a few days after they're home. [CM1]

Additionally, a caregiver's stress is often exacerbated by their frustrating experiences interacting with the health care system, according to case managers. Although unintentional, issues such as waiting for long periods of time to get questions answered, repeatedly providing the same information to different providers, and confusion distinguishing between providers can foster negativity within a family member, and can result in an expression of anger towards case managers in the community. Several case managers describe the frustration they have witnessed in informal caregivers:

But you know what, it happens, they sit there and wait and wait for a hospital case manager and they're frustrated, it's negative right from the get go which is not what you want. [CM6]

A lot of them say we have so many, we've told our story to so many people why do I have to tell you again. They ask the same questions and a lot of them are, they're confused about the whole, who are you, I thought you were coming. When are you coming, well it's not me that's coming, who's coming and how does that work. They don't understand the whole CCAC is funded by the government. Some people say

there are a lot of people in and out of our house, you know do we have to have this many people? I think they're overwhelmed with the whole situation. [CM4]

I'm pretty thick skinned now, I get yelled at a lot. But reasonably so sometimes, right. It is frustrating, they just had surgery, you go home, you have no wound care things, you have no this, you have no nothing, what am I supposed to do. Where do I get this stuff, right? [CM2]

Further, case managers described that informal caregivers often express fear as the emotion resulting from the above negativity experienced in the hospital setting while planning to assume the responsibility for facilitating the transition between hospital and home. One case manager stated:

It's scary a little bit, right. So there's, there isn't a lot time to get used to the idea that they're coming home with you and you're going to look after them. [CM4]

As previously stated, case managers consistently recognized the inherent variety between families dealing with medical crisis situations. This variability shines through in emotional coping for family members as well. Unfortunately, case managers described the experience of the above emotions often culminating as self-doubting behaviour and apprehension about providing care for a loved one:

Some people will take on anything and they think I can manage this and I can but then there are those that are very willing to learn, they are eager to help, they get right in there when the caregiver with the therapists or nurses are there but there are a lot of other ones that just; I'm so far out of my element and I'm old and I don't want to learn or I have no interest in this and don't want to learn so yeah, I think confidence for sure. [CM4]

In addition to feelings of apprehension, this quote demonstrates the importance of self-confidence in influencing a family member's ability and willingness to provide care for their loved one. Several case managers touched on the necessity of uncovering feelings of apprehension in order to find ways to build self confidence in family members. One resource case manager stated:

If they can't do it because they don't feel confident then you give them the feedback that they need to make them confident. So understand right here what is preventing them from being confident and providing care and accepting that role and fulfilling that role, definitely. [CM 3]

Overall, case managers unanimously agreed that a caregiver's emotional journey has a major impact on the success of a smooth transition between hospital and home for their loved one who has experienced a medical crisis. According to case managers, the ultimate emotional need of caregivers is to feel self-confident, in order to balance the stress and frustration often inherent to transitional care.

Caregivers receive limited practical information and education to manage care at home

As older hip fracture and stroke patients are returning home from hospital more acutely ill, informal caregivers are faced with more difficult medical tasks in the home, in addition to providing assistance with a loved one's daily routines. However, consistent across all case manager interviews was an expression of concern regarding inadequate medical education for family members in the hospital. Specifically, several case managers described scenarios where family members were ill equipped to handle wound management:

I think that a lot of the informal caregivers feel, like I think sometimes overwhelmed because like I say they, this person's been in the hospital could be for like three weeks, have been seen by nurses everyday and they feel like oh I don't have the skill to do this or even I find like simple dressings, like even if they do have nursing in, the nurses are teaching them to do it, like teaching a family member to do the dressing and then supposed to be discharging them right once they learn to do it. And a lot of people I think are really apprehensive about learning to do something like that for their family member because they don't feel like, like that's something a nurse should be doing. But where they are capable to do it, most people are, I think if they have the proper teaching. [CM2]

When asked to clarify why caregivers were not receiving the proper information and teaching, case managers discussed the modes of information delivery as being the issue, not the receipt of the information itself. Case managers described the problem of bombarding informal caregivers

with verbal information, which is often not absorbed in times of such high stress. For example, one case manager stated:

I think that it's explained, but also it's just when everything comes at you at once it's hard to keep things straight what someone told you, you know at the hospital. [CM1]

In order to facilitate more effective communication between health care providers and informal caregivers, case managers stressed the importance of providing written information, which they can refer back to whenever it is needed:

So I think if people are very clear even if it's and sometimes it would be more helpful I think if it's a written communication as opposed to a verbal because I think people get overwhelmed and then at some point you stop taking it all in, especially in crisis situations. There's so much information being thrown at you, you don't always remember, you don't always hear clearly. So even sometimes if you give people written information; this is what I've set up or this is who's coming and when they're coming, I think that would be more helpful sometimes than the verbal to help them with those pieces so they know; ok don't need to call, in terms of CCAC I don't need to call physio - it's arranged. This is when they'll be coming by. [CM4]

On the other hand, case managers cautioned that solely providing written information was also dangerous, as these pieces of information are often lost or are difficult to interpret. Therefore, several case managers suggested that written information be complemented with verbal explanations:

Because they have our folder and they just put it aside or it's in the suitcase from going home and they haven't gotten it out and they have all that but just the conversation, the face to face and the knowing that there's contact numbers you know if you need to contact someone you contact this, you contact your surgeon that sort of thing. [CM1]

The problem is you can provide them with paper with everything from A to Z on it that they could ever possibly need but I think the face to face, the sitting down, like somebody whether it's a hospital case manager or someone within the hospital but I think that is done to its best of ability but that does help reduce a lot of the anxiety and make the transition smoother if they have the information directly and not just on hard copy. [CM5]

In order to achieve effective verbal and written communication with family caregivers, case managers made several recommendations to improve the organization of how

information is delivered. First, one case manager suggested providing information that is organized according to the care trajectory of an individual:

Maybe a care plan that looks more like a timeline because I know the one we have now says these are the services that CCAC has put in place; so they'll have physio and the agency checked off but maybe like I know sometimes they have other things that aren't, CCAC hasn't put in place but they get the discharge from the hospital, this is your follow up visit with your doctor. Maybe if it was something that came more all together in one; that was like the hospital discharge plan and the CCAC one altogether and more of a timeline to say you'll be going home, this the day that the physio will come visit you by, this is your follow up; I don't know, something like that. [CM3]

Furthermore, case managers suggested that there be a form of follow-up with the caregivers themselves, to ensure that they have grasped and are comfortable with the information that has been given and explained to them. For example, one case manager suggested:

And there should be some documentation there that the client, that the caregiver understands what's written there. Maybe in the form of the nursing notes or the discharge note or something to document that the caregiver is comfortable with this role and that they understand the information that's been given. So not just hope it's been done and hope they understand it but that they do understand it that you tested it. [CM3]

Overall, it seems that practicality is essential in delivering information to informal caregivers.

Although case managers felt confident that caregivers were being given information either verbally or written, the general consensus was that they are receiving too much, in a short period of time, and in an inconsistent fashion.

As a whole, case manager interviews suggested that informal caregivers of hip fracture and stroke patients experience a variety of challenges during the transition from hospital to home. Unfortunately, it seems that many of the issues faced by family members are intrinsic to the fast-paced system design and rushed delivery of formal hospital care. As such, the current context of informal care during transitions between hospital and home for older hip fracture and stroke patients can be described as unsupported. This is resulting in poor emotional outcomes

for both family members and their loved ones, which often lead to caregiver burnout and patient re-hospitalization (Palmer & Glass, 2003). Informal caregivers should be regarded as a valuable resource, as these individuals have great potential for providing high quality continuous care for geriatric patients across the continuum and into the community.

Although the current picture of transitional care for families seems dismal, case managers remained optimistic in the capabilities of family members to balance stressors and resources in order to manage care transitions between formal and informal settings following a medical crisis. A heightened awareness of unique family situations, and an effort to target families with more practical information and education might help to promote, strengthen, and sustain caregiver ability to adjust and adapt to the caregiving role.

CHAPTER 5: INFORMAL CAREGIVER INTERVIEWS

5.1 INTRODUCTION

The following chapter details the data collection and analysis procedures surrounding interviews conducted with a variety of informal caregivers of older adults who have experienced a hip fracture or stroke. Treating the aforementioned context of transitional care uncovered during case manager discussions as a foundation, this chapter will present the results of informal caregiver interviews as the properties that comprise caregiver needs during transitional care.

5.2 RECRUITMENT

Eligible caregiver participants were self-identified, informal caregivers of hip fracture or stroke patients aged 65 or older who had experienced a care transition from hospital to home. The researcher attempted to recruit caregivers as early as possible following their transitional care experience, and up until approximately six months post-transition, in order to adequately capture the needs of caregivers following a medical crisis. Reasoning for this decision stemmed from two studies. Saltz and colleagues (1999) found that caregivers reported the greatest degree of strain overall at two months post-fracture, and by six months this degree of strain only decreased to 38%. Further, it has been identified that the time spent in hospital and the first few months at home were most difficult for 76% of caregivers of stroke patients (King & Semik, 2004). Additionally, as a large component of this study was interview based, informal caregivers were required to speak and understand English. The researcher strived to recruit a variety of caregiver profiles in order to adequately represent the heterogeneity of caregivers within the Canadian population. Caregiver participants were not excluded based on age or relation to the patient, in order to improve the generalizability of the study findings (Blair & Zinkhan, 2006).

Recruitment of caregiver participants took place using multiple methods, as advised by Charmaz (2006) to obtain information-rich cases. The researcher recruited caregivers of hip fracture and stroke patients from the Kitchener-Waterloo community using three strategies: 1) CCAC support worker two-phase consent process; 2) Flyers posted in the community; 3) Consent to contact individuals from a previous study (ORE # 15885).

Using the first method, participants were recruited by implementing a two-phase consent process. Office support workers at the Waterloo-Wellington CCAC identified potential participants using a set of inclusion criteria to use in selecting from hip fracture and stroke patient caseloads. Support workers contacted eligible individuals using a telephone script, developed by the researcher, which detailed information about the various study components (Appendix H). Consent to contact was obtained from interested individuals, and support workers signed a form to verify this process with the researcher (Appendix I). The researcher then scheduled information sessions with interested individuals (please refer to Appendix J for telephone script) to explain study details, as well as to provide an information letter and written consent form for participating in the study itself (Appendix K and L). A total of four participants were enrolled in the study using this method.

Furthermore, after a newspaper advertisement in the *Kitchener-Waterloo Record* was unsuccessful in attracting participants (Appendix M), the researcher adapted the advertisement as a single page flyer containing study details, the University of Waterloo logo, and researcher contact information that could be ripped away if an individual was interested in contacting the researcher about the study. Flyers were posted in various public places within the community, including grocery stores, community centres, the library, and a medical building (Appendix N). Four participants were recruited using this strategy.

As a final recruitment strategy, researchers obtained contact information of patient participants in a previous study, who consented to be contacted for participation in future studies (ORE #15885: Quality of Care Transitions for MSK Rehabilitation Patients). Researchers telephoned the past participants, explained the present study, and asked the patient to forward the researcher contact information to their informal caregiver. If the caregiver was interested in participating in the study, they telephoned the researcher directly. Four participants were recruited using this method.

5.3 THEORETICAL SAMPLING

Due to time constraints, it was difficult to recruit participants using one strategy at a time. Instead, the researcher employed the first two recruitment strategies continuously and simultaneously, and used the third strategy to strategically incorporate certain caregiver profiles into the sample. Further, when several caregivers were recruited at once, the researcher chose the order in which to interview participants based on the evolving theory of caregiver needs. Specifically, each subsequent interview was used to “fill out” and explore relationships between emerging themes abstracted from the data. The first participant was an older wife of a hip fracture patient, who was recruited using method three. Following the analysis of this first interview, the researcher sought to hear a male perspective on the transitional care experience, and through method one, was able to interview an older son of a female hip fracture patient. The researcher then intended to use method three to recruit a husband and daughter of an elderly hip fracture patient in order to capture the perspectives of the opposite gender to the first two interviewees. However, only a middle-aged daughter was successfully recruited. Next, the researcher sought to gain perspectives on emerging properties and themes from a stroke caregiver, and was able to recruit an older wife of a male stroke patient to participate in an interview using method two. This

interview was useful for the researcher to compare and contrast concepts identified by hip fracture and stroke caregivers in order to tease out common information and education needs of both caregiver profiles in preparation for the caregiving role. The researcher intended to follow a similar interview trajectory for stroke caregivers including interviews with a son, daughter, and husband caregiver, but was unsuccessful to recruit any of these caregiver profiles right away. Instead, the researcher recruited a middle-aged son of a male hip replacement patient, using method one. The researcher was unaware, until part way through the interview that the individual had cared for a loved one who underwent a hip replacement surgery rather than a hip fracture. After careful consideration, the researcher decided to go forward with the interview, as a way to determine whether hip replacement patients have the potential to be typical or deviant cases of the developing theory of caregiver needs (Polit & Beck, 2004). Interestingly, the researcher found the experience of transitional care of a caregiver of a hip replacement patient similar to a hip fracture patient. For example it was apparent that there existed a shared experience of pressure due to a lack of time to prepare for their role. Therefore, the researcher decided to use method three to recruit an additional hip replacement caregiver to see if their experiences were confirmatory of the above observation, and to fill out the developing timeline of caregiver needs. This participant was a middle-aged daughter of a female hip replacement patient. Results from interviews with hip replacement patients served to confirm and clarify the need for time to prepare for the caregiving role, in the sense that time is needed as a resource, and also that information and education needs to occur at specific points during the course of hospital stay. These findings suggest that the developing theory of caregiver needs might have the potential to be more broadly applicable to other medical issues requiring acute hospitalization.

At this point, the researcher had developed a preliminary framework of informal caregiver needs to support a successful care transition from hospital to home. As the sample thus far consisted mainly of caregivers for hip fracture patients, the researcher was determined to recruit additional stroke caregivers using methods one and two. In the meantime, the researcher recruited two additional caregivers of hip fracture patients; one was a daughter in law of an older male hip fracture patient, and the other was a daughter of an older male hip fracture patient. These interviews were instrumental in confirming the preliminary timeline of caregiver needs and specific informational and educational requirements to fulfill caregivers' instrumental needs in preparing for the caregiver role. Further, these interviews helped the researcher to add additional detail to the developing theory through uncovering the emotional journey caregivers experience during the transition between hospital and home. Finally, the researcher was able to recruit an additional stroke caregiver participant. The individual was a middle-aged son of a female stroke patient. This perspective was beneficial as the first stroke caregiver participant was older, female and cared for a male patient. Results from this interview were supportive of the initial finding that both medical crises result in similar needs for family members providing informal care. Further, the researcher was able to identify the common core concept of caregiver needs across patient populations as "building capacity to care".

The final three interviews were conducted with caregivers of older hip fracture patients and were strategically carried out to explore some remaining patient-caregiver relationships that had not been captured in the first nine interviews, in order to further detail the emotional experience and needs of caregivers during the preparation for their role during the transition between hospital and home. Additionally, the researcher sought to confirm that the core concept of "building capacity to care" was broadly applicable across different patient-caregiver

relationships Through method one, the researcher was able to recruit a middle-aged son of a female hip fracture patient. Using method two, the researcher was also able to recruit a middle-aged daughter of a female hip fracture patient. Finally, the researcher was successful in capturing the husband spousal perspective, and interviewed an older male husband of a female hip fracture patient. Following this interview, the researcher felt confident that the point of theoretical saturation had been reached, as the final three interviews were very repetitive, both in nature of the interview itself, and in the needs and experiences that were discussed.

