

**THE EXPERIENCE OF PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS
DURING ACUTE HOSPITALIZATION**

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Abstract

Background: Due to the growing number of individuals suffering from dementia, many will require acute hospital care as other indirectly related conditions appear throughout the course of the disorder. Significant concerns have been raised about the provision of quality care. Understanding their experiences is essential.

Method: Semi-structured interviews were conducted with caregivers and people with dementia after acute hospitalization. Data was analyzed using qualitative content analysis.

Results: Twenty-nine participants experienced hospitalization and commented primarily on the negative experience. Despite the importance of caregiver involvement, and evidence of caregiver burden, they commented they were rarely included in care plans and lacked support. Continuity of care was said to be affected by absent communication amongst health care team members. The acute hospital process and environment was perceived as not supportive of dementia person-centred care principles, with reports of poor staff knowledge and recognition of the disorder.

Conclusion: Reports of acute care hospital experiences of people with dementia and their caregivers provide insights for potential gaps in care delivery.

Résumé

Contexte: Due à l'augmentation du nombre d'individus atteints de démence, une grande proportion de la population nécessitera une hospitalisation suite aux problèmes de santé encourus durant l'évolution de leur maladie. De nombreuses inquiétudes ont été soulevées vis-à-vis la qualité de soins prodigués en hôpital de soins aigus. Comprendre l'expérience de ces individus est essentielle.

Méthode: Des entrevues semi structurées ont été entreprises avec les gens avec démence ainsi que leurs aidants naturels suite à une hospitalisation en soins aigus. L'analyse qualitative de contenu a été utilisée.

Résultats: L'expérience des vingt-neuf participants interviewés a été majoritairement négative. Malgré l'importance des aidants naturels et une présence évidente de fardeau et de stress, on rapporte leur exclusion dans les plans de soins et une absence de soutien. Le manque de communication auprès des professionnels de la santé occasionne une mauvaise coordination des soins qui sont fréquemment interrompus. Le milieu hospitalier manquait de soutien pour les gens avec démence et n'encourageait pas les soins centrés sur la personne. On soulève aussi des déficits de connaissance des professionnels de la santé en ce qui a trait aux soins adaptés pour les gens atteints de démence et leurs aidants.

Conclusion: Les expériences de soins lors de l'hospitalisation pour les gens avec démence ainsi que leurs aidants naturels indiquent une absence de soins axés sur la personne. Bien comprendre leurs expériences est utile pour identifier les lacunes de soins.

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To all the individuals affected by dementia, may this work help your voice be heard, and may your experiences come to light in making this journey through acute care hospital better.

Table of Contents

| | |
|--|------|
| Acknowledgements | iii |
| List of Tables | vi |
| List of Figures | vii |
| List of Appendices | viii |
| Interdisciplinary relevance | ix |
| Abbreviations | x |
| CHAPTER 1: INTRODUCTION | 11 |
| 1.1 The impact of dementia | 11 |
| 1.2 Caregivers of people with dementia | 2 |
| 1.3 Acute care hospitalization and dementia | 7 |
| 1.4 Importance of the hospital environment for people with dementia | 11 |
| 1.5 Theoretical framework: Person-Centred Care | 14 |
| 1.6 The experience of people with dementia and their caregivers' with acute hospitalization | 18 |
| CHAPTER 2: RESEARCH QUESTION | 23 |
| 2.1 Question | 23 |
| 2.2 Sub-questions | 23 |
| 2.3 Objectives | 23 |
| CHAPTER 3: METHODOLOGY | 24 |
| 3.1 Study design | 24 |
| 3.2 Participant recruitment | 24 |
| 3.3 Data collection | 25 |
| 3.4 Data analysis | 27 |
| CHAPTER 4: RESULTS | 32 |
| 4.1 Participant description | 32 |
| 4.2 Coding process results | 32 |
| 4.3 Coding results | 32 |
| 4.3.1 Category: Process (Part 1) | 33 |
| 4.3.1.1 Trigger to hospitalization | 33 |
| 4.3.1.2 Pre-hospitalization facilitators | 34 |
| 4.3.1.3 Emergency department process | 35 |
| 4.3.2 Category: In-hospital trajectory | 38 |
| 4.3.2.1 In-hospital cognitive trajectory | 38 |
| 4.3.2.2 In-hospital medical trajectory | 40 |
| 4.3.2.3 In-hospital environmental factors affecting in-hospital trajectory | 41 |
| 4.3.3 Category: Impact on caregiver | 42 |
| 4.3.3.1 Caregiver stress/burden | 42 |
| 4.3.3.2 Caregiver fear and worry | 44 |
| 4.3.3.3 Caregiver time commitment | 45 |
| 4.3.4 Category: Communication | 45 |
| 4.3.4.1 Communication with the physician | 45 |
| 4.3.4.2 Communication with caregivers/family | 46 |
| 4.3.4.3 Communication: PWD as an agent | 47 |
| 4.3.5 Category: Health care professional satisfaction | 48 |
| 4.3.5.1 Satisfaction or dissatisfaction with physician | 49 |
| 4.3.5.2 Satisfaction/dissatisfaction with nurses | 49 |
| 4.3.5.3 Satisfaction/Dissatisfaction with other health care professionals | 51 |
| 4.3.6 Category: Process – Part 2 | 52 |
| 4.3.6.1 Discharge process | 52 |

| | |
|--|----|
| 4.3.6.2 Post-acute care environment | 54 |
| 4.3.6.3 Care continuity and coordination | 55 |
| 4.3.7 Category: General Opinion/Recollection | 56 |
| 4.3.7.1 Caregiver's general opinion about hospitalization | 57 |
| 4.3.7.2 People with dementia's recollection about hospitalization – Telling their stories | 58 |
| CHAPTER 5: DISCUSSION | 60 |
| 5.1 The chronology of the transition through hospitalization | 61 |
| 5.2 Main themes | 62 |
| 5.3 Meeting the needs and expectations | 68 |
| 5.4 Person-centred care | 70 |
| CHAPTER 6: LIMITATIONS | 74 |
| CHAPTER 7: CONCLUSION | 75 |
| CHAPTER 8: REFERENCES | 77 |

List of Tables

| | |
|---|-----|
| Table 1: Participant characteristics | 99 |
| Table 2: Coding frequency | 100 |
| Table 3: Coding scheme including categories | 103 |

List of Figures

| | |
|--|-----|
| Figure 1: Coding process | 104 |
| Figure 2: Schematic representation of the hospitalization experience | 105 |

List of Appendices

| | |
|---|-----|
| Appendix A: Research Ethics Board approval | 106 |
| Appendix B: Research Ethics Board termination | 107 |

Interdisciplinary relevance

This thesis is prepared using an interdisciplinary approach. With the aging of the population and the increasing number of people suffering from dementia, dementia care delivery is of prime importance. The results of this research will shed light on dementia care in acute care hospitals as experienced by the people with dementia and their caregivers.

There are a variety of disciplines in health care that are often organized and studied independently. Although studying these disciplines independently may be a more clear and concise method of identifying discipline-specific issues, evaluation through an interdisciplinary context may be a more appropriate method for identifying and solving complex system-level problems. Since disciplines are inherently connected and affected by one another, it is ideal to take an interdisciplinary approach when evaluating health care system issues. By analyzing the participants' experiences with acute hospitalization, we are able to gain insight into the consequences of impairments of the brain, as well as appreciate the difficulties this population has with gaining access to proper health care as a result of their compromised cognition. The analysis of the participants' experiences may provide vital information to stakeholders, policy makers, funding agencies and health administrators, and may influence how system-level issues are addressed by these professionals. The information that the participants share can help health care professionals including physicians, nurses, and other formal caregivers like personal support workers and volunteers to adopt an informed view of dementia. Beyond the obvious relevance to healthcare, the analysis of the participants' experiences offers insight into the psychological impact of transitions and dementia.

Abbreviations

ADL: Activity of daily living

CG: Caregiver

CGs: Caregivers

ED: Emergency Department

IADL: Instrumental activity of daily living

PCC: Person centred-care

PWD: Person/People with dementia

QOL: Quality of life

CHAPTER 1: INTRODUCTION

1.1 The impact of dementia

It is well known that the population is ageing (World Health Organization, 2012). The ageing population is largely due to health care improvements over the past century, which have contributed to longer and healthier lives. However, the increase in elderly individuals has also resulted in an increase in the number of people with health conditions, for example, dementia (World Health Organization, 2012). Dementia is characterized by progressive memory loss as well as declines in other aspects of cognitive functioning (Grossberg, 2003). It can be associated with a wide range of symptoms including but not limited to: impaired memory, disorientation, poor concentration, as well as naming and language difficulties (Archibald, 2003). People with dementia (PWD) have an impaired ability to learn or recall learned information, difficulty with motor skills, coordination, thinking in a clear and coherent way, as well as difficulty understanding or following a sequence (Jacques & Jackson, 1999). In the advanced stages of the disease, dementia is also associated with mood and behavioural symptoms including aggression, agitation, anxiety, depression, psychosis, irritability and wandering (Grossberg, 2003). Dementia affects approximately one in eleven Canadians over the age of 65 (Chief Public Health Officer Report, 2010). With the number of seniors on the rise, this value is expected to double by 2038 (Chief Public Health Officer Report, 2010). According to a recent study commissioned by the Alzheimer Society of Canada (2012), approximately 747,000 Canadians are living with cognitive impairment, including dementia, and this number will double to 1.4 million by 2031. These shocking values represent a rapidly growing and costly health problem, especially since dementia requires care from both chronic primary care as well as acute medical care in a hospital setting (Malone et al. 2009). As it stands, Canada's health-care system is ill equipped to deal with the staggering costs of dementia: the combined direct (medical) and indirect (lost earnings) costs of dementia currently total approximately \$33 billion

per year. By 2040, this figure will rise steeply to \$293 billion per year (Alzheimer's Society of Canada, 2012).

Dementia is a syndrome characterized by progressive deterioration of cognitive function that is sufficient to impact daily life and occupational functioning (Prince & Jackson, 2009). Irreversible dementias that are associated with progressive neurodegenerative diseases include Alzheimer's, vascular, fronto-temporal and Lewy Body dementias. Alzheimer's disease is the most common type, accounting for approximately 69% of all dementias (Alzheimer's Society of Canada, 2012; Blennow, de Leon & Zetterberg, 2006). The National Institute of Aging – Alzheimer's Association (NIA-AA) has established diagnostic criteria for dementia (McKann et al. 2011). A diagnosis is made once symptoms of delirium or major psychiatric disorder are ruled out, and when changes from previous levels of functioning in cognitive or behavioral (neuropsychiatric) domains begin to interfere with the person's ability to function. Cognitive impairment is detected and diagnosed using a combination of gathering history from the patient and a knowledgeable informant, as well as through the use of objective cognitive assessments in the form of a bedside mental status examination or other neuropsychological testing. It is possible that the cognitive or behavioral impairment may involve multiple domains, for example: impaired ability to acquire and remember new information, impaired reasoning and handling of complex tasks, poor judgment, impaired visuospatial abilities, impaired language functions, as well as changes in personality and/or behaviour (McKhann, et al. 2011).

1.2 Caregivers of people with dementia

Dementia not only affects the individual with the disease, but it also drastically affects and changes the lives of family members of the individual with the disease; including caregivers (CGs) in dementia care is therefore essential (World Health Organization, 2012). A diagnosis of dementia usually implies not only an extended period of profound disability and suffering for the person with dementia, but also severe strain and financial burden on family and caregivers

(Etters, Goodall & Harrison, 2008; Swedish Council on Technology Assessment, 2008), health providers, the health care system, the business community, and society in general.

Although no standard definition of family caregiving exists, there is a general consensus that it “involves the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships” (Schultz & Martire, 2004 p. 240). Caregiving is also described as “the activities and experiences involved in providing help and assistance to relatives who are unable to provide for themselves” (Pearlin, Mullan, Semple & Skaff, 1990, p. 583). Caregiving for people with dementia typically involves a significant expenditure of time, energy and money over potentially long periods of time; it also involves tasks that may be unpleasant and uncomfortable and can be psychologically stressful as well as physically exhausting (Shultz & Martire, 2004).

Family caregivers of PWD – who are often referred to as the ‘invisible second patients’ – are critical to maintaining the quality of life (QOL) of the care recipients (Brodaty & Donkin, 2009) because they provide direct assistance, emotional support and also act as advocates. Dementia caregivers are often elderly themselves, and their physical and mental health may become negatively affected by their caregiving role (Clissett, Porock, Harwood & Gladman, 2013a). The impact of the role of caregiving is often described in terms of “caregiver burden”. It has been defined as a multidimensional response to the negative appraisal and perceived stress that results from caring for an individual who is ill (Kim, Chang, Rose & Kim, 2011). Some research has shown that dementia caregiving may be different from other types of caregiving. Schultz and Martire (2004) have outlined the differences between dementia caregiving and caregiving for an older relative or friend who has physical impairment; their analysis confirms anecdotal reports that dementia care is the more stressful type of family caregiving. It has been shown that CGs of PWD provide more caregiving (e.g. assistance, support, supervision) and report that care provision is more stressful compared to caregiving for loved ones with other chronic conditions and disabilities (Light, Niederehe & Lebowitz, 1994; Schultz & Martire, 2004).

Caregivers of people with dementia spent more hours per week on caregiving tasks, as well as assisting with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). This type of care is associated with high levels of burden as a result of caring for someone with emotional, cognitive and behavioral problems that requires constant supervision and assistance with daily activities (Schulz & Martire, 2004). When compared to other CGs, CGs of PWD were more negatively affected by their caregiving responsibilities in terms of employment complications, caregiver strain, mental and physical health problems, and for leisure and other family conflicts (Miller, Rosenheck & Schneider, 2012; Ory, Hoffman, Yee, Tennstedt & Schultz, 1999). Compared to other CGs, CGs of PWD have to give up vacations and hobbies more often, they have less time for other family members, and they report more work-related difficulties (Ory et al., 1999). Dementia CGs face substantial stress due to physical, mental and emotional strain, financial hardship, as well as occupational insecurity (Miller, Allen & Mor, 2009) with the demands of their caregiving role.

Each caregiver may experience caregiver burden differently. This burden is described as the interaction among care receiver (e.g. PWD) characteristics (e.g. functional disturbances, disturbing behaviour), caregiver characteristics (e.g. age, gender, multiple social roles, health status, ethnicity, level of education, relationship to care receiver), and caregiving context (e.g. financial situation, informal and formal care resources) (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Multiple predictors of caregiver burden have been recognized, including the total hours of caregiving (Kim et al. 2011). Since dementia is a progressive, degenerative disease, the amount of time needed for caregiving increases as the severity of dementia increases (Etters et al. 2008), thus increasing CG burden. Characteristics of caregivers may also result in increased CG burden. For example, kinship ties, which include spouse, child and siblings, was found to be an early factor that influences CG burden (Etters et al., 2008). In addition, older caregivers (Kim et al. 2011; Rinaldi et al. 2005) and CGs who live in the same house as the care recipient (Kim et al. 2011) are also predictors of increased burden. Gender may also influence

kinship ties and perceptions of the CG burden. Some evidence indicates that female CG tend to have a higher rate of CG burden (Campbell et al. 2008; Kim et al., 2011; Papastavrou, Kaloderinou, Papacostas, Tsangari & Sourtzi, 2007) as well as more health problems and depressive symptoms (Almberg, Jansson, Grafstrom & Wimbald, 1998; Gallicchio, Siddiqi, Langenberg & Baumgarten, 2002). Individual characteristics such as self-efficacy and coping strategies have been shown to be important contributors to perceptions of caregiver burden and may account for some differences throughout the literature (Etters et al., 2008). Research has also shown that CGs with a history of a functional family structure experience less strain and burden compared to CGs with a history of poor family functioning; this finding suggests that fundamental family dynamics have an influential role on CG burden (Heru & Ryan, 2006).

Not only do CG characteristics influence CG burden, but the characteristics of the PWD influence the level of CG burden as well. Studies have found that the PWD's behavioural disturbances are one of the largest contributing factors to CG burden (Beeri, Werner, Davidson & Noy, 2002; Sink, Holden & Yaffe, 2005). Behaviours such as aggression, agitation, night time wandering and depression are strongly associated with CG burden, as well as depressive symptoms in the CG (Gaugler, Kane, Kane & Newcomer, 2005). Evidence suggests that CGs frequently suffer from depression, exhibit maladaptive coping strategies, and express concerns about poor quality of life (Molineux, McCarthy, McEniff, Cryan & Conroy, 2008). According to Schultz and Martire (2004), CGs as well as PWDs both have a high incidence (20-40%) of concomitant mood disorders such as depression, which adds to the burden. Compared to CGs of people with cancer, CGs of PWD experience and suffer the greatest impact across all dimensions of well-being (Clipp & George, 1993). Despite the similar functional limitations related to ADL the added difficulty of coping with compromised intellectual abilities (e.g. memory loss and disorientation), behavioral problems (e.g. combativeness and wandering), and shifts in personality may place CGs of the PWD at additional risk for poor outcomes. This added risk of poor CG outcome encourages efforts to identify and reduce CG burden, which is very important

to do since it is considered an essential element of dementia health care.

Research on the effects of dementia on CG burden also suggests that CG burden is an important determinant of institutional service use. Individuals who have caregivers who feel burdened are at greater risk of entering a hospital and institutional placement (Balardy, Voisin, Cantet, & Vellas, 2005; Cohen, Gold, Shulman, Wortley, McDonald & Wargon, 1993; Cox, 1997; Gaugler, Leach, Clary & Newcomer, 2004; Miller et al. 2012). In fact, disinhibited behaviours, which are common in PWD, were found to be a unique predictor of frustration and embarrassment for the CG, as well as a strong predictor of nursing home placement (Gaugler, et al. 2010). Furthermore, due to the negative health experiences for CGs, these behaviours ultimately affect the continuance of the caregiving role (Schultz & Martire, 2004) which leads to admission to hospital or a long term care facility. In a study examining the moderating effect of CG burden on the relationship between the health status of PWD and their use of institutional services, the results indicated that CG burden moderated the relationship between the PWD's general health status as well as institutional service use (Miller et al. 2012). The study also found a positive relationship between increased CG burden and the likelihood of entering a nursing home, hospital, or residential care facility (Miller et al., 2012); this finding also supports prior research (Miller, Rosenheck & Schneider. 2010).

The cost of caregiving is a significant factor to consider in dementia care. In 2011, family CGs spent 444 million unpaid hours per year looking after someone with dementia, which represents \$11 billion in lost income and a reduction of more than 227,000 full-time employees in the work force (Alzheimer's Society of Canada, 2012). By 2040, CGs will devote a staggering 1.2 billion unpaid hours per year (Alzheimer's Society of Canada, 2012). Previous research has shown that family members, friends and other unpaid caregivers experience considerable psychological and physical comorbidity and reduced QOL (Dunkin & Anderson-Hanley, 1998). This finding outlines not only the importance of the role of these informal CGs, but also the consequences that caregiving has on the CG's and PWD's health. It is evident that not only are

there enormous monetary costs associated with dementia care, but also personal costs on CGs' personal health.

Many transitions experienced by the PWD will generate outcomes that are likely to further burden CGs. One common transition that a PWD experiences is an event that precipitates admission to an acute care hospital. Shankar, Hirschman, Hanlon & Naylor (2014) were the first group to specifically examine CG burden at the time of hospitalization. Similar to the findings reported on CG burden in the community, personal characteristics of the CG and PWD were also associated with higher CG burden; these characteristics include increased age, spousal relationship status, depressive symptoms, limited finances, self-efficacy and distress associated with neuropsychiatric symptoms. Characteristics of the PWD that are associated with increased CG burden at the time of acute hospitalization include episodes of delirium and the ability of the PWD to carry out their ADL. The presence of delirium is a relatively new variable in the study of CG burden (Shankar, Hirschman, Hanlon & Naylor, 2014) and is viewed as an additional complexity that can be caused by acute hospitalizations and may directly affect not only the PWD, but also the CG and the entire health care team.

1.3 Acute care hospitalization and dementia

In Ontario, more than 90% of community-dwelling PWD are living with two or more coexisting chronic medical conditions (Gill, Camacho & Poss, 2011). People with dementia face unique challenges related to self-management of their general health, as well as difficulties managing chronic conditions such as hypertension, diabetes, coronary artery disease, heart failure and chronic obstructive lung disease (Phelan, Borson, Grothaus, Balch & Larson, 2012). The challenges they experience in managing their chronic conditions are often due to deficits in memory, insight, judgment, language and decision making ability (Phelan et al., 2012). Research has shown that compared to individuals without dementia, PWD have more chronic conditions (Bynum, Rabins, Weller, Niefeld, Anderson and Wu, 2004), which increases their risk

of acute hospital admission. People with dementia are prone to cyclic use of emergency departments, hospitals and eventual discharge to their home once stabilized (Alzheimer's Society of Ontario, 2012). Due to cognitive losses experienced by PWD, this cycle can lead to poor self-management, health status deterioration and re-admission; a pattern referred to as the "domino effect" (Wait Time Alliance, 2012). Furthermore, during hospitalization, PWD are at heightened risk of acute medical illness due to the potential for episodes of delirium, functional decline in response to the acute illness, and other iatrogenic complications (Phelan et al., 2012).

Estimates from Europe and North America suggest that dementia is common among hospitalized patients. Typically, PWD comprise between 20-25% of people admitted to a hospital (Department of Health, 2001; Silverstein and Maslow, 2006). Sampson, Blanchard, Jones, Tookman & King (2009) found that 42% of individuals aged 70 years and older, and 48% of people aged 80 years and older who had an unplanned admission to an acute general hospital in England had dementia; suggesting a higher prevalence of dementia with increasing age (Sampson, Blanchard, Jones, Tookman & King, 2009). Moreover, the prevalence of dementia across acute care hospital wards varies widely and is dependent not only on the demographic profile of patients on the ward, but also on the type of ward (Mukadam and Sampson, 2011). In some cases, dementia is first discovered following admission. For example, one study found that 15.8% of patients admitted to an orthopedic hospital for elective or traumatic surgery had evidence of significant cognitive impairment without an established diagnosis (Hickey, Clinch & Groarke, 1997). This finding indicates that significant cognitive impairment can often be undetected prior to admission to an acute care hospital.

During the course of the disease, many of the PWD require hospitalization either for acute medical problems, dementia related complications, or issues related to caregiver burnout (Andrieu et al, 2002; Voisin, Andrieu, Cantet, Vellas & REAL.FR group, 2010). In a review by Andrieu et al. (2002), reasons for hospitalization for PWD were classified in the following groups: 52% were due to behavioural disorders, 19% were due to fall-causing fractures, 11% were from

a breakdown in the caregiver network, and the remaining 18% was due to other acute medical problems, including falls without fractures, anorexia bronchopneumonia and urinary tract infections (Andrieu et al., 2002). In a more recent study by Fong, Jones, Marcantonio, Tommet, Gross & Habtemariam (2012), it was reported that acute care hospital admission diagnosis of PWD were as follows: 27% were secondary to syncope, falls and trauma, 16% were due to ischemic heart disease, 9% were due to gastrointestinal complications, 7% for pneumonia and the remainder were from other medical or psychiatric problems.

Several possible explanations of the relationship between dementia and frequent hospitalization have been hypothesized. First, there are underlying conditions that increase the risk of dementia (e.g. stroke) or those that develop in the context of an established dementia diagnosis (e.g. dysphagia, aspiration pneumonia) (Phelan et al. 2012). Second, the effects of dementia on cognitive functions (e.g. impaired executive function, language, perception of symptomatology and insight) impairs the ability to manage chronic conditions, identify new symptoms and seek medical attention when needed (Phelan et al. 2012). Lastly, the threshold for admission to hospital may be lower in seniors, especially in PWD, because their nervous and metabolic systems are more vulnerable to acute illness, and are at an increased risk for complications (Inouye et al., 1999; Wiltoix, Eurelings, de Jonghe, Kalisvaart, Eikelenboom & van Gool, 2010).

Acute care hospitalization of PWD can have major implications, not only for the PWD but for the entire health care system. Several studies (Draper, Karmel, Gibson, Peut & Anderson, 2011; Guijarro et al., 2010 Mukadam & Sampson, 2011) have published findings that the frequency and duration of hospitalizations were greater in patients with Alzheimer's disease (Filenbaum, Heyman, Peterson, Pieper & Weiman, 2000) compared to patients without a diagnosis of Alzheimer's disease. The median length of stay in hospital for PWD was more than twice that of seniors without a diagnosis of dementia (20 days versus 9 and 16.4 days versus 8.9) (Alzheimer's Society of Canada, 2010; Draper et al., 2011). Complications of

hospitalization for PWD include delirium, loss of independence, institutionalization, and death as common outcomes (Fick, Kolanowski, Waller & Inouye, 2005; Fong et al., 2012; Pedone et al., 2005). These complications also contribute to the economic burden of dementia because they prolong hospital stays, increase health care needs due to loss of independence, as well as increase Alternate Level of Care (ALC) days due to an increased need for institutionalization. The Alzheimer's Society of the United Kingdom (2009) highlighted the detrimental effect that hospital stays can have on the ability of PWD to maintain their independence with their ADL (Gill, Allore, Holford & Guo, 2004). These effects are prevalent in PWD who have had an acute hospitalization due to primary non-neurologic causes (Gill et al. 2004). Even once discharged, the PWD can develop cognitive and functional decline. Some cases can be especially bad if the hospitalization was for a critical illness or involved superimposed delirium (Devere, 2012). In an observational study by Boyd et al. (2008), dementia was found to be associated with more difficult recovery and failure to return to baseline function after acute hospitalization compared to recovery of patients without a diagnosis of dementia. As a result, PWD may not be able to return home at the end of the acute episode of care, which can be devastating for the PWD and their family members, and can result in economic consequences for the health care system (Alzheimer's Society of the United Kingdom, 2009; Bynum et al., 2004; Hennessey & Lawlor, 2008). Furthermore, there is evidence that the admission of a PWD to hospital with acute medical illness is a critical event associated with high 6 month mortality rates (Morrisson & Siu, 2000). For instance, PWD are over three times (18%) more likely to die during admission and this value increases to five times (24%) more likely to die with worsened cognitive function (defined as a Mini-Mental Status Exam (MMSE) score between 0-15). According to Sampson, Blanchard, Jones, Tookman & King (2009), these results remain significant after controlling for age and severity of acute physical illness.

1.4 Importance of the hospital environment for people with dementia

It is well established in the literature that PWD are particularly vulnerable to adverse outcomes of hospitalization (Watkin, Blarehard, Tookman & Sampson, 2012). There have been hypotheses that improving the acute care hospital care environmental design to better suit the needs of PWD may enhance satisfaction for both the CG and PWD (George, Long & Vincent, 2013) and decrease the risk of delirium (Inouye & Charpentier, 1996).

As a result of the cognitive impairment, PWD appear to be highly vulnerable to changes in their environment (Waller, 2012). An acute care hospital stay is a prime example of a drastic change in environment, which can result in significant distress for the PWD. For instance, the hospital environment includes multiple stimuli including noises (e.g. call bells, moaning, swinging doors, discordant television and radio, trolleys clattering), ward rounds, visitors coming and going, staff changeovers, cluttered ward layouts and poor signage. These environments are not ideal for a person with a cognitive impairment and may be viewed as frightening and hostile for this population. Even cognitively impaired people who function well in their home environment can become extremely confused and unsettled in a general hospital setting (Thompson, Girling, Green & Wai, 2010).