5.4 DATA COLLECTION

A total of 10 in-depth semi-structured interviews were conducted with informal caregivers of hip fracture and stroke patients, and two additional interviews were conducted with caregivers of hip replacement caregivers. Therefore a total of 12 informal caregiver interviews were conducted, lasting an average of 44 minutes each. Nine interviews were conducted in a face-to-face format within the caregiver's home, place of work, or at a local coffee shop. Due to restrictions regarding distance, three caregiver interviews were conducted over the phone. All interviews were audio-recorded, and directed by a semi-structured interview guide. Overall, the guide was structured according to caregiver challenges, needs, and the use and awareness of available resources. The researcher was interested in exploring the unique and individual experiences of informal caregivers, and to determine if their perspectives of transitional care between hospital and home were similar to what was witnessed and described by resource and community case managers. Taking into consideration the context of informal care identified by experienced case managers, the researcher targeted specific questions to delve deeper into the uniqueness of families, caregiver time restrictions, the emotional journey of transitional care, and the receipt of practical education and information (Appendix O). Additionally, the researcher

documented observational notes regarding the location and time of day each interview took place, the interviewee's tone of voice, and any non-verbal cues that would help to understand the interview during the analysis.

5.5 DATA ANALYSIS

Data analysis took place in an integrated fashion with the above data collection procedure. Following each interview, audio files were numerically coded in order to protect the identity of interview participants, and subsequently transcribed verbatim by an external transcription company. In total, caregiver interviews resulted in approximately 138 one and a half-spaced pages of transcribed text for analysis. Each transcript was analyzed individually, with the intent to build on initial properties abstracted from case manager interviews, describing informal caregiver needs during the transition between hospital and home. The ultimate goal was to uncover the central concept of caregiver needs, and to organize emerging properties about this concept as a structured theoretical depiction.

5.6 FINDINGS AND INTERPRETATIONS

5.6.1 Sample Characteristics

Table 2 details the sample characteristics for the 12 caregivers interviewed. Seven of the informal caregiver participants were female, and five caregivers were male. The researcher was successful in incorporating a variety of patient-caregiver relationships; however, the majority of interviewees were adult children. Further, four interview participants were same-sex caregivers of female hip fracture/replacement patients, and only one same-sex male caregiver was interviewed. The average age of caregiver participants was 58 years.

Caregiver	Hip or Stroke	Age	Sex	Sex of patient	Relationship	Format
1	Hip	71	Female	Male	Wife	Face to face
2	Hip	66	Male	Female	Son	Face to face
3	Hip	49	Female	Female	Daughter	Telephone
4	Stroke	79	Female	Male	Wife	Face to face
5	Hip rep	61	Male	Male	Son	Telephone
6	Hip	50	Female	Male	Daughter-in-law	Face to face
7	Hip	46	Female	Female	Daughter	Face to face
8	Hip rep	47	Female	Female	Daughter	Face to face
9	Stroke	54	Male	Female	Son	Face to face
10	Hip	53	Male	Female	Son	Telephone
11	Hip	47	Female	Female	Daughter	Face to face
12	Hip	82	Male	Female	Husband	Face to face

Table 2. Informal caregiver sample characteristics

5.7 INFORMAL CAREGIVER NEEDS TO SUPPORT A SUCCESSFUL CARE TRANSITION FROM HOSPITAL TO HOME

Six properties describing informal caregiver needs during the transition from hospital to home were identified during interviews with caregivers of older hip fracture and stroke patients, each consisting of several important concepts fostering its understanding. Each property corresponds to one of the themes identified by case managers in defining the context of informal care during care transitions. The following properties defining caregiver needs will be discussed in detail below: 1) Assessment of unique family situation; 2) Practical information, education and training; 3) Involvement in care planning process; 4) Agreement between formal and informal

caregivers; 5) Taking action in personal life; 6) Emotional Readiness.. In addition to these themes, the researcher noted that caregivers were aware of the need for research in the field of family caregiving, expressed concern, and offered advice to help support future caregivers who might face similar challenges.

5.7.1 Assessment of Unique Family Situation

Similar to case managers, informal caregivers were cognizant that each family has a unique situation, which might influence their ability to cope with a medical crisis and manage a loved one's care following a transition from hospital to home. Caregivers suggested that while each family may face unique challenges, they also may be well equipped with valuable skills to make contributions to planning their loved one's care trajectory. Therefore, caregivers felt it would be beneficial for health care providers to perform an initial assessment of a caregiver's knowledge base upon patient admission to the hospital in order to gain a sense of their baseline medical skill set and understanding of the health system. One family caregiver participant was a retired nurse, and therefore had an extensive medical and health systems knowledge base.

However, she expressed great concern for families who have not had medical exposure:

Because I have medical knowledge and experience I could fill in the gaps and ask the questions for answers I needed to know but for those without that medical background I think they would go home not really knowing anything about what they should be doing. [CG1]

Particularly, families expressed the need to feel comfortable with their loved one's medication regimen. Generally, it was a shared sentiment between caregivers, that formal health care staff tend to make many assumptions regarding an individual's understanding of the need for, use of, and side effects of medications. One caregiver recommended that health care providers make more of an effort to uncover caregiver knowledge on prescription drugs:

I mean I know enough about the drugs and I know enough, you know I have kind of a working knowledge so I kind of knew but it would have been nice if someone told me or just checked to see if I knew. That would have been really helpful. [CG8]

Further, not only is it important to recognize a family's baseline medical knowledge and skill set, caregivers described that an awareness of an informal caregiver's comfort levels in performing medical tasks is also important to note, as this can complement or inhibit their ability to put medical knowledge to use in caring for their loved one. For example, one caregiver noted:

Yeah, and I think even like how is this person going to manage with their bathing, you know. That you know is I think, I had the comfort to put mom on a transfer bench and you know help her in but someone else is not necessarily going to have that comfort and initially like just even imagine okay she's going to stand at the sink, do a sponge bath, and then she's just going to bend her head over the sink and I'm going to shampoo or whatever, like even that was to me like I kept think how am I going to get her hair washed if she doesn't go in the shower. Like you know and I'm not, 'cause I don't do the nursing care. [CG3]

Furthermore, both hip fracture and stroke caregivers discussed the importance of assessing family dynamics when trying to understand a family's unique situation. For example, one stroke caregiver discussed the issue of requiring someone to mediate decision-making processes when there are multiple perspectives involved during a very emotional time:

It's just the family dynamics, every family is different. So we have four, three of my siblings, so the four of us because Erin wasn't included, she wasn't capable of being included at that time, so it was the rest of us. We all have our own personalities, we all have our own way of looking at issues and some of us handle them different than others and I can see that within our family dynamic. So there was a difference between how my brother and I looked at what was going on and my sisters. Everybody's unique so you could probably take a look at a family dynamic and say this family needs this type of counselling for a couple of weeks or a couple of sessions and we should, with this type of family dynamic we probably want to do it with them separate or this type of family looks like they can talk and respect each others opinion so let's do it as a group so everybody's on the same page. [CG9]

When asked to detail the pragmatics of assessing family circumstances, family caregivers most often suggested that social work or nursing staff be included in this process, in conjunction with

case managers, who can then coordinate services based on family expectations, and need for community resources based on a family's financial situation. The following caregiver quotes illustrate these ideas:

Even just, I don't know maybe even at the hospital setting I mean if someone was more aware or came in or even with the nurses, like who comes to see them you know, are they, do they look like they're close, like I'm sure the nurses pick up quite a bit just by seeing who visits, the same faces and how they get along with each other and communicating that with the social worker, like okay who was that, the nurses could keep track. I mean it's not part of their job but who was here to visit, oh my kids were all here or whatever.[CG4]

Yeah, cause the person they're sending in is almost someone who just wants to coordinate a few services but they don't want to spend the time to do that other portion. So if there are social work staff that can meet that part you know what you're talking about, that or somebody that's going to look into that whole functioning of the family and what's available and what's not available.[CG3]

Fostering an initial understanding of the unique family situation is important in planning the care trajectory for an elderly hip fracture or stroke patient. It is important to be aware of the extent to which a support system exists for the patient once they return home, in order to build on family strengths, and also to supplement knowledge gaps and negative circumstances with available system resources.

5.7.2 Practical Information, Education and Training

Similar to case managers, caregivers expressed difficulty in navigating the incessant and unorganized information they receive through oral and written communication during the transition between hospital and home. A lack of structure in the education and training of informal caregivers within formal care settings was discussed as a barrier to enabling individuals to provide high quality care once a patient returns to their home in the community. Several caregivers discussed the current lack of practical education for family members within the hospital setting:

Well I would certainly suggest to them that if they don't have the background or the knowledge to feel comfortable giving the care to get help at this point but I am not sure where that help would come from. [CG1]

No not really they gave us our prescriptions, had the nurse come in for the bed sores, physiotherapist and the occupational therapist, but as for medical knowledge for myself, no. [CG2]

Furthermore, caregivers felt that information was not delivered effectively in the hospital in order to promote learning. Individuals often expressed feeling uneasy about asking questions of health care providers to obtain necessary information, as hospital settings and procedure were described as uninviting and rushed. As such, caregivers stressed the need to present information earlier during the hospital stay, and for health care providers to teach caregivers using an active and inclusive approach, rather than a passive directive approach. This was described as having an early involvement in formal care. One caregiver specifically discussed the potential to attend therapy sessions for their loved one:

Okay and I would suggest that, if I had it to do over again maybe the first couple of sessions I might have been present just to see how, you know how they get along just to see what the process is and in effect there's no reason why the family member couldn't be part of this process. [CG5]

Given the opportunity to be present during important therapy sessions for their loved one, caregivers would have the platform to be proactive in their learning and have the opportunity to ask questions in "real time".

In conjunction with early involvement and observation of formal care activities within the hospital, caregivers discussed the usefulness of raising their awareness of available community supports as soon as possible, in order to make necessary arrangements to supplement their care efforts once their loved one returned home to the community. Interestingly, one middle-aged caregiver expressed concern regarding the difficulty that older adults, especially older caregivers, face in terms of accessing community supports on their own:

Which is you know another piece of the puzzle sometimes with seniors is that they, there are a beautiful array of services out there and folks who are afraid to access them or don't know how or don't even know where to begin. [CG8]

Obviously, Informal caregivers need to be made aware of their options early on in the transition process. For example, one caregiver expressed difficulty and frustration in trying to organize periods of respite, once they were home in the community. This individual explained that he was unclear that he needed to book a short-stay bed at a retirement home months in advance in order to take a short holiday:

Well you have to book months ahead of time to find a place. We wanted to go away this winter for a holiday I called up in probably early June and they really had nothing available in the area, finally I was able to find [one, and] book her into a place in Milton. [CG2]

Being made aware of their options, caregivers would have the opportunity to plan ahead for their care role, and find a working balance between their sense of duty, responsibility and obligation to provide care, and their willingness to give up personal time to accomplish this. Several caregivers made suggestions as to how to improve family awareness in-hospital of available community resources, in order to temper the stress caregivers face when managing their loved one's care and balancing their lifestyle in the community. For example, a conversation regarding attainable options between a health care provider and caregiver midway through a patient's hospital stay was suggested as being an appropriate solution:

But you know I think it really is a matter of if you walk the steps with someone, if you give them the community support information in the middle so that they can educate themselves better in the middle than when it comes time for someone to get home they can know what's, you know what they can access when someone gets home. [CG8]

As a whole, interviews with caregivers suggested overall agreeability towards extending caregiver education to occur throughout the entire hospital stay. Caregivers felt that an improvement in the practicality of information delivery would enhance the likelihood that

information is absorbed and used effectively upon return to the community.

5.7.3 Involvement in Care Planning Process

There was a general consensus among caregiver participants that taking the opportunity and time to plan for care in the community is next to impossible within current models of acute care delivery for older patients who have experienced hip fracture and stroke. This was attributable to a lack of caregiver involvement in the care planning and decision-making processes throughout the hospital stay. Instead of having the opportunity to gradually adjust and adapt to assuming the caregiver role, family members described the stress that overwhelms them on the day of hospital discharge, when they come to an immediate realization that they are now left to shoulder the responsibility of care for their loved one. Several caregivers expressed their discontent with their lack of involvement in the planning process:

No, I actually wasn't. I was told kind of after the fact but I wasn't included in the discussions ahead of time even though I requested to be included in all of the discussions I wasn't. [CG8]

We were pulling it on our own because otherwise it was just a black hole, her name's in, they'll let us know when a bed comes up. Well what, how long... and they probably don't know but it's just you're kind of thirsting for information that whole time and there's no point, there's no family meeting, there's no kind of sit down saying ok, this is, your mom's had a stroke, she's had this kind of stroke, this is what you can expect in the next week, this is what you can expect in the next month, this is what you can expect in 6 months, this is what you can expect in a year within a range. [CG9]

As a solution to these issues, caregivers describe the need to be introduced to the planning process and included in a family-friendly discharge meeting early on in the hospital stay. One caregiver who had previous exposure to the health care system, compared her sub-optimal personal experience with discharge planning to what she had witnessed professionally, and suggested that more effort be made to meet with family members:

“Like I thought there would have been like a little family conference or something but maybe because I had been chatting there wasn't a need for one, you know what I

mean. Maybe that's the difference because I've worked before on orthopaedic rehab or something and they have a discharge meeting with, planning meeting with the family and that sort of thing" [CG3]

Furthermore, caregivers described the necessity for everyone involved in the care of an individual to be on the same page with regards to a care plan, prior to the care transition taking place. Unfortunately, without a consistent understanding across all individuals involved in care, miscommunication can occur, cause confusion, and waste family members' time as they attempt to compensate for a mistake in the information provided. One caregiver discussed such an instance:

So I would have really appreciated that type of meeting being pulled together at the beginning, somewhere in the middle and somewhere closer to the end so that I would have the opportunity to hear how she's doing. I would encourage her to have an in on it that so that she and I could hear the same things and they can, you know if they met with everybody they would see you know who's on the same page, who isn't and you know and that would be really helpful in someone's care in terms of getting them back home and providing us folks with the information in advance. [CG8]

5.7.4 Agreement between formal and informal caregivers

Complementing the necessary discussions required to ensure that all individuals are on the same page, caregivers further requested that they be provided with a written outline detailing both their responsibilities for care in the home, as well as any ongoing CCAC services that the patient was eligible for, and relevant contact information for the individuals involved in ongoing care activities. One caregiver stated:

I really think that there needed to be a written outline for people as well as a definite time, maybe the day before when the nurses would have talked to the caregiver specifically and gave them guidelines and asked if they had any questions, but I really did feel that Saturday morning because he was being discharged that you know he was not our concern now. [CG7]

Overall, it seems that caregivers need written documentation to complement verbal instructions given during the hospital stay, in order to foster a deeper understanding and more concrete

memory of care details discussed within the circle of care. Primarily, this would provide a mutually beneficial means of ensuring both professional and personal accountability to care tasks. Additionally, this written document would give caregivers the opportunity to refer to pertinent information, as they need it, or to refresh their memory periodically.

5.7.5 Taking Action in Personal Life

As previously discussed, the majority of informal caregivers are middle-aged adult daughters and wives. As such, these individuals often have busy personal lives with hectic schedules including both professional and family commitments. On the other hand, older caregivers may be managing their own health issues, which might require a heavy time commitment as well. Therefore, not surprisingly, caregivers of patients who spent time in short-stay rehabilitation or in convalescent care prior to being discharged home, had a more positive experience, as they were more confident in providing care to their loved one when they were less acutely ill. Further, these individuals had the chance to rearrange their schedule, organize the home environment, and feel more mentally prepared to provide care. One caregiver discussed the effect of rehabilitation on her confidence and comfort levels in providing care:

Yes and then when I saw that she was finally getting on to walking and following exercises with the aides, the physio aides and that kind of thing was working with her then I felt the comfort to go home and I actually, I don't believe I was there when she actually came home I think another sibling was there. But at least I knew she could you know, and she was getting up to the toilet and that kind of thing so that, that gave me the comfort for her to leave and go home. [CG3]

Combined, all caregivers expressed the need for time to prepare to shoulder the responsibility of care for a loved one, rather than assuming this role amidst the chaos on the day of discharge. Rather than suggesting that health care providers facilitate additional meetings and create new processes to accomplish this task, caregivers wish instead to be included in the collaborative processes that already exist within the hospital setting.

5.7.6 Emotional Readiness

According to caregivers, case managers were correct in describing the caregiver experience of transitional care as an emotional journey, or rollercoaster, of several negative emotions. When asked to describe how they felt during the process of managing a medical crisis for their loved ones, caregivers described very similar emotions to those discussed by case managers including fear, frustration and stress. For example, several caregivers described their emotions during the transition between hospital and home:

I was challenged with the additional feelings of not knowing, not knowing what to expect, how to handle it, where to go. [CG6]

No I think that I have already told you what my feelings were, just as a I say how shocked and disappointed I was and I yeah, I just wondered how other people, if they got the same lack of discharge information and assistance, how they would handle things and as I say I know of some dear people that it had been very difficult for them because they were elderly and not too well and they were terrified, you know when my husband comes home and what do I do if something happens. [CG1]

I didn't have anybody else to handle it and you know so they were kind of cold from that stand point and you know it almost, there almost seems to be some expectations that the health care system in its current state needs the family people, the family support system to kick in and take over and that's good but I need to feel able.[CG5]

Furthermore, similar to case manager interviews, caregiver interviews revealed self-confidence as the ultimate goal for individuals managing an informal care situation. When asked how it would be possible to transform the initial negative emotions and energy caregivers experience following a medical crisis, caregivers discussed the need to have their emotions validated and be provided with hope for a positive outcome. The following caregiver quotes demonstrate this need:

The biggest question I would have as a caregiver or family member of someone who's had a stroke is what's the prognosis here? Like what? So I basically started to pull nurses aside and say, 'this is the first time I've been involved with anybody with a stroke, I have no idea where we're going from here, there's my mom right there today, she can hardly sit up in bed and the soup's drooling out of her mouth and she has no feeling, she can't really move her leg too much and where do you see her in

six months?’. The one nurse said ‘I can see her walking on her own with assistance, maybe a cane or a walker’, and at that time that was like a miracle like it was unbelievable that that would happen within 6 months. So at least you have some hope, you’re not sure how realistic it is, but it was hope [CG9]

It would be nice to have someone to talk to, to refer to, you know a person who is like the social workers, if you can get hold of them. Right, cause I don’t remember the social worker, I guess she was, but I really didn’t meet with her the first time, I talked to her and she was pretty nice. [CG6]

Ultimately, caregivers need to feel, and have it communicated to them, that the emotions they are experiencing are normal and can be overcome. Caregivers want to be able to express their feelings, and feel that their concerns and questions are valid.

Combined, caregiver interviews suggest that many improvements could be made during the transition between hospital and home to better support families as they adjust and adapt to taking on the caregiver role. The needs described by caregivers fit well within the context of formal to informal care transitions described by case managers. Therefore recommendations given here seem both reasonable and realistic from both a professional and layperson perspective. Interestingly, the needs discussed by caregivers do not suggest that adding resources and new roles within the system are necessary to better support their efforts. Instead, caregivers wish to be appreciated, included, and viewed as valuable contributors to the care provision of older adults who have experienced a hip fracture or stroke. This would require a redesign in service delivery to be more family-friendly and inclusive in nature.

CHAPTER 6: THEORY DEVELOPMENT & PARTICIPANT FEEDBACK

6.1 INTRODUCTION

The following chapter presents a *Theory of caregiver needs to support a successful care transition from hospital to home*. The previous two chapters have focused on explaining thematic development through the constant comparative method, using open and axial coding, coupled with theoretical sampling, to uncover preliminary relationships between codes and properties describing caregiver needs. Building on this analysis, the present chapter details the interrelationships between properties discovered through selective coding, which culminate in a description of the core concept of caregiver needs during the transition from hospital to home for hip fracture and stroke patients. Further, this chapter details feedback from case manager and informal caregiver participants regarding the working theory of caregiver needs.

6.2 THEORY OF CAREGIVER NEEDS TO SUPPORT A SUCCESSFUL CARE TRANSITION FROM HOSPITAL TO HOME

Figure 3 below depicts the developed *theory of caregiver needs to support a successful care transition from hospital to home*. The core concept of the theory is *building capacity to care*. Threaded throughout the entire dataset was the notion that informal caregivers are, in most cases, both physically and mentally capable to provide some level of care and/or support for their loved one. However, as a result of the emotional stress they face in dealing with a medical crisis, family members may not be able to initially recognize, or feel able to shoulder the responsibility of informal care prior to the care transition between hospital and home taking place. Therefore, health care providers in the formal setting may work in conjunction with family members to address three levels of need required to build an individual's capacity to care during the hospital stay, in order to adequately prepare the patient-caregiver unit for the transition home. Figure 3

depicts these three levels, each building on the next, and is described in detail below.

6.2.1 Timeline of Caregiver Needs

First, informal caregiver needs have a temporal component. Through case manager and caregiver interviews, the researcher learned that most often, caregivers feel rushed into the caregiving role, without adequate time to adjust and adapt to the new responsibilities they must assume. Consistent across all interviews, was the need to begin caregiver preparation early in the formal hospital stay, so as to more gradually introduce the information, skills, community resources, and documents necessary for family members to successfully manage an informal care situation at home. As is represented on the care trajectory between hospital and home in Figure 3, the majority of informal caregiver needs fall in sequence, prior to patient discharge.

6.2.2 Instrumental Needs

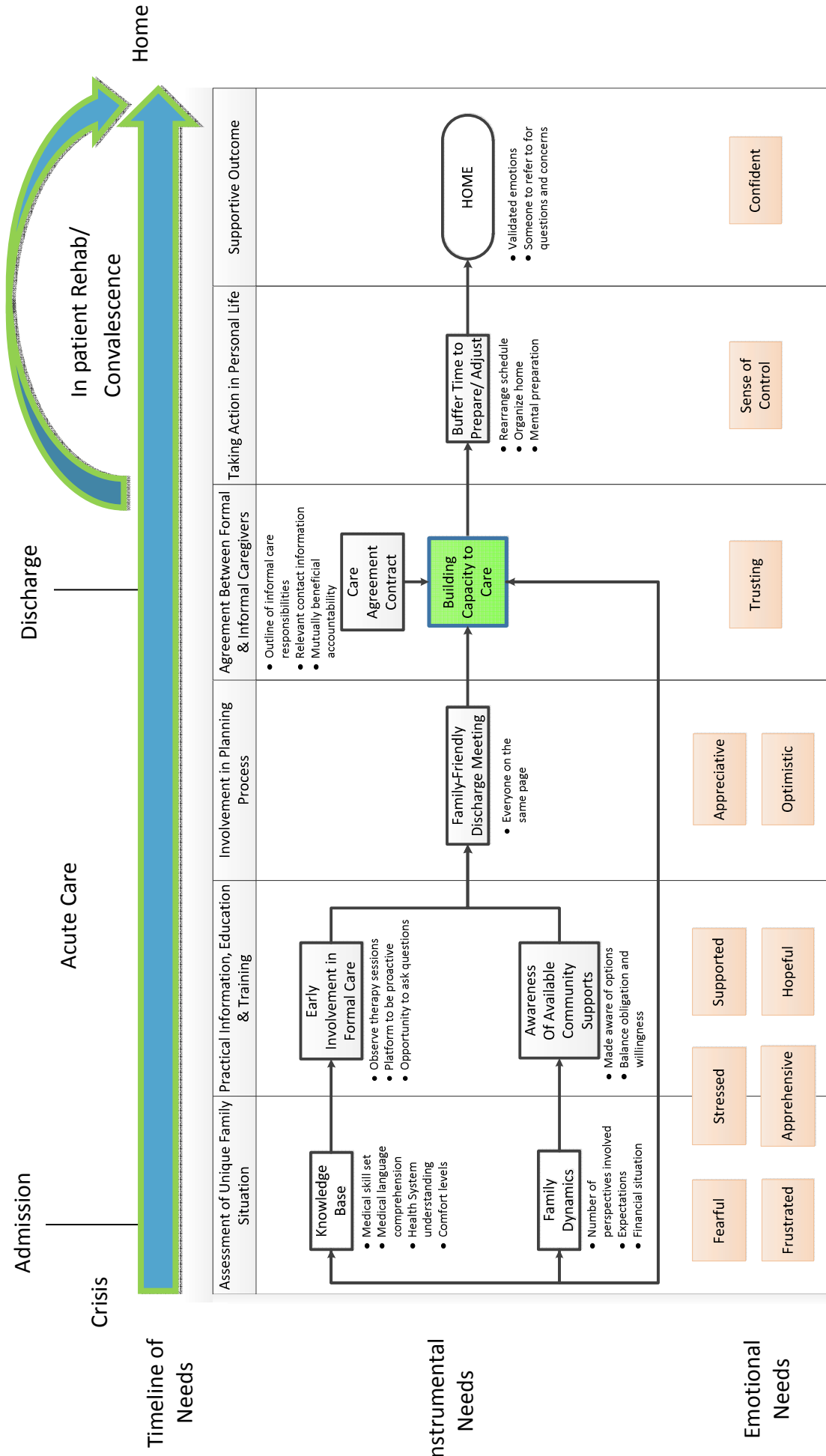
Most importantly, these needs are different for each caregiver, and are directly related to their baseline capacity to care. According to the double-headed arrow in Figure 3, an individual's capacity to care is not a static concept, and is dynamically related to the caregiver's knowledge base and family circumstances. For example, a caregiver may have a health care employment background, as well as a very supportive and financially stable family, and therefore have a very high baseline capacity to care at the point of patient admission to hospital. On the other hand, a caregiver may have had very limited interaction with the health care system, and have no family support to assist financially or physically with care tasks. In this situation, a caregiver might have a very low capacity to care at the point of patient admission to hospital. As was suggested in both case manager and caregiver interviews, a caregiver's knowledge base and family dynamics should be assessed at hospital admission, in order to determine an individual's baseline capacity to care. This preliminary understanding could then guide health care providers to scale

information and training methods accordingly, using both verbal and written information in building capacity to care. According to Figure 3, a caregiver's capacity to care should be at its highest at the point of hospital discharge.

6.2.3 Emotional Needs of Caregivers

The emotions caregivers experience during transitional care between hospital and home can also be described as a journey along the aforementioned timeline of caregiver needs. Consistently throughout the interviews, both case managers and caregivers referred to confidence as the ultimate goal and required emotion for caregivers to support and manage a successful care transition from hospital to home. However, fear, apprehension, frustration and stress were unfortunately the most prominently discussed emotions during interviews. According to caregivers, addressing the temporal, instrumental needs described in sections above, would work to stabilize initial caregiver emotions, and empower caregivers to feel optimistic, trusting, and eventually sustain feelings of support and self-confidence. Please see Figure 3 below for the complete emotional journey along a timeline of caregiver needs.

Figure 3. A theory of caregiver needs to support a successful care transition from hospital to home



6.3 PARTICIPANT FEEDBACK

6.3.1 Introduction

As the present study was conducted from a post-positivist epistemological stance, the researcher employed a member-checking process as the final stage of this research, in order to determine if the theory was a credible representation of caregiver needs. To ensure that the *Theory of caregiver needs to support a successful care transition from hospital to home* was truly representative of the data, the researcher conducted individual interviews with four of the original caregiver participants, and one focus group with five of the original case manager participants, to determine theory clarity, relevance, ease of understanding, and any level of ambiguity (Streiner & Norman, 2003). The researcher also sought participant recommendations for future research and intervention strategies.

6.3.2 Data Collection

Following theory development, the researcher contacted all original participants by phone to ascertain their interest in providing feedback on the working theory of caregiver needs (Appendix P). Four informal caregivers were eager to participate in an individual interview, and five case managers were willing to participate in a focus group interview. The interview format was chosen over a focus group for caregiver feedback, as the physical distance between caregivers would not allow for the gathering of participants in one place. Two interviews were conducted in-person, and two were conducted over the phone. Questions for both interviews and the focus group were centered on participant agreeability with the theory, as well as their criticisms, suggestions, recommendations, and ideas for future intervention strategies (Appendix Q and Appendix R). One interview and the focus group were audio-recorded. For the three

interviews that were not audio-recorded, the researcher took detailed notes using a laptop, to capture important feedback.

6.3.3 Data Analysis

Caregiver interviews and the case manager focus group were assessed to determine the face and content validity of the developed theory of caregiver needs (Yam et al, 2005). Face validity was ascertained through analyzing transcripts and notes to determine whether case manager participants felt the theory properties related to their individual experiences working with families, and whether caregivers felt the theory was representative of their expressed needs during transitional care for their loved one. As well, content validity was determined based on whether the participants felt the theory was inclusive of enough properties to successfully cover the range of important issues involved in caring for an individual during the transition from hospital to home (Yam et al, 2005). Lastly, the researcher made note of any suggestions for future research ideas and intervention strategies, which could evolve from the developed theory.

6.3.4 Results

Overall, both case managers and caregivers were very agreeable to the developed *theory of caregiver needs to support a successful care transition from hospital to home*. Informal caregivers felt that the theory was very representative of their own experiences, indicating strong face validity for the model. For example, when asked if they would make changes to the format or content of the theory, one caregiver stated:

No, not at all. Like I said, I was really impressed with it. Like how simple it was to follow, and how effective you were at getting a nice little model. It really helps to walk through the steps, and understand the emotions and you know, I think if something like this was followed, it would mean better outcomes for folks. I really really do. [CG8]

Moreover, caregivers appreciated the layout of the theory, and the comprehensiveness of incorporating three levels to represent the multi-component aspect of their needs. This indicated a strong content validity for the theory, as caregivers did not wish to add or change any properties included in the model. In particular, caregivers seemed to relate well to the emotional level of caregiver needs, which helped to facilitate their understanding of the rest of the model:

I appreciate the way it was laid out. It's very comprehensive. I really liked the way you added the feelings across the bottom. You know, when I thought about my own caregiving experience, I really kind of remember going through most of that. [CG1]

Additionally, feedback from a caregiver of an older adult who experienced a hip replacement surgery rather than a hip fracture suggests that the working theory of caregiver needs may be applicable to additional medical situations for older adults when there is potential for unplanned events, and acute hospitalization:

Yes, and in particular because my mom—yes the surgery was planned, but she had an unplanned event, she developed pneumonia in the hospital which was not-planned. So the minute we kind of went from planned, to not planned, I feel like I entered the model. So I had been with her for all of the pre-surgical stuff and knew what to expect, but as soon as she got to hospital it all went out the window. And a lot of what you have here, I wasn't included in any of it. And I'm a person who has a great deal of knowledge of what's going on in the community. So for me, being the caregiver, I was quite frustrated that I wasn't included. [CG8]

Similar to informal caregivers, both community and resource case managers also expressed strong endorsement for adopting the theory of caregiver needs to guide formal practice:

I think it looks good like this. I like things in charts. [CM5]

I think it's a good idea. I think it should be rolled out. [CM3]

Specifically, one case manager suggested giving family members a copy of this model at their loved one's admission to hospital so that they could begin to understand their role in care:

I think this model or theory would be really helpful in the hospital setting as well, in defining how family members can be involved. [CM4]

According to the feedback above, it seems that the *theory of caregiver needs to support a successful care transition from hospital to home* is, in fact, a valid representation of the temporal, physical, and especially emotional needs of caregivers.