During a hospital stay, not only will a PWD enter a new environment, but transfers between care units, rooms and health services are common (Digby, Moss & Bloomer, 2012). In addition, spatial disorientation is a common symptom of dementia (Marquardt, 2011). Furthermore, when a PWD is hospitalized, behavioural issues associated with dementia can become exacerbated as a result of changes in their environment (Digby & Bloomer, 2014). These changes may precipitate delirium, feelings of being unsettled, as well as symptoms of withdrawal and occasional aggressive behaviour, thus significantly impacting the health care received by both the PWD and their CG (Digby et al., 2012).

In contrast to previous findings, in the Digby et al. (2012) study, it was found through the use of in-depth interviews with in-patient PWDs and their CGs that the reason for admission to

hospital was to receive care to improve their health and that the physical environment was only a secondary concern. The concept of “homeliness” was also found to be preserved in a sub-acute facility compared to the acute facility, which indicates that prioritizing non-institutional design features assists with PWD well-being (Day, Carreon & Stump, 2000). In addition, participants spoke of their challenges with anxiety and insecurity associated with getting lost due to poorly designed environments that failed to compensate for the spatial disorientation associated with the cognitive changes. Participants who indicated dissatisfaction with shared rooms also noted a sense of loss of privacy and personal space. Access to a welcoming environment for CGs was found to be an important environmental factor because they spend a considerable amount of time with their relative. Lastly, access to nature, the outside world and fresh air was identified by PWD as important factors in order to maintain a sense of peacefulness. (Digby et al. 2012). This study demonstrated that the physical care environment has a significant impact on care for both the PWD and the CGs. This has also been reported by Edvardsson & Nordvall (2008) with reports that to the older person, the physical environment and the care delivery have to be incorporated together, indicating the standard of care they expect to receive with a feeling of safety and being cared for being of prime importance.

The challenges associated with offering an appropriate care environment for PWD have also been identified by health care staff (Borbasi, Jones, Lockwood and Emben, 2006). Health care staff members have commented that the acute care environment is characterized as “strange”, “unsafe” and a “dangerous environment” for PWD. They have described the environment as unfamiliar to confused patients. Staff members have also expressed concern that they do not know enough about their patients in order to provide appropriate care, including difficulties with the ability to recognize how their patients were able to function and cope on a daily basis, especially at night time. Excess stimuli and noise was also identified as a potential contributor to behavioural changes and subsequent risk to safety. Staff members noted that the

spatial layout of the ward could lead to wandering and visual issues (e.g. location of toilets). There was also a general worry about not having enough staff to keep PWD safe in acute care.

Since dementia is a progressive condition for which no cure is available, it remains of utmost importance that the hospital environment be as “PWD friendly” as possible. Failure to adopt a PWD friendly environment may lead to poor outcomes including patient safety issues, worsening confusion of the PWD, as well as agitation and behavioural problems (Digby et al., 2012). In addition, formal and informal caregivers may experience undue stress as a result (Goodall, 2006). It has been suggested that if changes are made to the acute care environment, similar to the adaptations seen in care units for PWD, satisfaction may be increased and agitation may decrease (Goodall, 2006). Since most research has been done in the Long Term Care setting, there is still a significant knowledge gap in the literature about which improvements to the acute care environment can improve care and support the wellbeing of PWD (Fleming & Purandare, 2010). Prior to investing significant funding into re-designing hospitals, more research is required.

The environment where PWD live has a profound influence on their physical and psychological well-being (Sloane et al., 2002). Unfortunately, the environmental design of the traditional acute setting has been shown to place PWD at risk of harm (Borbasi et al., 2006). The imperative to provide dementia-friendly environments is being increasingly recognized in light of the rising prevalence of dementia (Alzheimer’s Australia, 2004). Alzheimer’s Australia (2004) stipulates that optimal design should compensate for disability and be able to maximize independence, reinforce personal identity, and enhance self-esteem and confidence in PWD. Dementia-friendly environments should be easy to navigate and be a place that is welcoming to relatives. In addition, special consideration should be made to ensure that various stimuli commonly found in a hospital setting are controlled (Golant, 2003). Evidence suggests that current service delivery is staff-centered, noisy and often includes highly complex medical treatments provided to very sick patients by personnel with severe time constraints for patient

care (Borbasi et al., 2006). On the other hand, in these settings PWD require familiarity, order, peace, serenity, redirection and time. Unfortunately, PWD are then viewed as “problematic” compared to sicker, non-cognitively impaired individuals; this leads to the failure of applying good care practices (Borbasi et al., 2006; Traynor, Brisco & Coventry, 2005) such as provision of dementia person-centered care.

1.5 Theoretical framework: Person-Centred Care

Person-centered care has been identified as the ideal approach to caring for PWD (Clissett, Porock, Harwood & Gladman, 2013b). The concept of person-centred care was initially developed by Kitwood (1988, 1997). At the time, he challenged the prevailing attitude regarding working with PWD, by proposing that the experiences and actions of PWD are affected by other factors than simply the disease process itself. Kitwood strived to differentiate ways of working with PWD that were not framed within a biological or technical model (Kitwood, 1997). In order to do so, he insisted that the dementia experience reflect knowledge about the many factors that contribute to its complete understanding, for example, by acknowledging the stage of neurological impairment, the individuals’ personal health and fitness level, his or her life history, personality and coping style, and the individual’s social situation. Kitwood (1988) first distinguished person-centred approaches by de-emphasizing the medical and behavioural management of dementia. He used the term “person-centred care” to describe ideas and methods that emphasized communication and relationships between the PWD, the CG and the health care team.

The goal of person-centered approaches to care in dementia is to respect personhood despite cognitive impairment (Skaalvik, Normann & Henriksen, 2010). Kitwood described the characteristics of person-centred care as follows:

- The individual must be acknowledged as someone who can experience life and relationships despite the progressive disease and the cognitive dysfunction;

- The individual should be offered choices and these should be respected;
- The person's past life and history should be included in their care to make the individual feel valued;
- The focus should be on what the person can do, rather than the abilities they have lost from the progressing disease (Kitwood, 1997).

In short, person-centred care is defined as supporting the rights, values and beliefs of the individual as well as involving the individual in all aspects of care, thus allowing for shared decision-making (Edvardsson, Winbald & Sandman, 2008). This model focuses on the individual and assumes that all behaviour has meaning, even if it may be difficult to interpret. Interactions between the staff and PWD, or the environment and PWD, can precipitate or cause these behaviours, which makes identification of unmet needs essential to ensure that subsequent care can be adjusted accordingly (McCormack, 2004; Richards & Beck, 2004). When the concepts of person-centred care are incorporated into dementia care practices, there are better outcomes, including reductions in agitation and distress, as well as improvements in the ability of health care professionals to identify and meet the PWD's physical and psychological needs (Chenoweth et al., 2009).

Building on Kitwood's work (1997), Brooker (2004) developed a model of person-centered care using four guiding principles summarized in the acronym VIPS. This framework was developed specifically to support health care provision in long term care homes. The acronym represents the following concepts: **V**alue the PWD and those who care for them; treat people as **I**ndividuals; ensure the **P**erspective of the PWD is emphasized and a positive **S**ocial environment in which the person living with dementia can experience relative wellbeing. The four elements have also been further developed, but this framework is meant for use and application only in care homes. This model has yet to be applied to the acute care setting.

Since VIPS is an guiding principle developed initially for long term care settings, it is possible that this model may not be directly applicable to the acute care hospital setting. For

example, caring for PWD in large groups with low staffing may place healthcare workers in a position that may not be conducive to providing a positive psychological milieu. Methods to balance the needs of an individual who requires a significant amount of attention with the needs of the larger group – which may consist of individuals who require equal attention but are unable to express their needs – is a dilemma that practitioners face on a daily basis (Brooker, 2004). Some factors that may impede rapid adoption of person-centered care in acute care settings include the need for urgent patient flow in and out of the emergency room, rapid investigations of the presenting illness, rapid diagnoses, and pressure to initiate discharge from hospital as early as possible to reduce length of stay. Nevertheless, dementia is a disease that requires a patient-centered approach. Multiple studies have found that health care professionals in acute care settings do not seize all opportunities to adopt person-centred care strategies (Clissett et al., 2013b; Dahhlke & Phinney, 2008; Douglas-Dunbar & Gardiner, 2007; Edvardsson & Nay, 2009; McBrien, 2009). Person-centred care practices appear to differ between individual practices and are not comprehensive or consistent across services (Clissett et al., 2013b; Royal College of Psychiatrists, 2011) even though this has been identified as the primary determining factor influencing the capacity of health care professionals (especially nurses) to deliver person-centred care (Edvardsson & Nay, 2009). Hence, changes to care practices require not only a change in individual practice, but also a change in organizational culture that encourages and supports the development of therapeutic relationships between health care professionals, PWD and their CGs (Webster, 2011). It is widely accepted that good quality care relies on effective needs assessments of PWD, and this information should guide the nature and delivery of care throughout the PWD's stay in hospital (Cohen, 2003; Wills & Ford, 2001). The staff members of acute care hospitals are pressured to deal with a wide range of demands from both the internal factors (e.g. patients and staff) as well as external factors (e.g. policies, workforce, funding) (Webster, 2011). Some of these pressures include the expectation to manage care using fewer resources (e.g. financial, staff, beds) while reducing length of stay in order to have enough time

to deal with patients with more clinical needs (Department of Health of the United Kingdom, 2009). A person-centred care approach places priority on the relationship with the individual rather than on the completion of tasks, leaving an urgent need for organizations to teach professionals how to use this care delivery approach (Clissett et al., 2013b). Unfortunately, evidence suggests that organizational factors prevent this from happening (Tadd, Hillman, Calnan, Bayer & Read, 2011) resulting in health care organizations focusing on meeting financial and productivity targets at the expense of care that is dignified and person-centred.

Despite these challenges in application, evidence suggests that person-centered assessment and care has the potential to offer better and more effective outcomes for patients, and may offer a more balanced and therapeutic hospital stay. Person-centred care is also linked to higher levels of job satisfaction; it can save health care professionals' time in providing care and has been associated with a reduction in challenging behaviours (Chenoweth et al., 2009; Webster, 2011).

While considering these organizational issues, Edvardsson & Nay (2009) did a review of the literature regarding the application of person-centred care principles in acute care settings. They identified eight dimensions of person-centered care that promote assessment and meet the needs of PWD in acute care. The final report consisted of 26 papers that employed evidence-based interventions to improve the management of PWD in acute care. Results indicated that using a person-centred and holistic philosophy of care helped health care personnel make care decisions while involving the PWD and their family members. This approach was also found to be useful with regard to uniting staff members with a shared philosophy and goal (Edvardsson & Nordvall, 2008). It is important that health care systems support this model and incorporate into their practice shared interdisciplinary assessments, communication and teamwork. The use of this system could result in the ability to develop care plans with the PWD through interdisciplinary collaboration between the care team, the patient, and the family members. Using person-centred interactions in combination with open

communication (Hickman, Newton, Halcomb, Chang & Davidson, 2007) and sufficient history taking, it will be possible to see the person and not just the disease, which will ultimately enhance the sense of self for PWD, improve their care (Brooker, 2004), and improve discharge planning (Hickman et al., 2007). It is important to consider person-centred care when completing care tasks by including meaningful activities and interactions with the PWD. These small changes can help the PWD maintain a sense of self (Edwardsdsson & Nay, 2009) in an environment that also promotes independence and reduces confusion. Lastly, there is a need to hire staff members that are knowledgeable in the care that is required for PWD who have complex co-morbid diseases. Hiring competent staff will prevent complications during hospital stay (Hickman et al., 2007).

1.6 The experience of people with dementia and their caregivers' with acute hospitalization

It is becoming increasingly obvious that the current models of acute hospital care may not adequately meet the needs of both the PWD and the CG (Flatley and Bridges, 2008). Unfortunately, the role and needs of CGs are often overlooked by health services (Alzheimer's Society of the United Kingdom, 2009; Brodaty et al., 2009) despite evidence suggesting that working with family members is key to providing appropriate care (Douglas-Dunbar & Gardiner, 2007; Moyle, Borbasi, Wallis, Olorenshaw & Gracia, 2011). Caregivers play a vital role in ensuring quality dementia care; however, health care teams have yet to realize this fact (Nichols & Heller, 2002). Caregivers serve as a critical source of information for the PWD's clinical assessment because they are aware of patients' cognitive, functional and behaviour baseline, and they have the ability to recognize subtle changes in the individuals' functioning (Tierney et al., 2003). Despite this unique perspective, most acute care interventions focus on rapid diagnosis and early treatment of the precipitating disease without input from the PWD or CG (Miller et al., 2009).

Although providing high-quality care to PWD and their CGs during acute care hospitalization is considered to be very important goal of patient care (Edvardsson, Fetherstonhaugh & Nay, 2010), there has been very little research that specifically examines the experience of the hospitalization process and care provision from the perspectives of CGs and PWDs (Clissett, Porock, Harwood & Gladman, 2013a; Cowdell, 2010; Douglas-Dunbar & Gardiner, 2007; Jurgens, Clisset, Gladman, Harwook, 2012; Simpson, Scothern, Vincent, 1995).

An exploratory study by Naylor, Stephens, Bowles and Bixty (2005) conducted interviews with five CGs-PWD dyads to examine the needs of cognitively impaired older adults during and immediately following hospitalization. The authors identified that the PWD and their CG had multiple unmet needs during their hospital stay, which raises concerns about the quality of care for PWD as well as the CGs. The study participants mentioned particular difficulty managing and negotiating care with care providers. They raised concerns about lack of information, lack of coordination of services and inadequate assistance with identifying appropriate resources. There were also significant concerns regarding management of the acute illness. Additionally, participants noted that psychosocial coping, which is a component of CG burden, as well as isolation, fear and the sense of loss were mismanaged. Discharge from hospital was also considered to be problematic. In particular, CGs experienced difficulty coping with their loved one's loss of physical functioning and independence, and they noted that poor care coordination led to frustration with accessing resources. It is important to note that these results may not be generalizable to other populations because the study was small and was limited to three tertiary care hospitals in the United States. Further research is required to ensure the validity and generalizability of the findings.