Further, when asked which area of the developed theory should be the focus in future research and intervention development, both case managers and caregivers suggested a focus on admission and discharge needs. Participants felt that addressing these particular aspects of the care trajectory would make the most substantial improvements in an informal caregiver's capacity to care for an older loved one who has experienced a hip fracture or stroke. For example, one caregiver suggested that an assessment of caregiver knowledge and family situation would be beneficial to clarify familial expectations regarding care outcomes, and to develop a commonly understood goal for patient return to the community across both formal and informal caregivers. For example, one caregiver stated:

I think the whole thing is important, but in terms of intervention I think the assessment piece right at the beginning is the thing that needs to be tackled first. It would help families I think cement the "home first philosophy" right from the beginning. The care agreement contract would be a close second for me. [CG8]

Without a common initial understanding between formal and informal caregivers regarding goals for return to the community, valuable hospital resources may be used unnecessarily in preparing the patient for unrealistic outcomes. For example, one caregiver described her frustration in learning that hospital staff had assessed her mother and arranged for her to transition to a retirement home, all the while her family was making the necessary arrangements for her to return to her own home. She suggested that an assessment phase be implemented to learn about a family member's capabilities, in order to prevent this from occurring:

And to know where I'm at, so they can determine whether or not you know I am capable of supporting my mom when she gets home because somewhere along the way they started talking to her about a retirement home, and you know, I said "why

on earth are they talking to you about that? You're going home". And there are adequate services in the community to support her. That was the other piece that I found frustrating. The plan all along in my mom's head and in my head was that she was going home, and yet home from a hospital perspective is 'out of the hospital'. Its not necessary back home to their own home, and in my head she was going to her own home to where her bed, TV, and friends are. [CG8]

Furthermore, assessing an informal caregiver's family circumstances could inform formal health providers about a patient's premorbid functioning and capabilities which would be beneficial in developing realistic and achievable care goals. For example, a caregiver of a stroke patient stated:

I really, that's one thing I would have really appreciated, you know from a caregiver perspective, I would have loved that—to be able to communicate what my mom's baseline was before she came to hospital so that they knew kind of what our expectation was what we expected her to get back to—that's the piece that really fell apart for us. Nobody ever asked me what she could do before. [CG9]

Finally, when asking case managers how this type of assessment would be feasible in the acute hospital setting, it was suggested that it be implemented in a pen and paper questionnaire format. One case manager even suggested that caregivers could fill out such a questionnaire during their loved one's surgery, or while waiting in the emergency department:

Why couldn't they fill it out? The family is there in the beginning usually. You've got family buzzing around everywhere, you might as well make use of that. They are there. Have the tool there to get the assessment –have a questionnaire, fill it out during surgery. [CM4]

Overall, both caregivers and case managers felt that the assessment of caregiver knowledge and family circumstances would be both a useful and feasible approach to including informal caregivers in care planning efforts from admission, and help to streamline and make the best use of available resources towards realistic outcomes for older patients.

Case managers and caregivers also felt it was equally important for families and health care providers to be in agreement on discharge from the hospital setting in order to support a

successful transition from hospital to home. Therefore, both groups of participants expressed strong endorsement for a care agreement contract strategy. A caregiver of a hip fracture patient, and a resource case manager expressed their support for this idea:

I really like the idea of the care agreement contract, or something to that effect, where everybody is on the same page, and you have that right there on the model, but I think that is really important, because that is so key when it comes to supporting someone at home, so there isn't this misunderstanding about what we are talking about here— 'home is this, this is what this means, this is the level of support you are going to need, and you need this medication'—those types of things that get spelled out". It's the pieces that folks just don't necessarily get. [CG1]

I would focus on the contract piece. Some sort of checklist for consistency, because not all hospitals and case managers do it the same way. A checklist so you know that everyone is doing their own pieces. Because our service plans do not have detail on them or outline what the caregiver needs to do, it's just the services we are putting in. [CM2]

Further, case managers felt that a care agreement contract would prevent miscommunication surrounding care task responsibilities, which often present as a health safety issue once a patient returns home to the community. For example, a resource case manager stated:

I think having all of their instructions written out all in the same place. Because you know how many people call and say 'when is the nurse coming to change these bandages?' and our answer is 'well the nurse gave you some bandages and you are to do it', and it's like 'I am?!?'. You know it could all be in the same place. [CM3]

Finally, when asked about the feasibility of implementing a care agreement contract within the hospital setting on the day of patient discharge home to the community, case managers began to brainstorm ideas surrounding the timeline of caregiver needs. Ultimately, case managers came to the conclusion that in order to address caregiver needs across the continuum presented in the theory, it would be appropriate to bridge caregiver assessment and care agreement as a learning contract to accompany each phase of instrumental needs. One case manager describes this potential intervention:

Maybe have the assessment at the beginning to be tied into the care agreement contract at the end. Like a learning contract, assess them at baseline and then they

need to learn and become comfortable with each step along this timeline here, and then they can sign off each time they are comfortable with something. [CM5]

Further, case managers felt that including the emotional level of caregiver needs as part of the learning contract would help to validate caregiver emotions:

... maybe set it up as a timeline to match this theory and the emotions would validate their feelings as they move along the different stages; make them feel normal. [CM3]

Overall, both caregivers and case managers agreed that the theory of caregiver needs to support a successful care transition from hospital to home has great potential to guide the development of caregiver intervention and support strategies. All participants in the member-checking phase of the present study expressed interest in participating in future studies in this area.

CHAPTER 7: OVERALL DISCUSSION, STRENGTHS, LIMITATIONS, & CONCLUSIONS

7.1 OVERALL DISCUSSION

The present study set out to understand the informal caregiver experience for caregivers of hip fracture and stroke patients during transitional care between hospital and home. Both case managers and informal caregivers described an unsupported context of care for these individuals during the transition between a formal setting and informal setting. This idea is supported by current literature. Graham and colleagues (2009) describe a similar context for hospital to home care transitions, calling the experience for caregivers “isolated and unsupported”. Further, in a review of 44 studies regarding the hospital to home interface for older adults and their family members, Coffey (2006) specifically focus on the discharge process, finding a general consensus across studies that it is “unsupported”.

In order to better support caregivers during transitional care, case managers and family caregivers were confident that there needs to be a shift in formal health care thinking and practice to view informal caregivers as a valuable resource for meeting the increased demands of older adults. Again, this idea is supported in current literature. Jones and colleagues (2011) developed a *Caregiver Empowerment Model* (CEM) to guide caregiver inclusion in the transition process, which is similar in content to the previously discussed FAAR model by Patterson (1988). The CEM highlights the importance in understanding a caregiver’s background, and promoting a balance between resources and demands, in order to predict positive outcomes for family caregivers of older adults. Further, the authors state: “revisiting family caregiving through an empowerment framework will guide health professionals in promoting caregiver well-being and lead to new opportunities to partner with families in meeting the challenges of community-based elder care”. A first step to achieving this goal involves a shift in the language

used within the formal care system to describe informal care situations. To promote a more collaborative approach to care, terms implying a dominant power relationship, such as “caregiver” and “care recipient”, should be replaced with more neutral, interactive terms such as “care partner”. For example, Dupuis et al., (2011) have titled this approach “authentic partnership” in dementia care, which recognizes all key stakeholder voices in decision-making processes and describes the care role as working *with* others, instead of *for* others. The developed *theory of caregiver needs to support a successful care transition from hospital to home* provides further evidence for this interactive model, indicating that authentic partnerships can be established both between the caregiver and care recipient, as well as between formal and informal providers. Overall, caregivers need to be better included and receive more support within formal settings, in order to feel capable upon return home to the community.

The second objective of the present study was to develop a theory of caregiver needs to support a successful care transition from hospital to home. The core concept of this theory, and ultimate caregiver need, was *building capacity to care*. Given, Sherwood, and Given (2009) recognize that “assessing caregivers’ capacity to provide care and identifying caregivers who need assistance is essential to improving patient care”, which is confirmed by the present study findings. In order to achieve this goal, the developed *theory of caregiver needs to support a successful care transition from hospital to home* depicts and describes capacity to care as a multicomponent concept with three levels of understanding.

First, caregivers each have unique needs, which change over time. Cameron and Gignac (2008) suggests that health care providers need to be cognizant of the dynamic aspect of caregiver needs, and must temper their communication, education style, and level of support according to different stages of onset in the caregiver role. These stages include: 1) medical

event/diagnosis; 2) stabilization; 3) preparation; 4) implementation; 5) adaptation. Interestingly, these five stages correspond well with the six properties of caregiver need described in the present study.. Therefore, employing practical, tailored education, information, and inclusion in care planning activities is a viable proposition according to current literature.

Finally, evidence exists to support the level of emotional needs for informal caregivers during the transition between hospital and home. The present study discusses self-confidence as the ultimate goal for individuals to successfully overcome negative emotions and manage a care situation at home. Similarly, Schmall (1995) describes caregiver self-efficacy as the biggest predictor of positive outcomes for patients and their family members during self-management of a medical issue. Additionally, Zeiss and colleagues (1999) describe self-efficacy as the primary mediator of coping strategies for caregivers managing medical care situations. Therefore, it is clear, that a caregiver's perception of their capacity to care through self-confidence and self-efficacy is equally important to their physical ability to conduct care tasks.

Overall, the present *theory of caregiver needs to support a successful care transition from hospital to home* suggests that the "role onset" portion of the Caregiver Career (Aneshensel et al., 1995) is, in fact, more complex than presented in the original model (Appendix B). According to Schumacher (1995), this finding is valid, as role acquisition for informal caregivers is described as complex and multi-stepped family role transition. Further, according to the Caregiver Career model (Aneshensel et al., 1995), the transition between role acquisition and role enactment is described much as a passive process, occurring almost naturally following the onset of an illness or disease. The present study challenges this idea, and suggests that successful role enactment in the home is only achieved when the temporal, instrumental, and emotional needs of caregivers are addressed through interaction and conjunctive efforts between health care providers and

family members. Schumacher (1995) supports this idea, further describing the caregiver role as something that is created rather than assumed, through interactions between the caregiver and care receiver, as well as the caregiver and various health care providers to build caregiver skills.

The present study offers suggestions for the development of future intervention strategies within formal care settings, in order to protect and support ongoing informal care efforts of family members in the community. The key factor threaded throughout all suggestions, was that the relationship between health care providers and caregivers is mutually beneficial, and therefore caregivers should not be expected to navigate the system of care on their own. Instead, interventions should be designed to promote communication and interaction between health care providers and informal caregivers consistently throughout the hospital stay in preparing for the transition home. Unfortunately, the design of current interventions to support the hospital to home transition for informal caregivers does not support this inherent need. As previously discussed, *The Next Step in Care* (UNF, 2006) is an online intervention strategy developed by expert clinicians, which provides a series of self-guided checklists that can be accessed by caregivers to support their preparation for returning home to the community. The delivery mode of this intervention assumes that caregivers are able to take initiative during times of high-stress and use proactive strategies to obtain and retain necessary information and education. However, based on current literature and the input of caregivers in the present study, this assumption is very unrealistic. According to the developed theory, building an individual's capacity to care for their loved one must be a joint-effort between families and health professionals in order to promote the highest level of self-confidence and feelings of support on return home to the community.

Case managers and caregivers both agreed that interventions focused on assessment of family knowledge and circumstances on patient admission, and implementing a care agreement document on discharge would be most beneficial to improving positive outcomes for patients and their families in the community. In fact, the overall idea of linking these processes through the development of a caregiver learning contract is further supported in the literature. Given, Sherwood, & Given (2009) suggests that health care providers need to evaluate initial caregiver capacity including knowledge, skills, family roles and available resources, and then use these assessments to promote ongoing caregiver education throughout the formal hospital stay. Further, Wells and Cagle (2011) describe a caregiver's basic knowledge and circumstances as the foundation for which to build their skills to provide care in the community over time. As such, it is important to understand a caregiver's learning needs and then to target teaching methods to match these needs over multiple encounters during the hospital stay in order to reinforce learning (Wells & Cagle, 2011). Finally, the present study uncovered the importance of ensuring that all parties involved in transitional care receive clear, specific and consistent information at hospital discharge, in the form of a care agreement document. Brown-Williams (2006) support this idea, suggesting that a feedback loop be established between health professionals and family members to maintain communication and promote a mutual understanding of ongoing care responsibilities. Further, Kripalani et al., (2007) suggest that providing patients and families with a written discharge summary has the potential to drastically improve the care a patient receives in the community.

Future research could work to develop a comprehensive intervention strategy incorporating the elements above. To begin this process, the researcher might consider a tool developed by the Hartford Institute for Geriatric Nursing (2010), called PREPARE (Appendix

S). Similar to The Next Step in Care, PREPARE is a best-practice checklist tool aimed to ensure caregivers are equipped with the essential skills and resources to provide care in the community. However, unlike The Next Step in Care, this tool was developed by home care nurses based on their experiences working with informal caregivers, and is therefore more representative of caregiver needs from their perspective. The PREPARE tool is meant to be administered by home care nurses in the home setting and has not been evaluated or undergone psychometric testing (Atkins et al., 2010). However, using the properties of the *developed theory of caregiver needs to support a successful care transition from hospital to home*, in conjunction the elements of the PREPARE tool might serve as a starting point for future research to develop a hospital-specific caregiver learning contract to prepare individuals for care responsibilities following the transition home.

7.2 STRENGTHS AND LIMITATIONS

This research has several notable strengths. Most importantly, this study contributes to current knowledge by helping to clarify the role and needs of informal caregivers during transitional care between formal and informal settings for older adults following a medical crisis. The developed *theory of caregiver needs to support a successful transition from hospital to home* has the potential to contribute to clinical practice by laying the groundwork for which to develop feasible and appropriate intervention strategies to support the three levels of caregiver need during transitional care. Further, this research contributes to the current research priorities of the Canadian Caregiver Coalition (2008), and the Family Caregiver Alliance (2006) and might be used to inform best practice development in care transitions management and caregiver assessment strategies.

Another major strength of this research is the representativeness of the types of

caregivers interviewed. Multiple types of caregiver relationships were included in the sample including spouses and adult children of different genders. The study sample is therefore indicative of the heterogeneity of the caregiver population. Further, there were more female than male caregivers interviewed and the average age of caregiver participants was 58 years. This is representative of the demographics of overall caregiver population in North America (FCA, 2010). As such, an additional strength of the model is that it accounts for the uniqueness of diverse family situations, and does not present an understanding of caregiver needs as a “one-size-fits-all” approach. The key concept of the model, *building capacity to care*, is dynamic, recognizing the inherent variability in both baseline and maximum caregiver ability to provide care, based on caregiver knowledge and family circumstances.