In a qualitative study that was designed to develop support services for CGs of PWD, Douglas-Dunbar & Gardiner (2007) interviewed nine CGs after acute hospitalization to understand their perception of the interactions they had with hospital staff. The authors identified that failure to develop a therapeutic relationship impacted not only the wellbeing of the

PWD but also the emotional well-being of the CG, which had consequences for the continuation of the caring role outside of the hospital. One of the most prominent themes was poor communication throughout the entire process, from admission to discharge. In these cases CGs felt that they wanted to share valuable information with the healthcare team but instead felt ignored. Caregivers were often excluded from decision-making and discussions on prognosis, diagnosis and treatment decisions. They felt that when the care staff were planning and implementing care for the PWD, they often failed to recognize the expertise of the CGs, resulting in missing valuable information about the patient. Caregivers felt very vulnerable, especially those who were older. They were in need of information and of support, which they felt was not provided. They also felt that the nurses lacked an understanding of dementia even though they were given reassurance to the contrary. They believed that the nurses were very busy, which resulted in a negative impact on the quality of care. The CGs felt that they needed to be with the PWD in order to ensure that their needs were met, especially CGs of patients who had communication difficulties. Overall, there was an overwhelming lack of the development of therapeutic relationships between the health care professionals, the PWD and the CG (Douglas-Dunbar & Gardiner, 2007). Although there are some limitations in this study, the research raises important concerns about care provision in acute care. One of the most notable limitations is that the study focused only on the experiences with staff with the goal to develop support services and failed to focus on the patient and caregiver perspective. In addition, the sample was derived from a very small number of participants from one District General Hospital.

In a recent qualitative interview study, Clissett et al. (2013a) used an interpretive ethnographic approach to explore the in-hospital experiences of relatives of older people who had a mental health problem, predominantly dementia, delirium or both. The participants identified that their anxieties and distress were most often due to interruptions in normal routines caused by the illness, hospitalizations and changes in patients' needs and behaviours. The participants attempted to gain a sense of control to cope with these interruptions by

communicating with staff, by trying to protect the PWD, and by attempting to monitor the quality of care received. The study raised concerns about quality of care and health care professionals' knowledge about care for a PWD. Caregivers believed care was poor when staff did not listen to them, and when they were not taken seriously. The authors concluded that health care professionals should maintain consistency when working in partnership with CGs, as well as recognize CGs as a source of expertise in relation to the specific needs of PWD. They suggest that CGs should be included as a partner in the health care team, and should feel welcome, supported and kept well informed throughout the entire hospitalization process (Clissett, et al. 2013a).

In a recent meta-ethnographic analysis of qualitative studies, Prorok, Horgan & Seitz (2013) examined health care experiences of PWD and their CG in primary care settings. Primary care settings are the first point of contact between patients and the health care system. Primary care includes community health centres and family medicine clinics where general practitioners or family physicians provide care. The important themes that were identified in this review of 46 studies are somewhat similar to the themes in the acute care literature. Challenges associated with accessing supports and services were an important theme that was raised. The CG's need for information was also documented, establishing once again the importance of effective communication between CGs and health care professionals. There was also recognition amongst health care professionals that sensitivity towards and validation of the CG's feelings was valued, and that treating CG's with dignity and respect was appreciated. This review suggests that the health care experiences of patients and their caregivers is less than optimal and that several areas could be improved. The authors identified the need for strategies that would increase public awareness on dementia, as well as the need for screening programs, self-management skills, dementia care managers, psycho-educators for caregivers, and improved access to services and linking to community resources (Prorok et al. 2013). While only six of the studies in the review were conducted in Canada, concerns about care gaps for

PWD and CG in acute and primary care are likely to be a concern in many other jurisdictions as well.

It is evident in the literature that the care of PWD and their CGs remains suboptimal in the hospital setting (Pritchard & Dewing, 2001), yet, few studies have investigated the experiences of PWD receiving this care, and even fewer studies have investigated the experiences of CGs (Clissett et al., 2013a; Cowdell, 2010; Douglas-Dunbar & Gardiner, 2007; Jurgens et al., 2012; Simpson et al., 1995). In an effort to fill the current knowledge gap in this area, this thesis explores the perceived experiences of PWD and CGs during acute hospitalization by using a qualitative approach. The “experience” of acute hospitalization will be the term used to describe the first-hand accounts and impressions of PWD and CGs, with a focus on preserving the uniqueness of their lived experience. Since person-centered care has been identified as a valuable approach to establish excellence in dementia care (Clissett et al. 2013b), and given that PWD and their CGs are valuable sources of health information, it is essential to understand their lived experiences during acute hospitalization in order to ensure that they receive optimal care during this often inevitable transition.

CHAPTER 2: RESEARCH QUESTION

2.1 Question

What is the experience of people with dementia and their caregivers during acute care hospitalization?

2.2 Sub-questions

- i. How did participants transition through this event in their lives? What factors helped or hindered the acute hospitalization process according to their perceptions?
- ii. Did the perceived help and care received during acute hospitalization meet the PWD and the CG's expectations?
- iii. To what extent was the perceived care provided during acute hospitalization "person-centred"?

2.3 Objectives

This study focuses on the experiences of PWD and their CG during a key transition in their illness trajectory: acute hospitalization. The specific objectives of this thesis are:

- To identify themes captured from the hospitalization experience of PWD and their CG.
- To look at different facilitators and barriers to the acute hospitalization for PWD and their CGs and how they play a role in the perceived experiences and outcomes.
- To attempt to determine if the perceived care provided in acute care hospitals could be construed as person-centred.

CHAPTER 3: METHODOLOGY

3.1 Study design

This project is part of a larger Canadian Institutes of Health Research (CIHR) funded study. The goal of the larger study is to determine the impact of environmental, functional and personal factors on the overall wellbeing of individuals with dementia during key periods of transition across the illness trajectory. The larger study is prospective, longitudinal and uses a cross-sectional design. There are three study centers, one in Edmonton, Calgary and Ottawa. The investigators examined nine specific dementia transitions from the perspectives of the PWD and the CG. The literature cited nine significant transitions, which were: initial problem identification, first occurrence of requiring external help with IADL and ADL, driving cessation, loss of financial autonomy, acute hospitalization, change in informal support, relocation to new community-based accommodation, relocation to long-term care, and end-of life care. Transitions were explored as they occurred, emphasizing the perspective of individuals living with dementia and their CG. Ethical approval was obtained in all three cities prior to the commencement of the project. The present study focused specifically on the transition related to acute hospitalization.

3.2 Participant recruitment

Participants were recruited from the three different Canadian centers that participated in the larger study. Participants were identified from a wide range of sources through geriatric clinics, memory clinics, dementia assessment units, family practices and the Alzheimer's Society. The recruitment protocol was unique to each study site. For instance, at most sites, a health professional identified potential participants who met the selection criteria; these potential participants were then given an information sheet about the study. The potential participants could write their phone number on the information sheet along with their signature to indicate that they granted permission to the study coordinator or research associate to contact them

regarding the study. Other research sites had a standard research protocol to access patient charts for individuals who consented to be contacted for research purposes; this protocol was followed for the present study.

Participants eligible for inclusion:

- Were 65 years of age or older
- Had a formal diagnosis of Alzheimer's type dementia, vascular dementia or mixed dementia (as per their medical chart)
- Were not living in a nursing home
- Were able to complete the Montréal Cognitive Assessment Tool (MoCA) (Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, ... Chertkow H, 2005) in English or French without translation on entry
- Were able to consent or assent to study participation, and
- Had a primary caregiver who also consented to enrol in the study

Once identified, potential participants were contacted in order to provide them with additional information about the study and to answer any of their questions. If the participant decided to participate, an appointment to review the informed consent form was made at a location and time that was convenient for both the PWD and their CG.

There were 108 participants in the larger 30-month study, and of those 108 there were 29 who experienced the transition of hospitalisation in an acute care hospital. For these 26 participants, there were, 25 caregivers and four caregiver-person with dementia dyads.

3.3 Data collection

Three research associates were recruited for each of the three cities: one was a research assistant, one was a health care personal support worker, and the other was a Registered Nurse. All three received basic interview training prior to the start of study.

Each month, a research associate made brief contact with each study participant (either the PWD or CG) by telephone to identify whether a significant transitional event had occurred in the time since they had last spoken or seen each other. A standardized questionnaire guided the data collection from the telephone interview. The script was adjusted according to whether the person with dementia or the caregiver was the respondent. People with dementia were included in the questions whenever possible. The following questions were asked:

- Please describe how (the person with dementia) has been over the past month.
- Please tell me how you (the caregiver) have been yourself over the past month.
- Have you experienced any of the following transitions over the past month (listed all 9 transitions)?
- Have you experienced any other significant changes over the past month?

If the “acute hospitalization” transition was identified as a transition that was experienced, additional interview questions were posed. Data collection was designed (with telephone contact every month) to take place as close as possible to the time of the transition. The questions were designed using a person-centred approach that focused on the wellbeing of the person rather than focusing on the symptoms and problems of the disease itself; these questions assessed the experience of the transition from the perspective of PWD and their CGs. Some of the questions were designed with the purpose of identifying and evaluating the PWD and CG’s perspective of the effectiveness of health provision and system configuration, since analysis of these components may be useful in terms of managing the transition to acute hospitalization.

The interview guide for the transition of acute hospitalization included the following questions for the caregiver:

- What was the reason for your family member’s admission to hospital?
- Did the help your family member received in hospital meet your expectations? Why or why not?

- What kind of help did you receive as a caregiver?
- Did the help you received meet your expectations? If not, why not?
- What kind of help did you expect to receive but didn't?
- (If discharged) Did you receive support for managing your family member's care when she or he left the hospital?
- Did the help you received meet your expectations? If not, why not?
- What kind of help did you expect or hope to receive, but didn't?

The interview guide for the transition of acute hospitalization included the following questions for the PWD:

- What happened to you during your recent admission to hospital?
- How did you feel about it?

These questions were submitted to interviewers as a guide. Since the questions were open-ended, there was flexibility in the interview to allow the PWD and CGs an opportunity to raise any issues they believed to be important regarding their experiences in an acute care hospital.

3.4 Data analysis

Research assistants transcribed all of the interviews verbatim. A second research assistant ensured data transcription accuracy. All interview transcriptions were transferred to the NVivo 10 software (QSR International, Version 10, 2012) for qualitative analysis and further data management.

Multiple methods were explored as potential options for analyzing the data, but the author and her supervisory committee ultimately decided that content analysis was the most appropriate method for this secondary data analysis. Grounded theory was eliminated as a possible method because the data had already been collected when analysis started. Because of this, it was not possible to analyze data to guide subsequent theoretical sampling decisions

for the next iteration of data collection. Due to the heterogeneity of the data, it was impractical to develop a unique theory about the phenomenon. Ethnography was eliminated as a possible method because there was no direct observation during data collection.

Finally, phenomenology was eliminated as a method of analysis since the interview questions had not been designed to offer an in-depth exploration of the phenomenon of hospitalization with an in-depth exploration of the context. The larger study addressed nine different transitions and did not rely on certain recruitment techniques (e.g. snowballing) in order to foster a more in-depth exploration. It became evident that content analysis was the most appropriate method to use in this study due to the nature of study, which included semi-structured interview and pre-collected data. This method is considered ideal for analyzing qualitative data that is unstructured and heterogeneous (Morgan, 1993).

Qualitative Content Analysis as a research method is a systematic and objective means of describing a phenomenon (Krippendorff, 1980; Sandelowski, 1995). It allows the researcher to test theoretical issues to enhance the understanding of the data (Elo & Kingäs, 2008). Using this method of analysis, it is possible to distil and classify words into fewer content-related categories, and provides the ability to regroup words that share the same meaning (Cavanagh, 1997). The goal of content analysis is “to provide knowledge and understanding of the phenomenon under study” (Downe-Wamboldt, 1992, p. 314). It is defined as a research method that is used for the subjective interpretation of the content of text data; the process involves a systematic classification process of coding and identifying themes (Hsieh & Shannon, 2005).

In a conventional Content Analysis (Hsieh & Shannon, 2005), data analysis begins with a thorough reading of all data in order for the researcher to achieve immersion obtain a sense of the whole dataset. The information collected (e.g. transcripts) is read word-by-word to derive initial codes (Miles & Huberman, 1994); this is achieved by highlighting words that appear to capture key thoughts or processes. Throughout this process, notes in the form of memos are made by the researcher to identify key first impressions as they emerge. These memos lead to

initial code generation that reflects more than one key thought from the text, thereby creating the initial coding scheme (Hsieh & Shannon, 2005). Codes are then sorted into categories based on the relationships and links between different codes, and links and relationships between categories are identified based on their concurrence, antecedents and consequences (Elo & Kyngas, 2007; Krippendorff, 1980; Morse & Field, 1995); these are then grouped into larger themes which will be further explained in the discussion section of the results.

The data analysis for the current project followed the eight steps that are traditionally used for achieving this type of content qualitative data analysis (Zhang and Wildemuth, 2012).

Step 1: Data preparation

After data transcription and verification, data was transferred in NVivo for analysis. The researcher read the entire dataset and provided a general impression of the information collected.

Step 2: Defining unit of analysis

The unit of analysis chosen for this project was defined as a sentence, a group of sentences, or parts of the interview that shared the same meaning. Choosing a unit of analysis that was too small (e.g. a word) could create fragmented data, whereas choosing a unit of analysis that was too broad (e.g. an entire interview) could risk introducing multiple meanings thus rendering subsequent coding inaccurate.

Step 3: Development of coding scheme

Since no theories are currently available, codes were generated inductively from the data with the objective of describing a phenomenon. This strategy was chosen because it is well represented in prior studies (Raivio, Laakkonen & Pitkala, 2011; Ziegert, Fridlund & Lidell, 2006) and the author's personal and professional experience as a geriatrician and most importantly from the current research questions. The constant comparative method (Glaser & Strauss, 1967) was used during coding. This method assures the systematic comparison of each coded text to other text that is already assigned to that code; this process facilitates the understanding of the

theoretical properties of the code as well as integrates codes and their properties through the development of interpretive memos.

In order to ensure internal homogeneity and exclusivity of categories of the external heterogeneity (Lincoln & Guba, 1985; Tesch, 1990; Weber, 1990), data included in each code was reviewed to ensure that similar ideas and concepts were included under the same code, and that data included in different codes represented different ideas and concepts.

Step 4: Testing the coding scheme

A sample of the coding scheme was created and reviewed by a second researcher to ensure agreement before proceeding with full data analysis. Following this process, some coding rules were revised, eliminated or created. Doubts and problems concerning the definitions and coding rules, as well as coding of specific cases was discussed and resolved with another researcher to reach consensus (Schiling, 2006).

Step 5: Coding text

Once coding rules were established and tested, the entire text was coded.

Step 6: Assess coding consistency

Once the whole dataset was coded, the coding consistency was re-verified because many new codes had been added since the testing of the coding scheme. A consistency check was completed by re-assessing the entire dataset numerous times to ensure intra-code homogeneity and inter-code heterogeneity.

Step 7: Categorize and draw conclusions from the coded data

Once the coding was completed, categories were created. Codes that were compatible with similar, larger concepts were combined to create a category. Inferences were then made from the data and these were re-grouped into larger themes.

Step 8: Assuring trustworthiness

The last step involved assuring trustworthiness as per Lincoln and Guba's (1985) proposed criteria. To ensure credibility, triangulation was completed using current literature, the

researcher's experience as a clinician in acute care hospitals, as well as by checking interpretations against raw data, conducting reviews with larger research team, and verification with two other qualitative researchers to ensure adequate representation of the coding scheme. Transferability of the study was ensured through rich description and reporting of the research process, as well as by providing a detailed description of each code. Dependability was ensured by verifying the coherence of the internal process with transparency of coding process and inter-coder verification (Bradley, 1993). Confirmability was ensured through regular audits of the research process and findings, ongoing discussion with co-researchers, as well as revision of the coding schemes and definitions to ensure precise representation of the data.

CHAPTER 4: RESULTS

4.1 Participant description

A total of 29 interviews were completed. Twenty-five of the 29 interviews were obtained from a CG, and four were obtained from a CG and PWD dyad. Six interviews came from the Calgary site, including one dyad; 12 interviews came from the Edmonton site, including one dyad interview; and 11 interviews were from the Ottawa site, including two dyads. Demographic information for the sample can be found in Table 1. The average age of the participants with dementia was 80, whereas it was 64 for the CG participants. Thirty eight percent of the PWD and 34% of the CG were male. Ninety-six percent of CG were living with the PWD prior to hospitalization and 45% of the caregivers were spouses. The majority of participants participated in English; only one participant was Francophone. The majority of CGs had a Grade 12 education (63%), followed by post-secondary education (37%). Of the participants with dementia, 14 had a Grade 12 education, 13 had a post-secondary education, and three completed Grade 8 or less.

4.2 Coding process results

The initial coding scheme consisted of 101 codes. This number was reduced to 82, then to 68 codes and then again to 24 codes. During the final revisions, the coding scheme was reduced to 22 codes and was it was ultimately decided that the final coding scheme consisted of 20 codes. Detail pertaining to the coding process results can be found in Figure 1. Coding frequency can be found in Table 2. These 20 codes were subsequently classified into six categories; see Table 3 for code grouping. The overall coding process and results are summarized pictographically in Figure 2.

4.3 Coding results

The results will be described within each of the six larger categories.

4.3.1 Category: Process (Part 1)

Codes that fall under Part 1 of the category *Process* include data related to events from pre-admission, to arrival, to hospital care, including the emergency department process.

4.3.1.1 Trigger to hospitalization

The trigger to hospitalization was defined as the precipitating event, as understood by the CG, that led to hospitalization and an admission diagnosis. Triggers to hospitalization can be classified as surgical, traumatic, infectious, or medical. Surgical triggers included hip surgery, bowel surgery, cataract surgery, hernia surgery, and bowel obstruction. Trauma triggers were falls and fractures. Infectious triggers included cellulitis, pneumonia, influenza and other non-specific infections. Finally, medical triggers included irritable bowel syndrome, gastrointestinal disorder, stroke, atrial fibrillation, gastrointestinal bleeding, congestive heart failure, peripheral vascular disease and lumbar puncture.

In this group of participants, the most frequent reason for seeking medical attention that led to hospitalization was due to trauma as a result of a fall. In this first example, the CG provides a description of a terrible fall that led to hospitalization.

CG1021: And all of a sudden, she collapsed right beside me. When she bowed straight down, she topped over her right and her right hand side of her head hit the floor. I was really scared, I thought she had died. But the very same time, all over her face had gone beet red when she collapsed. They came right back to normal right away.

CG1021: The bottom line was that she had fractured her right ankle in 3 places

This next example describes another dramatic event in which a PWD reports a bowel obstruction. The CG is unable to provide care at home due to the fear of symptom progression, thus resulting in acute hospitalization.

CG2013: She had a... they found a... blockage in her small intestine. No, she has not been sick for a while. All came about all really rather suddenly. She had diarrhea the Thursday before. It went away, she ate bland meals. Like on the Friday, uhh you know, then only 2 and then the 3rd meal I tried to feed her, she wouldn't even eat. So I knew there was something wrong. By Saturday morning, she was puking black.

It is evident from these examples that the CG senses fear and anxiety prior to entry into hospital. The CGs express worry about their loved ones' condition.

4.3.1.2 Pre-hospitalization facilitators

There were some pre-hospitalization experiences that caused feelings of anxiety for the CG, whereas in other cases, the pre-hospitalization experience appeared to have been facilitated. The "pre-hospitalization facilitators" code was defined as all external events that led to seeking care at the hospital; this code does not include hospital admission, but does include interactions with the family physician as well as emergency medical services staff. This code was defined as all events that facilitated the process of seeking care in an acute care hospital.

In the following example, the family physician's role is perceived as being a great advocate for patient care, because the physician identifies the urgency of the situation and the need for acute care. According to the CG, the physician was able to convince the PWD and the CG to seek emergency care.

CG1001: She had coffee grounds, and she's been having it for 3 days and we didn't know, she didn't tell us we thought it was just some gastric upset but then we had to make an appointment for her to see her family physician and on the way to the family physician she was vomiting more and in the clinic she vomited also and the doctor was really concerned and sent her immediately to the emergency because she thought, she didn't want her to bleed more because she was on anticoagulants and her INR (International Normalized Ratio) was very high.

CG1001: You know the blood thinner, they have to see how thin her blood is, when they take a blood sample, hers was very high and the highest so far, 4.6 that was high for hers. So, she was scared, the doctor you know was really worried that she might bleed more. You know? And she might bleed somewhere else, not just from her stomach so they sent her immediately to the emergency and they kept her there for 1 or 2 nights and then they transferred her to the special services building unit 36.

In this next example, the emergency medical service (EMS) staff was able to direct the PWD and the CG to go to the most appropriate place to receive the required care.

CG2017: Oh yeah even the 2 paramedics that came with the ambulance, one young guy that sat in the back with him said I hope they get him in straight away and the driver said well we're not going to the Hospital A we're going to the trauma unit at Hospital B, 'cause they have a better trauma unit. He felt they had a better trauma unit.

These pre-hospitalization facilitators appear to alleviate some of the fear and anxiety for the CG and the PWD because they provided assistance to ease the process that led to hospital admission. There is a sense that the health care providers discussed in these examples reassured the PWD and CGs that they will receive better care and much needed help at the hospital's emergency department and throughout the hospitalization process.

4.3.1.3 Emergency department process

The code for the emergency department process was defined as the series of actions or steps taken from the point of entry in the emergency department at an acute care hospital, to the emergency department discharge. This process is followed by admission to the inpatient unit in the acute care hospital. The code includes quotes that discuss the entire emergency department process including: the flexibility of family and CG visiting privileges, the lack of dementia recognition by staff, care provision that was not dementia-related, noise that was loud, and waiting times which were long and distressing. It is important to note that since visiting privileges are often restricted, CGs were very appreciative of permission to visit the PWD.

CG1001: The hospital helped us because in the emergency department, they allowed us to visit.

Participants noted that the long emergency department (ED) waiting times had a significant negative effect on the PWD. In addition, there is a substantial amount of noise in the ED, which can be distressing for the PWD and can thereby increase agitation. Due to the PWD's lack of understanding, the chance of the he or she experiencing distress and agitation can also be increased when the PWD experiences medical interventions. This distress is often seen when intravenous catheters or naso-gastric tubes are removed by the PWD; these events create an additional challenge to care provision, as well as cause distress to the PWD and their CGs. Recognizing pain and treating it appropriately can be especially difficult for health care

professionals who lack knowledge about dementia. Caregivers can be a useful resource to health care professionals, because they can provide valuable information about the interpretation of the PWDs behaviour, and can notify the care team when the PWD is experiencing pain or discomfort. Caregiver presence can be calming and reassuring for a PWD, but in some cases, participants stated that the CGs were not called on in these circumstances, thus resulting in worsening agitation that could have been avoided.

CG 1001: We were in the waiting room probably two and a half hours and I had to go up after an hour and tell them I didn't think she was going to last very long in that chair, that she had felt faint and she hadn't had much fluid. She was dehydrated. They said they were waiting for somebody to move and all the beds were full in the back. Sure enough about 45 minutes later, they moved her into a room. Once she got in the back, they were doing things quite expediently; she waited in emergency (in the back part where she had a bed) for probably about 18 hours.

INTERVIEWER: Okay, are you satisfied with this part of the time?

CG 1001: Um no, I wish she could have had a bed sooner, um what happened was in emergency because of being an Alzheimer's patient and being confused, and the level of noise in there was phenomenal. You're just separated by a curtain. I was there as much as I could but I left a little after midnight, 12:30 in the morning, when I had been there with her since 5 o'clock in the morning and she had a naso-gastric tube in her nose for her stomach. Apparently when I left, she pulled that out 3 more times and her IV she pulled out a couple times. I know distinctly that when I left, I told them to give her something for pain, give her something to help her sleep so that she won't be bothered by the tubes, but I think just because it was emergency, the nurse and they're so busy and they didn't have anybody to kind of sit and watch with her. I mean, it only takes a few minutes to take an IV out so when I got there, later in the morning again, she was black and blue from starting IVs and everything. It was very sad. And I distinctly told them to call me if they needed me and they didn't. I was disappointed when I got to the floor and they told me she pulled this tube 3 times and I hadn't been called to be told that, you know? Because when I was sitting there, when someone was sitting with her she didn't have that behavior to pull things out. And it's very noisy, it's very, I'm sure it's very confusing.

The emergency department is not the ideal place for the PWD because it is extremely busy; this busy environment can be over stimulating for the PWD, thus creating agitation on their behalf. Provision of dementia-sensitive care is often challenged. The participants also noted a lack of dementia recognition by ED personnel, which is stated in this next example. In these cases, appropriate care delivery becomes more challenging, even for basic needs and

assessments. People with dementia have special needs, including the need for information, assistance with basic activities of daily living, as well as help navigating the health care system.

CG 2013: She stayed in the emergency for quite a while. Did not have a room or whatever. I'm telling these people she has dementia, and you know, she's going to tell you she's fine when she is not. And they all say they understand and they don't (...) She was in the emergency for 3 days (...) Now, emergency is busy. There, she is not a priority, she is not an emergency. Even though I think she is, okay, she's not in emergency, she is there for an admission. So she sat in emergency from 3:30 in the afternoon on Monday until after 4 o'clock in the afternoon on Thursday on a hard gurney (...) no shower, no washing, no nothing, no gown, no...dick all. Okay? I'm sorry (...) she was in extreme pain, you know, and they don't even read the charts, you know, they don't even read the charts about her dementia. That's a joke too okay? (...) and I go to hell every time she goes to some place and I'm not with her.

INTERVIEWER: (...) they sent transfer papers with her but they just didn't give enough information?

CG2013: Well yea well, they gave information but nobody reads it. Nobody reads it! It was emerg, they are busy, they don't have time to go through that thick binder that goes with her everywhere, but it should have a great big red or pink sticker on the front that said this woman has dementia, look in here, you know... or, or this person has her personal directive invoked, look in here.

As this example states, the information transmission for care provision was not done properly. In the previous example, the information seems to be available but not used to its full potential to facilitate care.

In the next example, a PWD is sent to ED unaccompanied. It appears as though there was a miscommunication that she should have been accompanied by a CG, but she was not. The PWD is left in the waiting room with no assistance. Due to the cognitive impairment of the PWD, the PWD should not be sitting in the ED alone. As evidenced by this next quote, the CG appears distressed by the situation and lack of communication with health care personnel.

CG2013: Monday night, I get this phone call. She is upset, crying, confused um, she tells me that a cab took her to the hospital today and dropped her off and just left her. She doesn't know how she is gonna get back home, I don't know what's going on, she was totally confused. She was in the waiting room, and I said how did you get a phone? Somebody let me use the hospital phone she says. So she was able to ask, I guess after they triaged her, they just had her in the waiting room, in a wheel chair or something. She has been sitting there for hours, she was in excruciating pain and I don't know how she got somebody to get her to the phone. But then she phoned me, and she had to remember my number from memory.

INTERVIEWER: Okay.

CG 2013: But she was totally confused, totally upset, crying, and that's just, you know, that's just... I was like what, this is like 8 o'clock at night. I mean, this is just...

INTERVIEWER: This was in emerg?