Furthermore, the comprehensiveness of including three levels of caregiver need in the theory is a remarkable strength of the present study. Specifically, the temporal aspect of caregiver needs provides the unique opportunity to develop more targeted intervention strategies to support caregivers during different phases during the onset of the caregiving role. According to Cameron (2008), a clearer understanding of the common time specific needs across all caregivers has the potential to streamline and decrease resources needed to provide individualized programs. Further, incorporating a level of emotional needs strengthens a caregiver’s ability to relate to the model and understand its key phases, and also alerts health professionals to the emotional reactions involved in such a process. For example, Meiner (2006) discusses the importance of validating caregiver emotions in times of high stress, in order to promote learning and skill building.

A final strength of this research was the agreeability between health care professionals and informal caregivers on needs to support informal care efforts during transitional care. This

suggests that the issues and challenges uncovered during interviews were inherent to transitional care specifically, and not biased based on the individual's health professional or lay perspective. Further, this observation suggests that health care providers have the potential to welcome family members as partners in transitional care in order to work together towards a common goal of positive patient outcomes at home (Wells & Cagle, 2011).

Although this research offers a valuable contribution to both the transitional care and informal caregiving literature, the researcher faced some challenges and limitations throughout the study process. First, the concept of "home" was a source of confusion for many of the case managers and caregivers. Initially, the researcher defined home as an independent residential dwelling (ie. house, apartment, condominium) within the community. However, during case manager interviews the researcher was reminded that "home" can mean many things to different individuals. For example, during one caregiver interview, it was learned that "home" to this particular patient, meant independent living in a retirement setting, rather than an independent residence. Therefore, future research studies might clarify the conceptualization of "home" to include independent retirement living.

An additional limitation to the present study was the targeted sample population and focus on one specific transition in care between hospital and home, within one CCAC. Tappen (2011) points out that most studies on caregiving rely on a small, geographically restricted sample that lack power and may not be generalizable. Restricting the care recipient population to those experiencing hip fracture and stroke, and to the type of care transition explored limits the generalizability of the study findings to other medical situations and transitions between formal and informal settings of care. However, the congruence between hip fracture and stroke interviews and the added interviews with caregivers of hip replacement patients suggests that

additional research is warranted. Future studies could test the applicability of the substantive theory of caregiver needs to a broader sample of medical situations resulting in acute hospitalization. The present theory may have the potential to become a formal theory of caregiver needs during a transition between a formal and informal setting of care (Glaser & Strauss, 1967).

The researcher also faced several sampling issues. One of the most substantial limitations to the present study is the lack of representation of stroke caregivers in the study sample. Only two of 12 informal caregivers were of patients who had experienced a transition between hospital and home, following a stroke. Reasons for this limitation stem primarily from the employed sampling strategies. The third sampling strategy, recruitment of consent-to contact individuals from a previous study, was specific to hip fracture patients only, which biased the sample towards caregivers of hip fracture patients, as the researcher had to rely solely on sampling from the CCAC and the community to recruit stroke caregivers. Although the researcher made efforts to direct interview questions to general caregiver needs during transitional care, rather than questions specific to managing a particular medical situation, the present theory of caregiver needs is potentially biased towards the needs of caregivers caring for a hip fracture patient. Further, due to time constraints, the researcher included only one health professional opinion in the development of the *theory of caregiver needs to support a successful care transition from hospital to home*. As only community and resource case managers were included in the sample, findings from the present study might be biased towards community care needs, rather than formal care needs. Future research should consider including hospital case managers and nursing staff in the interview process to be more inclusive of the variety of health professionals involved in the care transition between hospital and home. Lastly, the researcher received

overwhelmingly positive feedback from interview participants during the member-checking phase of the study, indicating the potential presence of a social desirability bias. Social desirability is one of the most common biases in qualitative research, and occurs when participants misrepresent their opinions in a direction consistent with their interpretation of the researcher's opinion or social norms (Polit & Beck, 2004). Therefore, as participants were aware of the researcher's status as a student health researcher, they may have been more apt to respond favourably towards the developed *theory of caregiver needs to support a care transition from hospital to home*.

7.3 CONCLUSIONS

The developed *theory of caregiver needs to support a successful care transition from hospital to home* is a valuable tool for describing the optimal caregiver experience during transitional care between a formal and informal setting. Further, this model extends the concept of “role acquisition” during the caregiver career and suggests that caregivers need to be active and participatory members of the care team in order to manage this role onset effectively. Initially, the researcher predicted that a theory of caregiver needs might contribute to the development of a measure of transitional care success from a caregiver perspective. However, through case manager and caregiver interviews, it is clear that the present context of transitional care is unsupportive for informal caregivers. Therefore, current efforts to support transitional care are not meeting the needs reflected in the developed model, and it may be more beneficial for future research to focus on the development of intervention strategies to address phase-specific caregiver needs, rather than to assess whether needs are met overall. Strong agreement and endorsement of the theory by all study participants provides further evidence for the development of pilot intervention strategies. Overall, findings from this study will work to inform and assist health

care professionals to provide more timely and appropriate support to caregivers of patients following a medical crisis during a hospital to home transition.

REFERENCES

- Agency for Health Care Research and Quality (2000). Long-Term care users range in age and most do not live in nursing homes, Research Alert. Rockville, MD.
- Agar, M.H., MacDonald, J., (1995). Focus groups and ethnography. *Human Organization*, 54, 78–86.
- American Heart Association. (2001). 2001 heart attack and stroke statistical update, Dallas.
- Aneshensel, C.S., Pearlin, L.I, Mullan, J.T., Zarit, S.H., Whitlatch, C.J. (1995). Profiles in caregiving: The unexpected career. Academic Press: San Diego.
- Baxter, E. (2000). Caregiver assessment: Learn about the caregiver, distinct from the person with dementia. *Alzheimer's Care Quarterly*, 1(3), 62-70.
- Bengston, V.L. (2001). Beyond the nuclear family: The increasing importance of multigenerational bonds. *Journal of Marriage and Family*, 63, (1), 1-16.
- Blair, E., & Zinkhan, G.M. (2006). Nonresponse and generalizability in academic research. *Journal of the Academy of Marketing Science*, 34(1): 4-7.
- Blanchette, P.L & Flynn, B. (2001) Geriatric medicine: An approaching crisis. *Generations*, 25 (1) 80-84.
- Bradbury-Jones, C. (2007). Enhancing rigour in qualitative health research: Exploring subjectivity through peshkin's I's. *Journal of Advanced Nursing*, 59, (3), 290-298.
- Brown, J. & Furstenberg, A.-L. (1992). Restoring control: Empowering older patients and their families during health crisis. *Social Work in Health Care*, 17, 81-101.
- Brown-Williams, H., Neuhauser, L., Ivey, S., Graham, C., Poor, S., Tseng, W., Syme, S.L. (2006). *From Hospital to Home: Improving Transitional Care for Older Adults*. Health Research for Action: University of California, Berkeley, California.

- Bull, M.J. (1992). Managing the transition from hospital to home. *Qualitative Health Research*, 2(1):27-41.
- Bull, M., Bowers, J., Kirschling, J., Neufeld, A. (1990). Factors influencing family caregiver burden and health. *Western Journal of Nursing Research*, 12: 758
- Bull, M., Maruyama, G., & Luo, D. (1995). Testing a model for posthospital transition of family caregivers for elderly persons. *Nursing Research*, 44(3): 131-190.
- Cameron, J.I. and Gignac, M.A.M. (2008). "Timing it right": A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counselling*, 70, 305-314.
- Cantor, M. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist*, 23, 597-604.
- Canada's Association for the Fifty-Plus (CARP) (1999). *Putting a face on homecare: CARP's national forum on homecare—focusing on the informal caregiver*, Toronto.
- Canadian Caregiver Coalition. (2008). *A Framework for a Canadian Caregiver Strategy*.
- Carter S., & Little M. (2007). Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, 17(10), 1316–1328.
- Center on Aging Society. (2005). *How do family caregivers fare? A closer look at their experiences*. (Data Profile, Number 3). Washington, DC: Georgetown
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis*. Thousand Oaks, CA: Sage.
- Coffey, A. (2006). Discharging older people from hospital to home: What do we know? *International Journal of Older People Nursing*, 1, (2), 141-150.

- Coleman, E.A. (2003). Falling through the cracks: Challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatrics Society*, 51, 549-555.
- Coleman, E.A., Berenson, R.A. (2004). Lost in transition: challenges and opportunities for improving the quality of transitional care. *Annals of Internal Medicine*, 141, 533-536.
- Coleman, E. A. & Boulton, C. (2003). Improving the quality of transitional care for persons with complex care needs. *Journal of the American Geriatrics Society*, 51(4), 556-557.
- Coleman, E.A., Smith, J.D., Raha, D., Min, S. J. (2005). Posthospital medication discrepancies: Prevalence and contributing factors. *Archives of Internal Medicine*, 165, 1842 – 1847 .
- Coleman, E.A., & Williams, M.V. (2007). Executing high-quality care transitions: A call to do it right. *Journal of Hospital Medicine*, 2(5), 287-290.
- Cook, R.I.; Remder, M.; Woods, D.D. (2000). Gaps in the continuity of care and progress on patient safety. *British Medical Journal*, 320, 791-794.
- Covinsky, K. E., Palmer, R. M., & Fortinsky, R. H. (2003). Loss of independence in activities of daily living in older adults hospitalized with medical illnesses: Increased vulnerability with age. *Journal of American Geriatrics Society*, 51, 451-458.
- Cumler, E., Carter, J., Kutner, J. (2008). Failure at the transition of care: challenges in the discharge of the vulnerable elderly patient. *Journal of Hospital Medicine*, 3(4), 349-352.
- de Luise, C., Brimacombe, M., Pedersen, L., Sorensen, H.T. (2008). Comorbidity and mortality following hip fracture: a population-based cohort study. *Aging Clinical and Experimental Research*, 20(5), 412-418.
- Denzin, N.K., Lincoln, Y.S. (2005). *The SAGE handbook of qualitative research* (3 ed.) Sage publications: California.

- Donelan, K., Hill, C.A., Hoffman, C., Scoles, K., Feldman, P.H., Levine, C., & Gould, D. (2002). Challenged to care: Informal caregivers in a changing health system. *Health Affairs, 21*, 222-231.
- Dupuis, S., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., et al. (2009). *Moving beyond patient and client approaches: Mobilizing authentic partnerships in dementia care*. Published abstract for the 8th Global Conference: Making Sense of: Health, Illness, Disease. Oxford, England: Mansfield University.
- Dupuis, S.L., & Smale, B.J.A. (2004, March). In their own voices: Dementia caregivers identify the issues. Final report prepared for the Ministry of Health and Long-term Care and the Ontario Senior's Secretariat. Waterloo, ON: Murray Alzheimer Research and Education Program.
- Duxbury, L., C. Higgins and B. Schroeder (2009) *Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada*. Ottawa: Canadian Policy Research Networks Inc.
- Dye, J.F., Schatz, I.M., Rosenburg, B.A., Coleman, S.T. (2000). Constant comparison method: A kaleidoscope of data. *The Qualitative Report, 4*, (1), 1-16.
- Elliot, N.I., Lazenbatt, A. (2004). How to recognise a quality grounded theory research study. *Australian Journal of Advanced Nursing, 22*, (3), 40-44.
- Family Caregiver Alliance (2006). *Caregiver Assessment: Principles, Guidelines and Strategies for Change*. Report from a National Consensus Development Conference (Vol. I). San Francisco.
- Family Caregiver Alliance (2010). *Recommendations on family caregiving and long-term care services*: California.

- Fielding, N. (1994). Varieties of research interviews. *Nurse Researcher*, 1,(3), 4–13.
- Forster, A. J., Murff, H. J., Peterson, J. F., Ghandi, T. K., & Bates, D. W. (2003). The incidence and severity of adverse events affecting patients after discharge from the hospital. *Annals of Internal Medicine*, 138(3), 161-167.
- Freeborn, D.K., Pope, C.R., Mullooly, J.P., McFarland, B.H. (1990). Consistently high users of medical care among the elderly. *Medical Care*, 28(6), 527-540.
- Fredriksen, K.I., & Scharlach, A.E. (1999). Employee family care responsibilities. *Family Relations*, 48(2), 189-196.
- Funk, L.M., Stajduhar, K.I. (2009). Interviewing family caregivers: Implications of the caregiving context for the research interview. *Qualitative Health Research*, 19, (6), 859-867.
- Gandhi, T. K. (2005). Fumbled handoffs: One dropped ball after another. *Annals of Internal Medicine*, 2005, 142, 352-358.
- Given, B., Sherwood, P.R., Given, C.W. (2008). What knowledge and skills do caregivers need? *American Journal of Nursing*, 108, (9), 28-34.
- Glaser B. (1998). *Doing grounded theory: Issues and discussions*. Sociology Press: California.
- Glaser B. (2001). *The Grounded Theory Perspective I: Conceptualization Contrasted with Description*. Sociology Press .
- Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.
- Graham, C.L., Ivey, S.L., Neuhauser, L. (2009). From Hospital to Home: Assessing the Transitional Care Needs of Vulnerable Seniors. *The Gerontologist*, 49(1), 23-33.

- Grant, K. E., Compas, B. E., Thurm, A. E., McMahon, S. D., Gipsen, P. Y., Campbell, A. J., et al. (2006). Stressors and child and adolescent psychopathology: Evidence of moderating and mediating effects. *Clinical Psychology Review*, 26, 257 – 283.
- Guba E., & Lincoln Y. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In Denzin N., Lincoln Y. (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 191–215). Thousand Oaks: Sage.
- Haggerty, J.L., Reid R.J., Freeman G.K., Starfield B.H., Adair C.E., & McKendry R. (2003). Continuity of Care: A Multidisciplinary Review. *British Medical Journal*, 327(12), 19-21.
- Hallberg, L.R.M. (2006) The “core category” of grounded theory: making constant comparisons. *The International Journal of Qualitative Studies on Health and Well-being*, 1(3), 141-148.
- Han, B., Haley, W.E. (1999). Family caregiving for patients with stroke. *Stroke*, 30, 1478-1485.
- Health Canada. (2002). *National Profile of Family Caregivers in Canada*. (Final Report).
- Hébert, D.R. (2002). *Can Canada’s healthcare sustain the age transformation?* Canadian Institutes of Health Research. URL: <http://www.cihr-irsc.gc.ca/e/10518.html>. Accessed March 10, 2010.
- Hewitt, M., Rowland, J.H., & Yancik, R. (2003). Cancer survivors in the United States: age, health, and disability. *The journals of gerontology. Series A, Biological sciences and medical sciences*, 58(1),82-91.
- Ho, A., Collins, S., Davis, K., Doty, M. (2005). *A Look at Working-Age Caregivers Roles, Health Concerns, and Need for Support* (Issue Brief). New York, NY: The Commonwealth Fund.