CG 2013: Yea, and I knew she had gone, I knew she had gone that afternoon, but I thought an aid was going with her, I thought a, you know, like what's the procedure here. You know, nobody went with her, not when she goes to the paramedic, and the paramedics signed her off to the nurses in emerg. And then I told you the story, emerg is busy, they are not making, admitting a priority, and she sat there for 3 days, 4 days.

(...)

INTERVIEWER: Have you talked to the...

CG 2013: No, I haven't even asked them because I'm not getting anywhere with just finding out what the heck are they going to do. You know, let alone suggesting that they try to move her over and let her sit in the emerg there for another 3 hours, 3 days.

The discussions about the ED process identify many important issues concerning long waiting times, which are especially hard on the PWD. The participants also comment on the importance of the CGs in care provision, which, if they were included more frequently, the process could potentially be facilitated. Another common theme was related to miscommunication or no communication with the CG, which adds to the CG distress.

Following the ED process, the PWD are admitted to the acute care hospital, which was captured under the category "In-hospital trajectory".

4.3.2 Category: In-hospital trajectory

"In-hospital trajectory" is defined as the PWD's path or course in the acute care hospital setting, from the time of discharge from the emergency room until the time of discharge to their home or to another institution. This category includes the following three codes: in-hospital cognitive trajectory, in-hospital medical trajectory and in-hospital environmental factors affecting trajectory.

4.3.2.1 In-hospital cognitive trajectory

The in-hospital cognitive trajectory code was defined as the path or course of the CG or PWD while in hospital that relates specifically to the cognitive symptoms of dementia. Excluded from this code are physical manifestations, instead the focus is on the events related to the cognitive, behavioural and functional changes of dementia and delirium.

The information collected includes the recognition of special care needs by health care personnel. The information gathered noted examples of effects on cognitive symptoms, the PWD's short term memory problems related to failure to recognize danger, responsive behaviours requiring a need for increased supervision, as well as special staff intervention and CG involvement to help palliate these symptoms.

The following example is a report of a PWD's worsening cognitive abilities and functional decline since admission to hospital. It raises concerns about a potential systemic problem where PWD are not encouraged to be independent with their self-care. As a consequence, the PWD who were able to do their personal care prior to admission become dependent on others for basic activities, which furthers functional decline while in hospital.

CG 1010: No, she's regressed quite a bit, Alzheimer's wise. One of the nurses, that was there the first week, she was there was talking to me that afternoon when I was making a cup of tea. Bowel-wise she's totally incontinent now and she just lets them, she's in diapers all the time and she just lets them do that. She doesn't, she knows how to ring the bell but she doesn't ring the bell to call them. And she refuses to work, to walk, and it's almost like if she says no loud enough to them and try to stay sitting and not moving that they'll say okay, you're not going for a walk. Which is wrong. You know, especially after bowel surgery something that's really important is that you are moving to help move with the gas and stuff like that because it will just get worse again and so, so, so that part's really disappointing as I told somebody this afternoon, I said, she was going to the bathroom by herself during the daytime walking whether I was there or not there, with the cane or the walker and yes, she wore a pad just in case she had a dribble on the way because it was a way up that you know, she was to use the bathroom and here she's not and so is feeding her stuff. I walked in once and they had her hands all wrapped up in a blanket this and that and they were feeding her. I was like why are you feeding her? She can feed herself I mean you can cut up her meat and set her up, open any packages that are difficult to open and set up her cutlery and things like that but you don't have to feed her and it's almost like now because they've been feeding her and she doesn't use her hands, her hands shake a lot and she's having more trouble holding on. So those are some examples.

Here is another example of regression while in hospital:

CG 1010: Well like I said I see a regression in her Alzheimer's, I don't know if she is considered moderate to late now in her level of Alzheimer's. This afternoon, she's hardly talking to me. And she's always trying to close her eyes and says she's tired, and stuff she seems to be more sleepy.

According to this next description, the CG notes worsening confusion that could be interpreted as an episode of delirium. Unfortunately, it seems that this episode was not reported as a delirium, suggesting a lack of recognition or a lack of CG information and education.

CG 2016: She was quite disoriented when I came in the next morning, so I checked with the doctor and see what medications they gave her, and we do believe that she gave her Pill A, the same pill that she reacted violently to about 2 years ago at Clinic B. So however, she changed it immediately to pill B.

4.3.2.2 In-hospital medical trajectory

The in-hospital medical trajectory code relates specifically to the medical and surgical course related to the underlying illness bringing them to hospital. This trajectory excludes cognition-specific issues as well as environment-related issues during the in-hospital acute care trajectory. The code includes pain, medical complications, and medical interventions by the health care team.

In this example, there is a report of the challenges associated with pain assessment and pain management when caring for a PWD. A PWD may have an atypical presentation of pain manifestations, which requires excellent observational skills on behalf of the health care professional as well as CG involvement to ensure optimal pain management.

CG 2035: It's funny because she was complaining about this pain in her back just a few days after therapy, and she, every time there was a shift change, if we weren't there to tell the nurse then they'd just automatically talk to her. Um, she's dying in pain and I noticed, she had a morphine drip for a while, hey the morphine's gone, and they said, well they said she said she's fine, she's fine cause she's laying there, as soon as she moves it hurts. There was lots of trouble that way.

This next example describes the challenges of the medical treatment plan for a PWD when managing an acute lower extremity edema and infection. The complexity and struggle to adhere to treatment to ensure proper healing is challenged by the cognitive losses of the PWD, which complicates their understanding of medical instruction and intervention. Additional

supervision, reminders and CG involvement in the medical care plan can be helpful to avoid these complications.

CG 2013: Yes, that was the first time, and amazing ok, you know 24 hours in that bed because they didn't let her sit up, you know, they didn't let her be up like she was in there because of the severe edema and the infection right in the thigh. 24 hours in the bed and her legs went down 50%. It's very clear that the home is not like, either they are understaffed or whatever, but they are not getting on top of her about this. As soon as they go out of the room, they may have her up in the chair with her legs up. But as soon as they go out of the room, she lowers it herself. Okay? I mean, and they can't check her every... they don't go back every 20 minutes. If this is only 20 minutes, she would have been back to the way she was. They had it completely down, she had chicken legs when she got out of the hospital the last time.

This next quote describes an instance where the appropriate investigation measures took place to ensure malignancy was ruled out. This example is considered a facilitator. Proper investigation is important in the context of dementia because disease presentation can be atypical.

CG 1003: I felt... there's got to be something there, there's got to be something. So they did do diligence, I have to say that, they did the CT. Of course when they did the CT, they saw the image on his right hip... and we need to go back for a nuclear resonance, bone scan of the hip, but what it is it's a cancer which has metastasis. They were seeing... it's good and we knew that. We knew that it was okay, and I told one of the guys but they felt... again, it was diligent. The report came very, very good. It's not a metastatic lesion. It's there, but it's where it was when it metastasized to the bone. But it's not growing.

4.3.2.3 In-hospital environmental factors affecting in-hospital trajectory

The “in-hospital environmental factors” code included all factors that were external to the PWD and the CG that relate to the environment while in the acute care hospital setting. This code covers topics including: room transfers, presence of noise, cleanliness, nutrition, loss of personal valuables, and the impact of isolation measures. The code excludes staff interactions and communication issues.

In the following quote, a CG describes the positive impact of roommates in the hospital. While not having a private room can be perceived as negative, PWD and CGs have identified some benefits of sharing a room while in hospital. In this case, the presence of a roommate acted as a form of informal supervision as well as a source of information sharing.

CG 2019: What I found is... like the lady in the bed next to her, the first night my mom was on the ward... the lady in the bed next to my mom was 60 something, she's just had an operation and she immediately called me and said I will keep an eye on your mom. I know how difficult it is to have an older person, a mother, in the hospital, and the worry... and so she, she... was very active in listening to what the doctor was telling my mom and reporting it to us. It was wonderful.

Isolation was perceived as a barrier to a good hospital experience for the PWD. The infectious disease precaution measures are standard as per hospital infection control protocol. They are in place to ensure adherence with infectious disease practice; unfortunately protocol can have a significant impact on the PWD who may not understand the reasoning for the rules, or may have difficulty adhering to them because of memory difficulties.

CG 2025: Well, he didn't like it at all there. He didn't like it at all there because he was in isolation and I think there probably was a reason why they had to keep him in isolation. So I'm not saying anything about that but he just said, they kept his door closed. So he was in this private room by himself and he said, whenever he would like, wanted to go out, and when he opened the door, he said they'd yell at me to get back in there. So he didn't like it there.

It is evident that the hospital stay not only affects the PWD, but also the CGs. The next category is specific to the CG experience.

4.3.3 Category: Impact on caregiver

This category focuses on the impact of the hospitalization experience on the CG. People who care for another person with an illness often experience feelings of stress. This category includes experiences related to CG stress and burden, CG fear and worry, and the CG's time commitment.

4.3.3.1 Caregiver stress/burden

Caregiver burden has been defined as a multidimensional response to the negative appraisal and perceived stress that results from taking care of an individual who is ill. This response may include physical strain, emotional stress and financial hardship. The topics included in this code pertain to the restructuring that is required from the entire family to ensure supervision and visitation while the PWD is in hospital. It also includes the social impact on

family members due to hospitalization of the PWD; one example includes family members from out of town who need to travel back and forth, resulting in a loss of personal time as well as the need to take time off from work. This code covers experiences of tiredness and burn-out as a result of the stress related to the responsibility of proxy decision-making. Lastly, the lack of respite and the absence of support were also included in this code.

The CG burden and stress was most striking during the hospital stay. This first case illustrates how the PWD's hospitalization has had a significant social impact on the CG. The CG must restructure their social activities (e.g. work) in order to accommodate hospitalization of the PWD. There is also a financial impact and a need for assistance. At the expense of missing work-related obligations, some CGs are able to reduce their stress levels by being in the hospital with the PWD.

INTERVIEWER: So you're going to be cutting back on your working and spending time with your mom?

CG 2035: Yes

INTERVIEWER: Okay and is that a hardship for you with your job and that?

CG 2035: No, I would prefer it. I am very worried when I'm at work, and her and I, we can, you know I have "spending money". If I work Saturday, there's no reason somebody else in my family can't help out Saturdays. And then every other day I'm uh, it's you know, I would prefer to be there with her because we do little fun activities, you know.

CG 2035: They're trying to help you and they're afraid that with you working that it's stressful for you, just say it's not stressful, I can do it. If I need your help with it, I will ask because they're just, there's so little that they can do for you that they're trying to ease your burden type thing.

CG 2035: There's just certain things like that's when I said to her, if you guys want to help me then help me. Come over here and I'll take an afternoon off, you know kind of thing and you know that's when she said oh okay we'll try to figure out something like that.

This excerpt suggests that the CG acknowledges that he has been through a lot, and knows that this episode of hospitalization is probably not the last one. These comments raise concerns regarding the resilience of CGs. In the previous example, the CG's loved one presents quite well despite her cognitive impairment, which can complicate the CG's role since

the health providers may not notice that the high functioning PWD needs help from their CG. A lack of involvement can further burden the CG.

CG 2013: They look at me sometimes like they don't believe me because she presents so well. Like I'm some kind of, you know, I'm a daughter who just wants to, you know, like seriously, I got that kind of attitude, you know. I'm just like oh my god, are you kidding me. I'm just trying to get through this as fast and as efficiently as possible because I've done it so many freaking times. Trust me on this, you know.

4.3.3.2 Caregiver fear and worry

Caregiver fear and worry was defined as a distressing emotion felt by the caregiver that was triggered by impending danger, regardless of whether the threat was real or imagined. These emotions could be related to apprehension, concern, anxiety or a fear for their loved one's safety. These emotions may be experienced when the CG cannot ensure protection to the PWD because of the reality that the CG cannot be present at all times during the hospital stay. Caregiver fears were mostly related to the possibility that the PWD would fall or experience a bad outcome while in hospital. This fear makes the CG feel pressured to be constantly present at the hospital.

Because falls were the most common reason for admission, the CG feared that the PWD would fall again. Although the CG expects that the PWD will be kept safe in hospital, the CG still voiced concerns about trusting the wellbeing of the PWD to others.

CG 2019: So I had the same concerns, like her not having a fall... Um, because, you know, her being on heart medications and stuff... a bit of unsteadiness sometimes, you know, and strange environment.

Again, the issue concerning trust is mentioned regarding the difficulty with leaving the PWD alone in the hospital. The CG fears she would cause undue distress to the PWD

CG 2025: It was very hard to leave him at the hospital because he was always upset about something.

4.3.3.3 Caregiver time commitment

The CG's time commitment was defined as the CG's act or the pledge to ensure constant supervision of the PWD. This commitment involves the emotional, intellectual and physical commitment to the PWD at the expense of the CG's time. The CGs feel that the hospitalization process controls their personal and work time. They mention the need to reorganize their schedule to ensure that they can constantly be in the hospital with the PWD.

CG 1021: She wound up having a surgery on her right ankle. They put in, as I understand it, 3 pins and it caused a little upset in our plans as that particular weekend, our granddaughter was having her bat-mitzvah which is the Jewish religion. And we had arranged to attend a function Friday as well as Saturday as well as Sunday but we weren't able to attend naturally.

Despite the time commitment required for hospitalization, some employers can act as facilitators by providing flexible work hours and by allowing the CG to spend extra hours at the hospital.

CG 2025: Yeah, I'm managing okay, you know, I think. I'm lucky enough that I have a job that isn't a demand that I be here 8 full hours. So I have meetings that I have to do. There's still certainly stuff I can do at home that I will do at night and decide oh okay I'm not going in until 10 o'clock in the morning and that's because of the flexibility I have. I think if I had to be at an office at 8 o'clock every morning and then had to go directly from there to the hospital and then home yeah it would get very hard.

It was also noted in the interviews that the CG's experience of burden is affected by communication during the hospitalization process. The next category will look specifically at communication.

4.3.4 Category: Communication

The category "communication" was defined as all forms of information exchange and information sharing, including the conveying, dissemination and disclosure of information during acute hospitalization. The code captures communication with the physician, communication with the caregiver, and communication between health care staff and the PWD.