- Institute for Family-Centered Care. (2008). *Applying patient- and family-centered concepts to bedside rounds: A guidance document*. Bethesda, MD: Author.
- Jones, P.S., Winslow, B.W., Lee, J.W., Burns, M., Zhang, X.E. (2011). Development of a caregiver empowerment model to promote positive outcomes. *Journal of Family Nursing*, 17, (1), 11-28.
- URL: www.elsevier.com/locate/ecoecom. Accessed April 10, 2011.
- Kahana, E., Kahana, B., Johnson, J. Hammond, R., Kircher, K. (1994). Developmental challenges and family caregiving: Bridging concepts and research. In Kahana, B. & Wykle, M. (Eds.), *Family caregiving across the lifespan*. NewburyPark, CA: Sage.
- Kaplowitz, M.D, Hoehn, J.P. (2000). Do focus groups and individual interviews reveal the same information? *Ecological Economics*, (2), 237-247.
- King, R.B., Semik, P.E. (2006). Stroke caregiving: difficult times, resource use, and needs during the first 2 years. *Journal of Gerontological Nursing*, 32(4), 37-44.
- Kinney, J., Stephens, M., Franks, M. & Norris, V. (1995). Stresses and satisfactions of family caregivers to older stroke patients. *Journal of Applied Gerontology*, 14,3-21.
- Kripalani, S., LeFevre, F., Phillips, C.O., Williams, M.V., Basaviah, P., & Baker, D.W. (2007). Deficits in communication and information transfer between hospital-based and Primary care physicians: Implications for patient safety and continuity of care. *Journal of Applied Hospital Medicine*, 1, 354-360.
- Krueger, R. A. & Casey, M. A. (2000). *Focus groups. A practical guide for applied research* (3rd Ed). Thousand Oaks, CA: Sage Publications.
- LaForest, J. (2009). Guide to organising semi-structured interviews with key informants. Charting course to save living. Quebec: Government Quebec.

- Lanteigne, G. (2011). There's no place like home: 'Home First' philosophy provides care options for seniors, Champlain Community Care Access Centre.
- Lazarsfeld, P. F. (1958). Evidence and inference in social research. *Daedalus*, 97, 47-67.
- Levine, C. (2000). *Rough Crossings: Family Caregivers' Odysseys Through the Health Care System*. New York: United Hospital Fund.
- Levine, C., Reinhard, S.C., Feinberg, L.F., Albert, S., & Hart, A. (2004). Family Caregivers on the Job: Moving Beyond ADLs and IADLs. *Generations*, 27(4), 17-23.
- Levine, C., Halper, D., Peist, A., & Gould, D.A. (2010). Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care. *Health affairs*, 29(1), 116-124.
- Lincoln, Y., Guba, E.G. (2000). Paradigmatic controversies contradictions and emerging confluences. In: Denzin N, Lincoln, Y, Eds. *Handbook of Qualitative Research* (2 ed). Thousand Oakes: Sage Publications, 163-188.
- Lindlof, T.R., Taylor, B.C. (2002). *Qualitative communication research methods* (2 ed.) Sage Publications: Thousand Oaks, California.
- Lofland, J., & Lofland, L. H. (1984). *Analyzing social settings*. Belmont, CA: Wadsworth Publishing Company, Inc.
- Lyons, A. (1997). Clinical outcomes and treatment of hip fractures. *The American Journal of Medicine*, 103(2), S51-S64.
- MacKean, G.L., Thurston, W.E., Scott, C.M (2005). Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations*, 8, (1), 74-85.
- Martin, F. (2010). Comprehensive assessment of the frail older patient. *British Geriatrics Society*, 1-11.

- Marshall, M.N.(1996). Sampling for qualitative research. *Family Practice*, 13, 522-525.
- McWilliam, C.L., & Sangster, J.F. (1994). Managing patient discharge to home: The challenges of achieving quality care. *International Journal for Quality in Health Care*, 6, 147-161.
- Meiner, S. (2006). *Gerontological Nursing* (3 ed.) Mosby Elsevier: Missouri.
- Moore, C., Wisinvesky, J., Williams, S., & McGinn, T. (2003). Medical errors related to discontinuity of care from and inpatient to an outpatient setting. *Journal of General Internal Medicine*, 18, 646-651.
- Montgomery, P., Bailey, P.H. (2007). Field notes and theoretical memos in grounded theory. *Western Journal of Nursing Research*, 21, (1), 65-79.
- Morgan D.L. and Krueger R.A. (1993) When to use focus groups and why in Morgan D.L. (Ed.) *Successful Focus Groups*. London: Sage.
- Murtaugh, C. M. & Litke, A. (2002). Transitions through postacute and long-term care settings, patterns of use and outcomes for a national cohort of elders. *Medical Care*, 40(3), 227-236.
- National Advisory Council on Aging. (1999). *Challenges of an Aging Canadian Society: 1999 and Beyond*. Ottawa, ON: Minister of Public Works and Government Services Canada.
- National Centre for Social and Economic Modelling (NATSEM) (2004). *Who's going to care? Informal care and an ageing population*. Report prepared for Carers Australia. Austin, J.
- National Consensus Project for Quality Palliative Care (2004). *Clinical Practice Guidelines for Quality Palliative Care*, New York.
- National Consensus Project for Quality Palliative Care (2004). *Clinical Practice Guidelines for Quality Palliative Care*, New York.

- Naylor, M.D. (2000). A decade of transitional care research with vulnerable elders. *Journal of Cardiovascular Nursing*, (3),1-14.
- Naylor, M. D. (2002). Transitional care of older adults. *Annual Review of Nursing Research*, 20(1), 127-147.
- Naylor , M. D. (2004). Transitional care for older adults: A cost-effective model . *LDI Issue Brief*, 9, 1 – 4 .
- Opinion Research Corporation (2006). *Backgrounder: Family Caregiving in America*.
URL:
<http://www.strengthforcaring.com/util/press/facts/family-caregiving-in-america.html>.
Accessed March 12, 2010/
- Palmer, S., Glass, T.A. (2003). Family function and stroke recovery: A review. *Rehabilitation Psychology*, 48 (4), 255-265.
- Pandit, N.R. (1996). The creation of theory: A recent application of the grounded theory method. *The Qualitative Report*, 2, (4), 1-21.
- Patterson, J. (1988). Families experiencing stress: The family adjustment and adaptation response model. *Family Systems Medicine*, 5, (2), 202–237.
- Penrod, J., Dellasega. C. (1998). Caregivers' perspectives of placement decisions. *Western Journal of Nursing Research*, 20(6), 706-722.
- Picker Institute (1999). Continuity and transition: preparing for discharge. New Visions: ideas worth sharing. URL:
www.pickerinstitute.org/PDF/documents/Discharge%20preparation.pdf. Accessed January 28, 2010.

- Pickett, W., Hartling, L., & Brison, R. J. (1997). Population-based study of hospitalized injuries in Kingston, Ontario, identified via the Canadian Hospitals Injury Reporting and Prevention Program . *Chronic Disease Canada*, 18, 61 – 69.
- Pinquart, M., Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging*, 18(2), 250-267.
- Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(1), 33-45.
- Pollara. (2006). Health Care in Canada Survey. URL:
www.hcic-sssc.ca. Accessed February 25, 2010
- Polit, D.F., Beck, C.T. (2004). Nursing research: principles and methods (7 ed.) Lippincott Williams & Wilkins.
- QSR International Pty Ltd. (2008). NVivo qualitative data analysis software, Version 8.
- Reid, R.J., Roos, R.N., MacWilliam, L., Frohlich, N., Black, C. (2002). Assessing population health care need using a claims-based ACG morbidity measure: A validation analysis in the province of Manitoba. *BC Centre for Health Services and Policy Research*, 37(5), 1345-1364.
- Reuss, G.F., Dupuis, S.L., Whitfield, K. (2005). Understanding the experience of moving a loved one to a long-term care facility: Family members' perspectives. *Journal of Gerontological Social Work*, 46,17–46.
- Rice, .P, Ezzy,D. (2000) Qualitative research methods: A health focus. South Melbourne: Oxford University Press.

- Riley, R. (1996). Revealing socially constructed knowledge through quasi-structured interviews and grounded theory analysis, *Journal of Travel and Tourism Marketing* 15(2), 21-40.
- Roche, J.J.W, Wenn, R.T., Sahota, O., Moran, C.G. (2005). Effect of comorbidities and postoperative complications on morality after hip fracture in elderly people: prospective observational cohort study. *British Medical Journal*,10, 331-1374.
- Rossi, P.H., Lipsey, M.W., & Freeman, H.E. (2004). Evaluation: A systematic approach. (7 ed.) Thousand Oakes, CA: Sage.
- Ruggeri, J. (2002) Population aging, health care spending and sustainability: Do we really have a crisis? *Caledon Institute of Social Policy*, 1-21.
- Ryan, Anne B. (2006) *Post-Positivist Approaches to Research*. In: Researching and Writing your thesis: a guide for postgraduate students. MACE: Maynooth Adult and Community Education, pp. 12-26.
- Saltz, C., Zimmerman, S., Tompkins, C., Harrington, D. & Magaziner, J. (1999). Stress Among Caregivers of Hip Fracture Patients: A Longitudinal Study. *Journal of Gerontological Social Work*, 30(3), 167-181.
- Schmall, V.L. (1995). Family caregiver education and training: enhancing self-efficacy. *Journal of Case Management*, 4, (4), 156-162.
- Schulz, P., & Sherwood, P. (2008). Physical and Mental effects of Family Caregiving. *American Journal of Nursing*, 108(9), 23-27.
- Schumacher, K. (1995). Family caregiver role acquisition: Role-making through situated interaction. *Research and Theory for Nursing Practice*, 9, (3), 211-226.
- Segal, M. & Schall, R. (1997). Life satisfaction and caregiving stress for individuals with stroke and their primary caregivers. *Rehabilitation Psychology*, 42, 91-111.

- Smale, B.J.A., & Dupuis, S.L. (2004). In their own voices: Guiding principles and strategies for change by and for dementia caregivers in Ontario. Final report prepared for the Ministry of Health and Long-term Care and the Ontario Senior's Secretariat. Waterloo, ON: Murray Alzheimer Research and Education Program.
- Spillman, B.C. & Black, K.J. (2005). *Staying the Course: Trends in Family Caregiving*.
- Spillman, B.C., & Pezzin, L.E. (2000). Potential and Active Family Caregivers: Changing Networks and the "Sandwich Generation." *The Milbank Quarterly*, 78, 347-374.
- Statistics Canada (2006). A portrait of seniors in Canada.
- Stiel, S., Pestinger, M., Moser, A., Widdershovem, G., Luke, U., Meyer, G. et al., (2010) The use of grounded theory in palliative care: Methodological challenges and strategies. *Journal of Palliative Medicine*, 13, (8), 997-1003.
- Strauss, A., & Corbin, J. (1998). Basics of qualitative research: *Grounded theory*, procedures and techniques. Newbury Park, CA: Sage.
- Streiner, D. L., Norman, G. R. (2003). *Health measurement scales: A practical guide to their development and use* (3rd ed.) Oxford: Oxford University Press.
- Streubert- Speziale, S. H., & Carpenter, D. (2003). *Qualitative research in nursing: Advancing the humanistic imperative* (3rd ed.). Philadelphia: Lippincott Williams & Wilkins.
- Suitor, J., & Pillemer, C. (1988). Explaining intergenerational conflict when adult children and elderly parents live together. *Journal of Marriage and the Family* 50:1037-1047.
- Tappen, R.M. (2011). *Advanced research: From theory to practice*. Jones & Bartlett Learning: Sudbury.

- Tavakol M, Torabi S, Zeinaloo, A.A (2006). Grounded theory in medical education research. *Medical Education Online*, 11, 30.
- URL : <http://www.med-ed-online.org> . Accessed March 12, 2011.
- The Next Step in Care (2006). *Family caregivers and health professionals working together*. United Hospital Fund, New York. URL:
<http://www.nextstepincare.org/> Accessed January 28, 2010.
- The Waterloo-Wellington Community Care Access Centre Quality report (2010).
URL: <http://www.ccac-ont.ca>. Accessed April 10, 2011.
- Thomson, B. S. (2010). Qualitative Research: Grounded Theory-- Sample Size and Validity.
URL: <http://www.buseco.monash.edu.au/research/studentdocs/mgt.pdf>. Accessed April 30, 2010.
- van Walraven, C.; Mamdani, M.; Fang, J.; Austin, P.C. (2004) Continuity of care and patient outcomes after hospital discharge *Journal of General Internal Medicine*, 19, 624-631.
- Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946-972.
- Waterloo Wellington Local Health Integration Network (WWLHIN), (2007). *Aging at home strategy*. A Directional Plan.
- Weaver, F.M., Perloff, L., and Waters, T. (1998). Patients' and caregivers' transition from hospital to home: needs and recommendations. *Home Health Care Services Quarterly*, 17 (3), 27 - 48.
- Wells, J.N., Cagle, C.S. (2011). Family caregivers: Present and accounted for. *Nursing made incredibly easy*, 46-51.

- Williams, M., Obert, M., Bjorklund, B. & Hughes, S. (1996). Family caregiving in cases of hip fracture. *Rehabilitation Nursing, 21*, 124-131.
- Williams, A. P., Lum, J. M., Deber, R., Montgomery, R., Kuluski, K., Peckham, A., et al. (2009). Aging at home: Integrating community-based care for older persons. *HealthcarePapers, 10*, (1), 8-21.
- Willyard, J., Miller, K., Shoemaker, M, Addison, P.(2008). Making sense of sibling responsibility for family caregiving. *Qualitative Health Research, 18*, (12), 1673-1686.
- Wister, A.V. (2005). Baby boomer health dynamics. Toronto: University of Toronto Press Inc.
- Wright, L.K., Hickey, J.V., Buckwalter, K.C., Clipp, E.C. (1995). Human development in the context of aging and chronic illness: The role of attachment in Alzheimer's disease and stroke. *International Journal of Aging and Human Development, 41*(2), 133-150.
- Wright, L.K. Hickey, J.V., Buckwalter, K.C., Clipp, E.C. (1995). Human development in the context of aging and chronic illness: The role of attachment in Alzheimer's disease and stroke. *International Journal of Aging and Human Development, 41* (2), 133-150.
- Yam, W., Chow M., Ronen, G. (2005) Chinese version of the parent-proxy health-related quality of life measure for children with epilepsy: translation, cross-cultural adaptation, and reliability studies, *Epilepsy Behaviour, 7*, 697–707.
- Zarit, S. (2006). Assessment of Family Caregivers: A Research Perspective. In Family Caregiver Alliance (Eds.), *Caregiver Assessment: Voices and Views from the Field*. Report from a National Consensus Development Conference (Vol. II) (pp. 12 – 37). San Francisco: Family Caregiver Alliance.
- Zeiss, A., Gallagher-Thompson, D. Lovett, S., Rose, J., Mckibbin, C. (1999). *Journal of Clinical Geropsychology, 5* (3), 221-230.

APPENDIX A

UNIVERSITY OF WATERLOO
OFFICE OF RESEARCH ETHICS

Notification of Ethics Clearance of Application to Conduct Research with Human Participants

Faculty Supervisor: Paul Stolee

Department: Health Studies & Gerontology

Student Investigator: Justine Toscan

Department: Health Studies & Gerontology

ORE File #: 16435

Project Title: Silent Partners in Care: Assessing Care Transitions for Caregivers of Hip Fracture and Stroke Patients

This certificate provides confirmation that the additional information/revised materials requested for the above project have been reviewed and are considered acceptable in accordance with the University of Waterloo's Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Thus, the project now has received ethics clearance. This clearance is valid for a period of four years from the date shown below and is subject to an annual ethics review process (see Note 2). A new application must be submitted for on-going projects continuing beyond four years.

Note 1: *This project must be conducted in accordance with the description in the application and revised materials for which ethics clearance has been granted. All subsequent modifications to the application must be submitted for prior ethics review using ORE Form 104 and must not be initiated until notification of ethics clearance has been received.*

Note 2: *All ongoing research projects must undergo annual ethics review. ORE Form 105 is used for this purpose and must be submitted by the Faculty Investigator/Supervisor (FI/FS) when requested by the ORE. Researchers must submit a Form 105 at the conclusion of the project if it continues for less than a year.*

Note 3: *FIs and FSs also are reminded that they must immediately report to the ORE (using ORE Form 106) any events related to the procedures used that adversely affected the participants and the steps taken to deal with these.*

Date

May 31/10

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APPENDIX B



Silent Partners in Care: Assessing Care Transitions for Caregivers of Hip Fracture and Stroke Patients

Case Manager Participant Information Letter

Contacts:

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Researcher: Justine Toscan; jtoscan@uwaterloo.ca; 519-888-4567 x33160

What is the purpose of this study?

Going through a transition, or a move, from one care setting (e.g., a hospital) to another (e.g., home) can be difficult and many different things can affect the quality of this transition. The purpose of this study is to learn about caregiver needs and experiences with transitional care as a hip fracture or stroke patient moves from hospital to home. This study will help us answer important questions about the quality of care transitions for informal caregivers involved in a patient transition from hospital to home, in order to develop a tool to assess the success of care transitions from a caregiver perspective.

Who can participate?

We are looking for Waterloo-Wellington Community Care Access Centre (CCAC) Home Care Case Managers who have experience working with family caregivers of hip fracture and stroke patients who have transitioned from hospital to home.

What will I be asked to do?

We are asking Home Care Case Managers who have experience working with family caregivers of hip fracture and stroke patients who have transitioned from hospital to home to participate in a brief 30 minute interview in order to gain professional insight on the caregiver experience of care transitions. The interview will take place in-person at a convenient time and location for you. We will also ask you approximately 5 to 10 questions to ascertain your opinion regarding the needs, challenges, and support caregivers require with different aspects of a hip fracture or stroke patient's transition from hospital to home. We will also be collecting general descriptive information including your age, gender, and years of clinical experience. No personally identifying information will be attached to your audio-recorded interview responses.

The interview information is important, as it will allow us to identify areas that need to be assessed in order to improve caregiver preparation and support to assist in the rehabilitation of people who have experienced a hip fracture or stroke.

Where will the study take place?

Interviews will take place at your place of work, or if you would prefer, a private room at the University of Waterloo could also be provided.

How long will the study take?

The in-person interview will take approximately 30-45 minutes to complete.

Can I change my mind about participating in the study?

You may decline to answer any questions, or withdraw from the study at any time. If you wish to withdraw from the study, you can let the interviewer know any time during the interview, or you can contact Paul Stolee PhD, Principal Investigator, at 519-888-4567 ext. 35879

Are there any risks or benefits involved in participating in this study?

There are no direct risks or benefits for you related to participating in this study. However the study will contribute to current scientific knowledge through helping to clarify the role of the informal caregiver in transitional care. This research will greatly enhance our societal understanding of the unique care experiences, challenges, and needs of informal caregivers during unexpected, emergency care situations.

Will I be audio recorded during the study?

The in-person interview will be audio-recorded and the information entered into a secure computer database.

Confidentiality and Security of Data

The information you provide will be kept confidential and identified by number only. Your name will not appear in any report or publication resulting from this study. Any quotations used in reports from your interview will be referenced as anonymous.

You have the right to ask the researchers about the data being collected about you for the study and about the purpose of these data. You also have the right to ask the researchers to let you see your personal information and make any necessary corrections to it.

Data collected will be kept securely stored in a locked office for a period of 5 years, and then confidentially destroyed. The answers to the interview questions will be stored in a locked file cabinet, in a locked office, at the University of Waterloo for a period of 5 years. Electronic files, with no personal identifying information, will be stored on a secure, password protected computer for a period of 5 years. After 5 years, any written notes from the interview will be confidentially shredded and electronic files will be destroyed. Only members of the research team, who have signed a confidentiality agreement regarding information collected during the study, will have access to the study data.

Who can I contact if I have any questions?

If you have any questions regarding the research itself, please contact Paul Stolee PhD, Principal Investigator, at 519-888-4567 ext. 3587

This project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. The final decision to participate is yours. Should you have any comments or concerns resulting from your participation in this study, please contact Susan Sykes, Director, Office of Research Ethics, University of Waterloo at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca

APPENDIX C

TELEPHONE SCRIPT: RECRUITMENT OF CASE MANAGER PARTICIPANTS

Hello my name is _____. I am calling from the University of Waterloo. We want to know if you would like to participate in our research study. We are looking for CCCAC resource or community case managers to provide professional insight and share their experiences working with informal caregiver needs and experiences of care transitions for hip fracture and stroke patients. This information will be used in conjunction with information provided directly from caregivers themselves in order to develop a clinical tool to assess the quality of care transitions from a caregiver perspective. The study involves taking part in a 30 minute in-person interview. This interview can be scheduled during a convenient time and location for you. For example, the interview could take place in your place of work, or if you prefer, a private room at the University of Waterloo could be arranged. All responses will be confidential. Your decision to participate is voluntary. This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Waterloo. However, the final decision to participate is yours. A decision to participate in this study will in no way affect your position as a CCAC Case Manager, as this study is being directed by the University of Waterloo and not the CCAC.

. Are you interested in hearing more about the study and possibly participating?

****If yes:**

We are able to provide you with an information letter that provides further details about the study. What would be the best way for us to send this information to you? (eg email, fax, mail— whichever is most convenient)
Do you have any questions?

****If Yes, set up a convenient time and location to meet. The following information can be used to answer any questions the Case Manager might have**

- The interview questions are quite general (for example, “What challenges do caregivers face during the transition from hospital to home?).
- You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time.
- With your permission, the interview will be tape-recorded to facilitate collection of information, and later transcribed for analysis.
- All information you provide will be considered confidential, be stored in a secure location, and disposed of after 5 years.

***If No, thank them once again for their time**

APPENDIX D

Silent Partners in Care: Assessing Care Transitions for Caregivers of Hip Fracture and Stroke Patients

Case Manager Participant Consent Form

Contact:

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Researcher: Justine Toscan; jtoscan@uwaterloo.ca; 519-888-4567 x33160

I have read the information letter about the study that examines care transitions for caregivers of hip fracture and stroke patients. I have been informed that you would like my help to learn more about the needs and experiences of caregivers during the care transition from hospital to home of hip fracture and stroke patients. I know that this study is being conducted by Paul Stolee, PhD at the University of Waterloo. I have been informed that my participation in this study involves one, approximately 30 minute in-person interview, conducted at my convenience. I was also informed that I can refuse to participate in any portion of this study at any time.

I have had the chance to ask questions related to this study. I have had the chance to receive satisfactory answers to my questions and any additional details I wanted. I have been informed that I am free to withdraw from the study at any time by telling the researchers that I no longer wish to continue.

I know that if I change my mind about participating there will be no penalty.

I have been informed that as part of this study Paul Stolee, PhD and other investigators would like to gather some general descriptive information including my age, gender, and years of clinical experience. I have been informed that no information obtained from my interview will contain personal identifiers. I have been informed that this information will be retained in the strictest confidence and that I may withdraw my consent at any time. If I withdraw my consent to participate in the study after I have been interviewed, the information that was collect from me will be destroyed.

I have been informed that this project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. If I have any comments or concerns resulting from my involvement in this study I may contact Susan Sykes, Director, Office of Research Ethics at the University of Waterloo, at 519-888-4567 x36005 or ssykes@uwaterloo.ca.

I give consent for interviews conducted by the research team to be audio-recorded.

I give consent for quotations from my interview to be used in reports where they will be referenced as anonymous.

I agree to assist in recruitment of caregiver participants for the next phase of this study

Case Manager Name: _____

Case Manager Signature: _____

Witness Signature: _____

Date: _____

APPENDIX E

SAMPLE QUESTION TRANSFORMATION

Original Question #4

4. From your professional experience, what **challenges** do family members experience during the transition from hospital to home?

Probe: financial, emotional, relational, vocational, environmental?

Transformed Question #4

4. From your professional experience, how does the **fast-paced nature of the formal hospital setting** experience affect the transition from hospital to home for informal caregivers?

Probe: financial, emotional, relational, vocational, environmental?

APPENDIX F



Silent Partners in Care: Examining Care Transitions for Caregivers of Hip Fracture and Stroke Patients

Interview Guide for Case Managers

1. General Background Information about Case Manager

Year of birth: _____

Gender: Male Female

Resource Case Manager _____ Community Case Manager _____

How many years have you been employed in this position?

Overall, how many years of experience do you have as a CCAC case manager?

How many years of clinical experience do you have in total?

Opening Discussion Question

In your opinion, why do you think the transition from hospital to home following a medical crisis (ie hip fracture or stroke) has been identified in the literature as extremely challenging?

Probe: For whom?

2. Knowledge on Caregiver roles, needs and challenges

1. Can you please describe the process of transitioning from hospital to home for a hip fracture/stroke patient?

Probe: planning discharge, communication, equipment, formal to informal care setting

2. What is your **role** during this transition?

Probe: interaction with caregivers-- conversations, meetings, education, coordinates services

3. What is the transition **experience** like for informal caregivers?

a) What **role** does an informal caregiver play during this transition?

b) In your professional opinion, what are the **needs** of informal caregivers during this process?

Probe: informational, financial, and educational

4. From your professional experience, what **challenges** do family members experience during the transition from hospital to home?

Probe: financial, emotional, relational, vocational, environmental?

5. What factors are most important in ensuring a successful transition from hospital to home?

a) What **supports** are available to families during a transition from hospital to home?

Probe: community supports, homemaking services, home care

b) What **resources** need to be in place to support a smooth transition from hospital to home?

Probe: important information, equipment

6. How can a caregiver be **proactive in their role** during the process of transitioning their loved one from hospital to home?

7. In your opinion, are there areas for improvement in terms of caregiver **involvement** in the transition from hospital to home?

If yes: a) What could be improved?

b) Do you have recommendations for how?

APPENDIX G

Field Notes - CM interviews

Interviewee: CH1

Interviewer: JT

Date: August 10, 2010

Time: 9:30 AM

Location: Waterloo Wellington CCAC - Kitchener Office
- private office

Method: face-to-face & audio recorded.

Setting:

- odd & dark with no windows
- carpet floor
- whiteboard & desk with computer
- 2 chairs
- high security - need badge to get past reception

Notes: Feelings about interview

- CM did not smile very much
- seemed tired
- very "rules" oriented - reminded me of secret-free environment
- confident tone in voice
- inquisitive about study history, funding, purpose & literature to provide rationale
- very positive about the idea of helping caregivers
- sat with hands/arms crossed.
- interested in participating in phase 3 and receiving results and updates
- * big issue was medical care tasks for families

APPENDIX H



CCAC SUPPORT WORKER RECRUITMENT MATERIALS

A: Inclusion Criteria

Please use your professional judgment and patient records to identify potential caregiver participants based on the following inclusion criteria. Caregivers must:

- Be informal caregivers of a hip fracture or stroke patient who has experienced a care transition from hospital to home within the previous 6 months (from day of contact)
- Be caring for a hip fracture or stroke patient who is 65 years of age or older
- Be able to speak and understand English

B: Telephone Script for Caregiver Recruitment

Step 1: Telephone Patient

Hello my name is _____ calling from the Waterloo-Wellington Community Care Access Center (CCAC). I am calling to see if it would be okay to contact _____, your primary contact that we have listed on your file to see if they might be interested in participating in a research study about caregiving at the University of Waterloo. Is it ok if I telephone _____?

If yes, proceed to Part A of the Consent to Contact Form

Step 2: Telephone Caregiver

Hello my name is _____ calling from the Waterloo-Wellington Community Care Access Center (CCAC). I am calling about a University of Waterloo research study regarding caregiver involvement in the move from hospital to home for hip fracture and stroke patients. They are looking for caregivers to share their experiences in order to learn more about the quality of care transitions from a caregiver perspective. I am calling to see if you are at all interested in hearing more about the study. By agreeing to hear more about the study, you are under no obligation to participate. Are you interested in hearing more about the study?

If yes, here is some background information about the study to address any initial questions they may have about participation

APPENDIX I



Silent Partners in Care: Examining Care Transitions for Caregivers of Hip Fracture and Stroke Patients

Study Participant Permission to be contacted form

Contact:

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879 Student

Researcher: Justine Toscan; jtoscan@uwaterloo.ca; 519-888-4567 x33160

I am interested in participating in this study that examines care transitions for caregivers of hip fracture and stroke patients. A CCAC Home Care Case Manager has informed me about the study that requests my participation in a short in-person interview. I was informed that you would like my help to learn more about the needs and experiences of caregivers during the care transition from hospital to home of my relative/friend.

I have been informed that a Research Assistant will contact me by phone once he/she receives this Permission to be Contacted Form. I was informed that I will be given more information about the study and I can decide whether or not to participate without any consequences to my health care, or the health care my friend/relative is presently receiving or will receive in the future.

I was informed that this project has been reviewed and given ethics clearance by the Office of Research Ethics at the University of Waterloo. If I have any comments or concerns resulting from my involvement in this study I may contact Susan Sykes, Director of the Office of Research Ethics at the University of Waterloo at 519-888-4567 x36005 or ssykes@uwaterloo.ca

The CCAC Support Worker will complete this form over the phone with the potential caregiver participant and forward this form to the research office in Waterloo.

1. Caregiver Name (please print): _____

2. Can a Research Assistant contact the caregiver by phone? YES NO

3. Can they leave a message: YES NO

Telephone Number:

HOME: _____

WORK: _____

CELL: _____

4. Are they available: Morning Afternoon Evening
(Check all that apply)

5. Weekdays or Weekends: Weekday Weekend
(Check all that apply)

Signature of CCAC Support Worker: _____ Date: _____

APPENDIX J



INFORMATION SESSION TELEPHONE SCRIPT

Hello my name is _____. I am calling from the University of Waterloo. We have received your permission to be contacted from a local CCAC support worker.

We want to know if you would like to participate in our research study. This study will help us learn about caregiver needs and experiences during care transitions for hip fracture and stroke patients. The study involves taking part in a 30 to 45 minute in-person interview. This interview can be scheduled during a convenient time and in a convenient location for you. For example, the interview could take place in your home, or if you prefer, a private room at the University of Waterloo could be arranged. All responses will be confidential. Your decision to participate is voluntary. This study has received ethics clearance through the University of Waterloo's Office of Research Ethics. However, the final decision to participate is yours.

We would like to set up an information session with you. Is there a convenient time and location to do this? (*Set up date, time and location for information session*).

Do you have any questions?

If yes, the following additional information can be used to address questions

- The interview questions are quite general (for example, "What challenges did you face during the transition from hospital to home?").
- You may decline to answer any of the interview questions you do not wish to answer and may terminate the interview at any time.
- With your permission, the interview will be tape-recorded to facilitate collection of information, and later transcribed for analysis.
- All information you provide will be considered confidential, be stored in a secure location, and disposed of after 5 years.

APPENDIX K



Silent Partners in Care: Examining Care Transitions for Caregivers of Hip Fracture and Stroke Patients

Contacts:

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Researcher: Justine Toscan; jtoscan@uwaterloo.ca; 519-888-4567 x33160

What is the purpose of this study?

Going through a transition, or a move, from one care setting (e.g., a hospital) to another (e.g., home) can be difficult and many different things can affect the quality of this transition. The purpose of this study is to learn about caregiver needs and experiences with transitional care as a hip fracture or stroke patient moves from hospital to home. This study will help us answer important questions about the quality of care transitions for informal caregivers involved in a patient transition from hospital to home, in order to develop a tool to assess the success of care transitions from a caregiver perspective.