4.3.4.1 Communication with the physician

The communication with the physician was defined as the activity of physicians conveying meaningful information through the exchange of thoughts, messages or information through the use of speech, visuals, signals, writing, or behaviour.

In the following example, there is a lack of physician communication related to the pre-existing diagnosis of dementia. According to the CG, this lack of communication led to significant frustration on the CG's behalf. To provide context, at the time of the event, the CG had been present at the bedside of the PWD every day awaiting to convey personal and medical information to the supervising physician, however, this never took place. The physician was perceived as a barrier to effective communication.

CG 1021: This also results in me receiving a telephone call from her surgeon on Saturday, the day after the surgery. She criticized me very strongly because I had not told her that (name) had more than just early stage of dementia. And we had words over this and I said well if it was important for you to know the status of her dementia, it seems to me you would have contacted her husband who was being at the hospital every day since she's been there. And to be quite honest, I don't even know what you look like or what your name is or anything about you. So, we still had some strong words because she thought we were being careful and so forth, which was a bunch of garbage.

Contrary to the previous example, this next except illustrates an example of how a physician can be perceived as a facilitator to effective communication. The following CG statement identified the communication with the physician as instructive, honest and satisfactory.

CG 2025: Dr. (name) was very, I thought, straightforward and honest. He said he has some very serious problems. We need to assess him. We need to figure out exactly what he needs to be put on and what he needs to be taken off of and he said I'm going to get you this sheet to read and he said: "I need to be honest with you, sometimes it works and sometimes it doesn't and we will try the best we can to get him back to where he needs to be", and they certainly did.

4.3.4.2 Communication with caregivers/family

The code of communication with CG/family included statements of the exchange of information with or about the CG.

The transcripts suggested that the health care team lacked communication with the CG. It also suggested the health care team discussed directly with the PWD (without involvement of

the CG) about important medical issues and medication management. The lack of information sharing with the CG was interpreted as putting the PWD at risk of errors, especially if the care plan involved high-risk drugs like warfarin. There was the potential for misunderstanding or problems with remembering essential medical information when information was exchanged solely with the PWD.

INTERVIEWER: So they always turn to the family and gave the family the information? Or were you finding that they were interacting with your mom?

CG 2019: They were communicating with my mom. And they would, in fact, the whole issue around some help with medication came up... like for post discharge um, it's because I was concerned about Warfarin and that's a very potent drug and you know... so I was, and there's a lot of instructions around it...

In this next example, discharge care plans were made without the involvement of the CG, resulting in an inappropriate home care needs assessment. This lack of CG involvement can also be perceived as a barrier to the CG's experience, which can cause challenges in receiving care.

CG 2019: Yes, exactly. (...) when it came to the discussion about help with home care (...) whether she needs any support following discharge... and that my mom indicated no, that they were finally didn't need any help which, you know, is a common response. So I kind of intervened and spoke to the nurses (...) and I said that it was important that there would be some intervention at this stage (...) my mom have some support (...) And they sort of... there was a little bit of discussion that I think they felt she didn't need it because she had declared she didn't need it (...) She is quite able to have conversations with people and I think their observation, conclusion, was that, you know, things were fine. So I had to sort of pursue that discussion and in the end, there was a referral made to home care and something to progress.

4.3.4.3 Communication: PWD as an agent

Another area where communication appeared to be problematic was when complex medical information was shared with the PWD without the CG present. This situation was perceived as a barrier to effective communication, which could result in an undesirable outcome. Medical information and care information was given to the PWD but due to memory loss and cognitive impairments, this information was not relayed to the CG nor to the other health care team members. Due to the nature of their disease, the PWD often mistakenly provides

inaccurate information when questioned by health care professionals, which has an impact on care.

CG 1010: And um, during the week she seems to get the student nurses sometimes which means the student nurse does the care but then either the instructor or the regular nurse has to oversee her so sure enough today another male nurse came in. He was a student and he was taking care of her today and tomorrow and then the RN came in and I said did she have a shower? No. She told us no. I said listen you have to put her on the commode or take her for a walk. Bring the commode behind and sit her down and say we're going for a shower. That's it. Same with walking her. Some of them are either lazy and they're not taking her for walks if she says no I don't want to walk. Then they just let her lay in bed all day and that's terrible for a post-operative patient. They should never be laying in bed all day.

As exemplified in the next example, direct communication with the PWD to obtain medical information can lead to misinformation. Usually, the health care team members would like to be aware of the patient's opinion because they want to respect the patient's wishes concerning treatment plans. This type of information transmission created another barrier for the CG.

INTERVIEWER: They still didn't keep you close enough (...)

CG 2035: Yeah 'cause really, you're right that was kind of the only thing that everybody was talking to her, talking to her. They want her opinion you know and everything.

INTERVIEWER: And they'll say do you want homecare at home and most of them say "no I'm okay, I'm fine".

CG 2035: Exactly, that's exactly what she said! No the only thing was oh, she's definitely, they were going to give her a bath, but they were going to come in and bathe her. But that's so easy for me, and cause I'm, you know, at night time I said "it's okay, I'll give her a bath". And no no, no bathroom, my mom kindly said "I don't want you to bathe me, my daughter can".

Not only does communication impact the hospital experience for the PWD and CG, but it also affects all health care professional interactions, which has a significant impact on their experience as identified in this next category.

4.3.5 Category: Health care professional satisfaction

The category "health care professional satisfaction" is defined as all contacts with health care professionals; it includes codes for satisfaction and dissatisfaction with the attending

physician, satisfaction and dissatisfaction with nurses, as well as satisfaction and dissatisfaction with other health care professionals.

4.3.5.1 Satisfaction or dissatisfaction with physician

The satisfaction or dissatisfaction with physicians includes general comments about physicians that are not directly related to communication.

The following quote is an example of satisfaction with the trauma team. It is also an example of a time when the CGs' needs and expectations were met.

INTERVIEWER: And has the hospital, have you received the help that you needed, has it met your expectations?

CG 2017: Oh definitely, had it not been for that trauma team when they took him into ICU last week, I honestly, I don't know how things would have turned out, we've had the best possible care from the doctors and nurses.

CG 2017: there's a neuro, there's a lung team been in to see him and he keeps looking at me I said "they're just trying to make sure everything is in working order before they let you go home". He said okay.

On the contrary, the following quote is an example of complete dissatisfaction with physician care, more specifically, it is an example of a resident physician's lack of knowledge. It also includes a general comment about the perception of the attending physicians' arrogant attitude.

CG2013: We've had one and that one, I mean, it was ugh, I almost wanted to throw my hands up and go, what are you? ... and my daughter had to kind of calm me down so I just didn't alienate all of them. Because it wasn't even Dr. (name) it was one of the residents on the team you know, and she didn't really know dipshit. Sorry, excuse my language.

CG 2013: The doctors are all in their God complex okay?

4.3.5.2 Satisfaction/dissatisfaction with nurses

The satisfaction/dissatisfaction with nurses code includes comments made by the participants about the perceived skills and knowledge of nurses. It is defined as the proficiency,

ability or dexterity that is acquired or developed through training or experience in the nursing profession. The important ideas captured include: participants' perceived lack of knowledge about dementia on behalf of nurses, challenges related to nurses who are replaced by nursing aids without the proper nursing skills, difficult communication with CGs about nursing care issues, and lack of provision of basic nursing care (e.g. personal care).

CG 1010: But from a nursing standpoint I'm disappointed in the care, the lack of knowledge in regards to Alzheimer's is quite substantial.

CG 1010: Sure, sometimes I would go in and I could tell her hair wasn't combed and everything and I'd say "did she go for a shower this morning" and the nurse would say "no I asked her and she said no". And I'd say, and why would you ask her because she's an Alzheimer's patient she doesn't do her own self-care, and that had been documented from when I was there when she had been admitted into the hospital. I believe that, an idea, a plan of how I took care of her at home, you know that she showers 3-4 times a week. Um, every other day, and that I had to set it all up and be assertive about it to say use the shower. And so I try to instruct them that way and my understanding was that they documented it all but they weren't following that at all. And still not, even today, I was in this afternoon and again, she wasn't showered.

This code also includes information about systemic nursing factors, which are defined as issues pertaining to the health care system that have a direct impact on nursing care. Due to systemic factors like budget restructures and new care models, nurses are replaced by nursing aids who have less and different training which may not be suitable for patients with complex conditions and multiple comorbidities. Other systemic factors that were observed were overworked nurses and hospital protocols that affect the way nurses are able to provide care.

CG 1010: Right now they seem to be employing nurses' aid, which have a 3-month course on how to bathe a patient, proper lifting techniques, that's about it. They knowing nothing about Alzheimer's disease, they know nothing about surgical complications or diabetes or anything.

CG 1010: (...) I believe there's a place for nurse's aids, maybe in bathing and handing out trays and assisting in feeding. But I don't agree with all of the things that they're giving them to do. Because a registered nurse does the bath she gets to inspect that person's whole body, if there's any open sore, you know... I believe only professional nursing staff that should be dealing with acute care patients in a hospital.

Other systemic issues that impact nursing care provision are the infectious disease and infection prevention protocols and policies. These policies and procedures are in place to ensure that nurses to adhere to them. The following excerpt discusses a situation in which the

patient required isolation to prevent him from leaving. The management of this issue was perceived as impolite by the CG.

CG 2025: They kept his door closed. So he was in this private room, by himself and he said, whenever he would, like, wanted to go out, and when he opened the door, he said they'd yell at me to get back in there.

This code also includes the perceived attitudes of the nurses; these are defined as the general expression of favour or disfavour by the nursing personnel in the acute care hospital. This code includes examples of perceived lack of professionalism as well as nurses'-aid and nurses' general attitude.

The CG reports satisfaction with care provision because the nursing staff was concerned about the PWD's health and the care received met the CG's expectations.

CG 1021: Ok, going back to the hospital, it seemed to me that the care they were giving to her was pretty good. The nurses' aids seemed to be very concerned about her health and everyone seemed to be attentive to her. I personally accepted for the lost of those two items. I had no complaints, they seemed to be looking after her.

CG 1021: They had, like I said, they had three nurses' aids and one nurse in the area and they're all quite friendly and they seem to be right on top I think.

In other instances, participants expressed a general lack of concern and disinterest, and perceived a nonchalance attitude from the nurses.

CG 2019: It wasn't until we went back to the station and after some time, later, and the nurse again said, 'oh yeah, she's whatever'. And then I said, 'well, so how come', and I pointed to the monitor, 'why is this blank or showing not connected, or whatever the words were' 'Oh, I guess her leads came off'. So, there's this I find and I found that in other circumstances in hospitals, there's a quickness... um... a people or just personality types of... I'm not the nature...where I like to quadruple check something before I declare. Other people don't check anything at all, they are quick to declare based on, you know, some level of confidence they have... that whatever misplaced confidence. I've found that... so that, you know, it's a bit of a concern.

4.3.5.3 Satisfaction/Dissatisfaction with other health care professionals

Satisfaction/Dissatisfaction with other health care professionals was defined as the act of being satisfied or content with allied healthcare professionals (e.g. social worker, physiotherapist, occupational therapist).

The benefit of collaborative work in an interprofessional health care team may provide great results and satisfaction as reported by a CG in this next example.

CG 2025: When the doctor came in to see me she basically said they brought in, they call her an OT specialist and a PT, that's physiotherapy, all these different. The very first day they asked if I could stay, they were going to bring in people to introduce him to. So I stayed in and they brought all these different people in and introduced and said we're the team here. We will all be doing different parts of looking after him and they basically said, now the doctor has just told you that you know it's at least four weeks and maybe six weeks and prior to you leaving this place we will have a sit down talking about what do you need at home, do you need support at home

This next quote is another example of how great assessment skills, professional work and listening skills from the physiotherapy team can bring satisfaction and fulfilled expectations to the CG.

CG 2013: You know who was very helpful in there, who has been really helpful in her care? The um, the physiotherapist, but she was a little bitchy in the conference too, but she's been really good for mom, and her assistant, her male assistant he was really good, and this guy, what was he there for, he was something to do with, he was something to do with physio too...

CG 2013: But they were really really, they've been the most helpful. They you know, they listen to me when I told them about, they asked me questions. Does she stand up this straight when she's at home? Like is this how hunched over she is? Like they actually quite, doing their job when they assess her you know.

The last series of codes relating to the trajectory involve the discharge process.

4.3.6 Category: Process – Part 2

Codes falling under Part 2 of the category *Process* include items related to the chronological events that take place at the end of admission to hospital. This category includes codes for the discharge process, the post-acute care environment, as well as care continuity and coordination which is present throughout the hospital stay.

4.3.6.1 Discharge process

The discharge process is the point at which the discharge planning process for the PWD is initiated so that the PWD can leave the hospital. Plans are made for the PWD to either return

home or be transferred to another facility (e.g. rehabilitation center or nursing home). The discharge process includes: the discharge planning which involves the PWD and CG, discharge instructions, which includes discharge day, as well as evaluation of discharge care needs and the discharge destination including information regarding the PWD's candidacy for rehabilitation programs.

In the following example, the participant highlights the lack of inclusion of the CG in discharge planning, resulting in being unaware of discharge issues and the situation at home post-discharge. The example shows remarkable insistence on behalf of the CG to ensure a safe discharge home. The CG ensured that the discharge was delayed until a comprehensive plan was in place that included appropriate equipment and training. This example identifies the importance of the CG's advocacy on behalf of the PWD.

INTERVIEWER: I would like to summarize what happened when she was in hospital and your interactions with the healthcare professional. Now are you satisfied with your health? What can be improved? And your decision-making process of when you would have had to come back, so the process of your thinking.