Who can participate?

We are looking for primary caregivers of hip fracture or stroke patients who are 65 years of age or older and have experienced a care transition from hospital to home within the past 6 months.

What will I be asked to do?

We are asking people who have acted as the primary caregiver of a hip fracture or stroke patient during a care transition from hospital (Grand River or Freeport) to home within the past 6 months to participate in a 30 minute interview in order to learn about their individual experiences. The interview will take place in-person at a convenient time and location for you. We will also ask you 5 to 10 questions to determine the needs, challenges, and support you encountered with different aspects of your involvement in your friend/relative's move from the hospital to your home. We will also be collecting general descriptive information including your age, gender, and whether you live with your friend/relative. No personally identifying information will be attached to your audio-recorded interview responses. This information is important as it will allow us to identify areas that need to be assessed in order to improve caregiver preparation and support to assist in the rehabilitation of people who have experienced a hip fracture or stroke. When you have completed this part of the study, you may be asked to participate in the second phase of the study which involves taking part in a second interview at a later date, in order to gain your feedback on a theory of caregiver needs generated from caregiver interviews. You can refuse to participate in any part of the study at any time. A decision to participate or not in this study will have no impact on the care you or your care recipient receive now or in the future.

Where will the study take place?

The interview portion of the study will take place in your home, or if you would prefer, a private room at the University of Waterloo could also be provided. If you later agree to participate in a focus group interview, it will be held in a private room at the University of Waterloo.

How long will the study take?

The in-person interview will take approximately 30 minutes to complete. If you agree later to participate in the in-person focus group, it will take approximately 45 minutes to complete.

Can I change my mind about participating in the study?

You may decline to answer any questions, or withdraw from the study at any time. Withdrawal from the study will not affect any of the health care you or your friend/relative receives in any way. If you wish to withdraw from the study, you can let the interviewer know any time during the interview, or you can contact Paul Stolee PhD, Principal Investigator, at 519-888-4567 ext. 35879

Are there any risks or benefits involved in participating in this study?

There are no direct risks or benefits for you related to participating in this study. However, some participants may find discussing their experience with their friend/relative's transition from hospital to home distressing. If this occurs for you, please let the researcher know and the interview can be stopped or paused. This study will contribute to current scientific knowledge through helping to clarify the role of the informal caregiver in transitional care. This research will greatly enhance our societal understanding of the unique care experiences, challenges, and needs of informal caregivers during unexpected, emergency care situations.

Will I be audio recorded during the study?

Both the in-person interview and focus group interview will be audio-recorded and the information entered into a secure computer database.

Will any remuneration be provided for my participation in the study?

You will receive a \$10.00 gift certificate of your choice to either Tim Hortons or Shoppers Drug Mart for your participation in this study.

Confidentiality and Security of Data

The information you provide will be kept confidential and identified by number only. Your name will not appear in any report or publication resulting from this study. Any quotations used in reports from your interview will be referenced as anonymous. You have the right to ask the researchers about the data being collected about you for the study and about the purpose of these data. You also have the right to ask the researchers to let you see your personal information and make any necessary corrections to it.

Data collected will be kept securely stored in a locked office for a period of 5 years, and then confidentially destroyed. The answers to the interview and focus group questions will be stored in a locked file cabinet, in a locked office, at the University of Waterloo for a period of 5 years. Electronic files, with no personal identifying information, will be stored on a secure, password protected computer for a period of 5 years. After 5 years, any written notes from the interview will be confidentially shredded and electronic files will be destroyed. Only members of the research team, who have signed a confidentiality agreement, will have access to the study data.

Who can I contact if I have any questions?

If you have any questions regarding the research itself, please contact Paul Stolee PhD, Principal Investigator, at 519-888-4567 ext. 35879. This project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. The final decision

to participate is yours. Should you have any comments or concerns resulting from your participation in this study, please contact Susan Sykes, Director, Office of Research Ethics, University of Waterloo at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca

APPENDIX L



Silent Partners in Care: Examining Care Transitions for Caregivers of Hip Fracture and Stroke Patients

Caregiver Participant Consent Form

Contact:

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Researcher: Justine Toscan; jtoscan@uwaterloo.ca; 519-888-4567 x33160

I have read the information letter about the study that examines care transitions for caregivers of hip fracture and stroke patients. I have been informed that you would like my help to learn more about the needs and experiences of caregivers during the care transition from hospital to home of my relative/friend. I know that this study is being conducted by Paul Stolee, PhD at the University of Waterloo. I have been informed that my participation in this study involves one, 30 to 45 minute in-person interview, conducted at my convenience. I have been informed that I may be asked to participate in another part of the study, which would involve participating in a 45 minute in-person focus group interview to get my feedback on a list of items that might be used to measure care transitions from a caregiver perspective. I was also informed that I can refuse to participate in any portion of this study at any time.

I have had the chance to ask questions related to this study. I have had the chance to receive satisfactory answers to my questions and any additional details I wanted. I have been informed that I am free to withdraw from the study at any time by telling the researchers that I no longer wish to continue. I know that if I change my mind about participating there will be no penalty.

I have been informed that as part of this study Paul Stolee, PhD and other investigators would like to gather some general descriptive information including my age, gender, and relation to the care recipient. I have been informed that no information obtained from my interview will contain personal identifiers. I have been informed that this information will be retained in the strictest confidence and that I may withdraw my consent at any time. If I withdraw my consent to participate in the study after I have been interviewed, the information that was collect from me will be destroyed.

I have been informed that this project has been reviewed by, and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If I have any comments or concerns resulting from my involvement in this study I may contact Susan Sykes, Director, Office of Research Ethics at the University of Waterloo, at 519-888-4567 x36005 or ssykes@uwaterloo.ca

I give consent for interviews conducted by the research team to be audio-recorded.

I give consent for quotations from my interview to be used in reports where they will be referenced as anonymous.

I give consent to be contacted in the future to participate in the next phase of this study which would involve participating in one 45 minute focus group interview with approximately 5 other caregivers who have been interviewed.

Caregiver Name:

Caregiver Signature:

APPENDIX M



Are you a Caregiver for a Hip Fracture or Stroke Patient?

We need your help with our research about the needs of caregivers of hip fracture or stroke patients being discharged from hospital to home. Little is known about the experience of caregivers during these care transitions. What are their needs? How is their lifestyle affected? How could the health care system help to make their caregiving role easier? At the University of Waterloo, we are doing a research study to answer these questions! Participation involves a brief 30 minute interview. Your involvement in this study will help researchers and health professionals develop resources to address caregiver needs during patient transitions between care settings.

You will receive a \$10 gift card of your choice from Tim Hortons or Shoppers Drug Mart for your participation.

In order to be eligible for participation in this study, you must:

- have cared for a hip fracture or stroke patient who is 65 years of age or older, and who has been discharged from hospital to home within the past 6 months
- live in the Kitchener-Waterloo region
- be able to read and write English

Participation in this study is voluntary. All answers that you provide are confidential. If you are interested in receiving more information about this study, please contact Sheila Bodemer: 519-888-4567 x33160

APPENDIX N

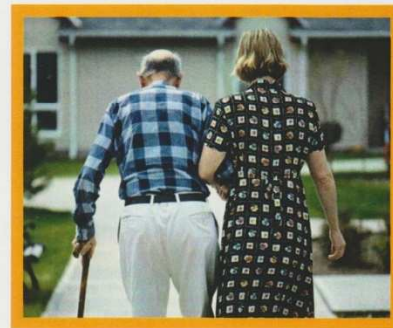
Are you a Family Caregiver for a Hip Fracture or Stroke Patient?

We need your help with our research about the needs of caregivers of hip fracture or stroke patients being discharged from hospital to home. Little is known about the experience of caregivers during these care transitions:

- What are their needs?
- How is their lifestyle affected?
- How could the health care system help to make the caregiver role easier?

At the University of Waterloo, we are doing a research study to answer these questions!

Participation involves a 30 minute interview. Your involvement in this study will help researchers and health professionals develop resources to address caregiver needs during patient transitions between care settings.



You will receive a \$10 gift card from Tim Hortons or Shoppers Drug Mart for your participation. In order to be eligible for participation in this study, you must:

- have provided assistance to a hip fracture or stroke patient who is 65 years of age older, and who has been discharged from hospital to home within the past 6 months
- be able to read and write in English

Participation in this study is voluntary. All answers that you provide are confidential.

There is a \$10.00 gift card remuneration for participating to either Tim Hortons or Shoppers Drug Mart

If you are interested in participating in this study please contact: Sheila Bodemer 519-888-4567 x33160

InfoRehab Caregiver Study
 Sheila Bodemer
 519-888-4567 x 33160

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APPENDIX O

Silent Partners in Care: Assessing Care Transitions for Caregivers of Hip Fracture and Stroke Patients

Interview Guide for Caregivers

1. General Background Information about Caregiver

- a) Year of birth: _____
- b) Gender: Male Female
- c) Relationship to person receiving care (experiencing hip fracture or stroke):

3. Exploring the Care Transition from Hospital to Home

Hospital Discharge

- 1. Can you tell me about the experience of your family members transition from hospital to home?
 - a. What was it like for you?
 - b. What was your **role** in this process?
- 2. What **needs** did you have during the transition process?
Probe: respite, education, support groups
 - a. Were your needs met?
 - b. (if no) how might your needs have been better supported during the transitions process?
- 3. What did you find the most **helpful** or supportive during the transition from hospital to home?
 - a. What information did you receive?
Probe: From whom? What format?
- 4. What **challenges** did you experience during the transition from hospital to home?
Probe: emotional, stress, vocational, environmental

Arriving Home

- 1. After arriving home from the hospital, how was your involvement in your friend/relative's care different from your involvement before their hip fracture/stroke?
- 2. How did you feel about taking on the caregiver role after your friend/relative returned home?

- a. What made you feel this way?
3. Did you feel **prepared** to take on the role of caregiver for your friend/family member?
If yes: how did you prepare?
What **resources** have you been able to access?
Have you received any other support (community or relatives?)
If no: Why?
4. What were some of your **concerns** in providing care for your friend/relative once they returned home?
Probe: emotional, stress, time management, education, financial
5. What **advice** would you give someone who has just had a friend/relative come home after suffering a hip fracture/stroke?
6. If we were to develop a program to help caregivers like yourself, what would be most helpful?

APPENDIX P



TELEPHONE SCRIPT: RECRUITMENT OF PARTICIPANTS FOR FEEDBACK

Hello my name is _____. I am calling from the University of Waterloo about the study you recently participated in regarding caregiver involvement in care transitions. You had indicated to us that you might be interested in participating in the second part of this study. Is this an OK time for us to talk about what would be involved? (*If not, reschedule*).

If you decide to participate in Part 2 of this study, it would involve a 45 minute interview (CG)

OR

a one hour focus group with approximately 5 other Case Managers (CM)

***If No, thank them once again for all of their help.*

***If Yes, provide the participant with the potential dates and determine a convenient time for them to participate.*

The day before the interview/ focus group, I will phone you to make sure that you are still able to make it. If you have to cancel your appointment, you can call Sheila Bodemer 519-888-4567 x33160. Thank you very much for your help. I look forward to seeing you on [day and time of the appointment].

APPENDIX Q



CAREGIVER PARTICIPANT FEEDBACK QUESTIONS TO CONSIDER

1. According to your experience of providing care for your loved one during the transition from hospital to home, does this theory adequately represent the needs of family members during transitional care between a formal (hospital) setting and informal (home) setting?
2. Is the format easy to understand?
3. Are there items that you would change or remove?
4. Are there items you would add?
5. What do you think about the idea of a “Caregiver Assessment” process?
6. What do you think about the idea of a “Care Agreement Contract”?
7. Based on this theory, what area do you see as the highest priority for intervention and support? What would you suggest as an intervention?

APPENDIX R



CASE MANAGER PARTICIPANT FEEDBACK QUESTIONS TO CONSIDER

1. According to your professional experience working with families during times of medical crisis for older adults, does this theory adequately represent the needs of family members during transitional care between a formal (hospital) setting and informal (home) setting?
2. Is the format easy to understand?
3. Are there items that you would change or remove?
4. Are there items you would add?
5. What do you think about the idea of a “Caregiver Assessment” process?
6. What do you think about the idea of a “Care Agreement Contract”?
7. Based on this theory, what area do you see as the highest priority for intervention and support? What would you suggest as an intervention?

APPENDIX S

Informal Caregivers of Older Adults at Home: Let's PREPARE!

Instructions: Let's PREPARE the informal caregivers to care for the patient at home. The visiting home care nurse will use this screening tool to evaluate informal caregiver preparedness during the initial home visit to obtain baseline information, and at each visit to intervene if there are any changes. Check each row to acknowledge you assessed these items:

<input type="checkbox"/> <u>P</u> Prescriptions	<ul style="list-style-type: none"> • Pharmacy location • Co-payment needed • Delivery by pharmacy or pick-up by caregiver • Knowledge of, purpose and side effects of medications 	<ul style="list-style-type: none"> • How to prefill mediset and/or insulin syringes • Medication administration • Prescribed and over-the-counter medications
<input type="checkbox"/> <u>R</u> Readiness to manage at home	<ul style="list-style-type: none"> • Review of hospital discharge plan • Home care needs for the older adult (e.g., ensure timely medical follow-up appointments) • Contact numbers of home care staff, primary care provider (PCP), hospital, and support system 	<ul style="list-style-type: none"> • Insurance • Supplies • Modifications of home to prevent falls and injury • Appropriate community resources (e.g., Meals On Wheels if no cooking facilities available, community mental health, social/medical day care)
<input type="checkbox"/> <u>E</u> Early changes in condition	<ul style="list-style-type: none"> • Knowledge of changes requiring urgent medical professional notification 	
<input type="checkbox"/> <u>P</u> Partnership among the home health care team	<ul style="list-style-type: none"> • Supplies • Equipment • Durable Medical Equipment (DME) 	<ul style="list-style-type: none"> • Personal Emergency Response System (PERS) • Individualized care plan (e.g., social worker, dietitian, physical, occupational, and speech therapists)
<input type="checkbox"/> <u>A</u> Assistance needed to perform procedures	<ul style="list-style-type: none"> • Wounds • Intravenous treatments • Suctioning 	<ul style="list-style-type: none"> • Tube feeding • Activities of Daily Living • Instrumental Activities of Daily Living
<input type="checkbox"/> <u>R</u> Realistic expectations and goals	<ul style="list-style-type: none"> • Does the informal caregiver have any physical or psychological disability, or any behavior such as drug or alcohol or tobacco misuse? • Does the informal caregiver have any other family responsibilities? • Is the informal caregiver employed? • Does the informal caregiver have back-up support? • Does the informal caregiver live with the older adult? 	<ul style="list-style-type: none"> • What does the older adult want to achieve? • Is care palliative (e.g. pain management, healing of a wound, or living to see a grandchild graduate from college or get married)? <p>(This information is obtained by asking the patient and informal caregiver)</p>
<input type="checkbox"/> <u>E</u> Education and empowerment	<ul style="list-style-type: none"> • Signs and symptoms of disease • Long-term care plan • Nutrition • Advanced directives • Contingency plan if home care aide does not arrive • Safety in the home 	<ul style="list-style-type: none"> • Problems with medications (e.g. PCP calling late evening after home care staff has left to inform patient not to take a medication or to increase or decrease the dosage of medication, such as insulin or Coumadin)
Follow-up nursing interventions are needed for any items that are not checked.		