CG 1021: She had the surgery on a Friday. So the Monday, they called and say they wanted me to take her home. I said "I can't take her home because she can't walk; she's has fractures and so and so forth". They said "well, have you got a bathroom on the main floor" and I said "yes, I have a half bath (a sink and a toilet there) but all our bedrooms and showers and everything, they're upstairs". They said "well, we can teach her to go up and down the stairs on crutches". They said "but could you bring the bed in", I said "no, we don't have room for it and I said on top of that, I suffer from sleep apnea and I have to wear a CPAP when I sleep. Also, I have a urine problem and if she fell off the couch downstairs or a bed, I wouldn't hear it". So I said "I refuse to allow her to come home".

CG 1021: I said she should be able to go to a resourceful hospital like a rehab center or something like that. They said, well we can't send her to that. They said we can't send her there because she has dementia, and she can't learn anything. I said well if she can't learn anything, how are you going to teach her how to go up and downstairs on crutches. I said what you telling me is a bunch of garbage. I said I won't listen to that. So I said, you'll just have to keep her in the hospital.

CG 1021: I got a call from that person supervisor saying that everything was all arranged to send her home. That's when we had the words over this coming home. So, I told her that Dr (name) had already planned to have an updated assessment of her dementia and after talking to her for a while; she realized that Dr (name) was her boss. So then, she changed her mind about continuing the conversation. She called me the next day, and said they're planning to put her into residuary hospital.

In this next case, a poor discharge plan was avoided as a result of the CG's knowledge of the health care system and their advocacy on behalf of the PWD. The CG identifies that the discharge plan is incomplete. Despite the patient being in the hospital for an additional week, the PWD and CG did not receive discharge instructions.

INTERVIEWER: Did you feel the staff answered your questions, did they support you, did they include you in discussion about his treatment or treatment plans?

CG 2025: I actually had to go and say, 'I want to talk to a doctor', and was based on deciding they were going to release him. He was on oxygen. He actually had a catheter in at that time. They had never told me anything about the fact they were going to release him and I came one day and they said they were going to release him, and I said, 'what about the oxygen? What about this?' and he said, 'No, don't you have oxygen at home?', and I said, 'No..', so they did reverse that decision and decided to keep him and then the next week when they released him, when I came to get, they did tell me they were going to release him but they said he doesn't need oxygen anymore. So when I went to get him, he was in the wheelchair at the desk, and I said, 'Can I talk to the doctor, like what about his medication,' and she said, the girl at the desk said, you can talk to, it was an intern, and he said to me, 'everything's in the bag for him'. That's what he said.

4.3.6.2 Post-acute care environment

The post-acute care environment includes all events that occur in a different health care setting (e.g. rehabilitation center) after the acute care hospitalization discharge. It includes care provision and the staffing ratio in this new environment.

In the post-acute care environment, a different focus is highlighted. The CG contrasts the increased focus on geriatrics and rehabilitation compared to that seen in acute care. They also describe better communication, better knowledge of the patients and a more rapid response to attend to patient concerns. Post-acute care can be perceived as a more inclusive care area for this group.

INTERVIEWER: And over at the Rehab Facility A, because it's more geared towards geriatrics and rehab, is the type of kind of communication with you better?

CG 2025: Very much better, very much better. When I go in and they, they know I usually come in around 4:30 or so and when I come in, I have to walk right past the nursing station and they will say, "he had a very bad night last night" or you know, or whatever.

CG 2025: The staff were good with him, they were immediately, we rang a bell for something. They were there, they're a small unit so the most they had on their unit was 11 people and when, everybody had a buzzer on their chairs or even their beds and you didn't wait like you did in the Acute Hospital A when somebody buzzed, half an hour later it was still buzzing. They were there like instantly, which I believe was beneficial in his improving and he really did. He really did improve.

4.3.6.3 Care continuity and coordination

Care continuity and coordination was defined as a logical sequence of coherent, uninterrupted, connected care. It relates to the level with which services are provided in an integrated, coordinated fashion and through which information is shared among providers. It also refers to the deliberate organization of patient care activities between two or more people in order to facilitate the appropriate delivery of health care services.

The perceived lack of continuity of care causes frustration as expressed by the CG in this next example. The participant highlights how a lack of continuity makes it difficult for the nurses to get to know their patients. The system does not offer appropriate scheduling which would allow nurses the opportunity to get to know their patients. This time constraint results in a reduced level of understanding of patient's situation, including sufficient knowledge about their medical conditions and their progress. It can also be a barrier to knowing each patient's abilities and prevents the establishment of an individualized care approach. These issues are illustrated in this next example from a CG who has a health care background.

INTERVIEWER: Um, so, my next question, what kind of help did you expect to receive but you didn't receive?

CG 1010: Well I expected her to receive some form of continuity of care and it seems like that isn't there anymore. When I worked on the floors like that, we were working 5 days. We generally worked with the same patients for 5 days. If they were there, so we could help them in a continual way and see that they were progressing because if you're being there for 5 days, you could tell the difference from Monday to Tuesday and Monday to Wednesday. Um, the level of pain, the level of comprehension of the person, how much they move, how much they eat and you could maybe work on some social stuff. You could sit down and talk to them, spend a bit of time with them. But it seems to be on that unit, I know particularly of one situation where there was a nurse that was on, and she had her for one day, and she was really good with her. And then the next day came on, and she was working, but she was assigned different patients. And

then I went in for the next 3, 4, days and the same nurse was there but she was with different patients and I thought oh, this is so sad.

In the following quote, there is evidence of frustration as a result of poor care coordination and a lack of care that is dementia sensitive. A participant describes an inter-hospital transfer that was arranged for investigative purposes. In this case, the CGs were unaware of the transfer. Because the PWD was transferred unaccompanied, she was unable to provide a good history, leading to a lack of understanding of the situation. This confusion led to an episode of incontinence. This lack of care coordination impacts everyone involved in the care, but especially impacts a PWD who relies on coordination and good communication to ensure care continuity. The absence of care continuity can lead to errors and frustration.

CG 2035: Like the doctor was there every day and we didn't even, she even went for a CT scan on her own and was pretty scared.

INTERVIEWER: Did she have to leave City A to do that?

CG 2035: Yes she had to go to the City B and she was very very confused.

INTERVIEWER: So they took her by ground ambulance or the inter-hospital?

CG 2035: Yeah and my sister was very very upset, because my sister kind of handles her medication and all that stuff and she was very, really kind of lost it on the nurses. She can't go alone anywhere!

INTERVIEWER: And then they would have left her on her own and then someone would have come and picked her up?

CG 2035: Yup and then she ended up having an accident and she sat in there and laid in there. My mom was very embarrassed she cried a lot that night.

4.3.7 Category: General Opinion/Recollection

The category "general opinion/recollection" is defined as the general opinion and comments from the PWD and CG regarding the hospitalization experience as a whole. These comments are general and not specific to one interaction or care encounter. This category

includes codes related to the CG's general opinion about hospitalization and the PWD's recollection about the hospitalization.

4.3.7.1 Caregiver's general opinion about hospitalization

The CG's general opinion about hospitalization was defined as a view or judgment formed about the entire hospitalization process as a whole. It includes general answers to the question: "Was this a good experience? Did the care meet your expectations?" An interesting observation was that all of the negative responses started with a sentence like: "Yes, the care met my expectations..." which was then followed by paragraphs of negative experiences and complaints.

In the next example, the CG reported general disappointment in the health care system as a result of what she determined was due to a lack of resources related to budget cuts.

CG 1010: What I have learned is that I'm disappointed in the health care system. Um, within the acute facility, like on a surgical unit like this, I see how things have changed from years ago and it's not for the better, not for the better of the patient, and I don't see how it can be for the better of the staff. And um, I'm disappointed in the resources that they don't have, you know, cutbacks here, cutbacks there.

The majority of comments were positive, with CGs acknowledging that the services and care they received was good.

CG 1001: She has been well looked after

INTERVIEWER: Did you receive good care?

CG 2012: Yes.

INTERVIEWER: Did it meet your expectations?

CG 2012: Yes.

INTERVIEWER: Is there any concerns or things that you would like to see change?

CG 2012: No, not at this time. It was very good.

INTERVIEWER: But you were satisfied with the hospital service?

CG 1001: The hospital service was super, was good.

INTERVIEWER: Okay, is there any services that you expect to receive but didn't get?

CG 1001: Nothing, no. She got good service and there was nothing to complain about.

INTERVIEWER: And did you receive good care? Did you feel comfortable?

CG2019: Um, yea. Um... as comfortable as anybody feels when they have an older person in the hospital.

CG 2019: Yea, I mean, overall, I was very pleased with the care. But you know, I don't think, you can't leave a person alone in the hospital, quite frankly.

This CG is very reserved when delivering this comment regarding her trust in the care system. The comments imply that the hospital is not necessarily a safe place for the elderly, and even less so for a PWD.

4.3.7.2 People with dementia's recollection about hospitalization – Telling their stories

This code describes the PWD's recollection of their acute hospitalization experience. Despite the interview taking place only a few weeks after the hospital stay, the recall of the events is poor.

INTERVIEWER: (...) In December, you were taken to the hospital, and do you remember why you were taken to the hospital?

PWD 2019: In December, I was taken to the hospital.

INTERVIEWER: You had some problem with your heart?

PWD 2019: Um, um, sort of...

INTERVIEWER: Hazy?

PWD 2019: Fuzzy.

INTERVIEWER: Okay, do you remember being in the hospital?

PWD 2019: Yea, I think so. Not too much.

INTERVIEWER: Not too many of the details about it?

PWD 2019: No.

INTERVIEWER: So there's nothing, you don't feel any negative thoughts about being in the hospital?

PWD 2019: No, none at all.

INTERVIEWER: Okay, and um I'm gonna ask your daughter how your treatment went when you were in the hospital, but the whole hospital experience... nothing about it that, that stands out?

PWD 2019: No, no, pretty good.

CHAPTER 5: DISCUSSION

The codes and categories represent the hospitalization experience in a chronological perspective. The first code is triggers to hospitalization, which includes pre-hospitalization facilitators and entry to hospital, including the emergency department experience. The in-hospital experience is captured by the in-hospital cognitive and medical trajectories codes, including environmental factors that may affect this trajectory. Throughout the hospital stay, communication between physicians, CGs and PWD was discussed. Satisfaction with health care professionals including nurses, physicians and other health care professionals were also noted. The data was then summarized in terms of discharge planning and entry into the post-acute care environment. Care continuity and coordination tied the process together. The overall impressions of the PWD and CGs were captured through their general comments about the hospitalization process as well as through the PWD's recollection of their experience.

The objective of this study was to focus on the experiences of PWD and their CGs during acute hospitalization. The discussion of the results will be broken down into four parts as a function of the research questions. First, a brief outline of the typical chronology of events of the acute hospitalization process will be discussed. Second, there will be a discussion regarding the key themes. This will lead to the third part which will focus on barriers and facilitators. Lastly, the results will be discussed using the concepts of the Person Centered Care for dementia framework.

The 29 participants who took part in this study were quite representative of the target population in terms of age and sex for both the PWD and the CGs. Elements of the sample population that may not have been representative include the level of education with 43% of the PWD having completed a high school education and 37% having attended post-secondary education. This would be considered slightly higher than what is seen in the general population of seniors. Turcotte and Schellenberg (2007) reported that about 47-52% of seniors have less

than a high school education. It is not unreasonable to question whether this might not have had an effect on participants' expectations of the quality of the health care provision.

5.1 The chronology of the transition through hospitalization

The acute care hospital transition and chronology of events was similar for all PWD and the CGs that were interviewed, despite the fact that they were recruited from different clinics in different cities. Beginning with the events that led to hospitalization, it was often reported by the PWD that there was a delay in symptom recognition, which led to a delay in seeking medical attention, resulting in subsequent acute and urgent need to hospitalize. In other instances, there was no delay in seeking medical attention due to an acute event, which is most often due to a fall (Donnelly, McElhaney & Carr, 2011). Admission to hospital increased CG burden, stress and depressive symptoms. Caregiving for a hospitalized PWD was also found to be an independent predictor of depression severity in Epsetin-Lubow et al.'s (2012) study. The distress of the CGs was evident in this study, although depression was not explicitly verbalized in this project. Participants reported the emergency room stay as an overall disastrous experience due to significant wait times, lack of communication, and lack of dementia recognition by staff. These experiences were also reported in the literature by Clevenger, Chu, Yang & Hepburn (2012) and Jurgens et al. (2012), suggesting a lack of dementia care guidelines to direct care in emergency departments. Following admission, the in-hospital stay was also reported as challenging due to lack of communication with health care staff, which was facilitated at times by roommates who provided medical information to CGs and supported the PWD. The in-hospital transition was further perceived as challenging as a result of a general lack of communication among and with health care professionals. Towards the end of the hospital stay, discharge planning was often described as absent, with inadequate preparation for discharge, and a lack of CG involvement. Fitzgerald, Bauer, Koch & King (2011) also reported poor coordination of discharge and poor engagement with family. In this study, CGs reported

that post-acute care discharge destinations offered superior care to the acute care setting. This finding was surprising given that the CGs reported that the PWD's functional status post-discharge from acute care was often worse than pre-admission; this contradiction is confirmed by previous literature (Devere, 2012; Fong et al., 2012; Sampson, Leurent, Blanchard, Jones & King, 2013).

5.2 Main themes

Throughout the acute hospitalization process, from admission to the in-hospital trajectory and eventual discharge, three important themes were present. The first related to the important role of the CG, the second is related to communication, and the third focuses on the general obstacles for the PWD created by the acute care hospital processes and environment.

The importance of CGs prior to and throughout the hospitalization process until discharge was a very prominent theme. Caregivers were the ones who provided assistance in seeking appropriate care. Their early recognition of symptoms was essential in initiating medical care, especially since PWD were often unable to recognize signs of their own illness and need for care. This advocacy on behalf of the PWD was crucial upon arrival at the emergency department. Their presence was reassuring for the PWD who had difficulty adjusting to this new, busy and noisy environment. The CG played an essential role in communicating and connecting with health care personnel. The transcripts suggest that the presence of the CGs decreased the PWD's agitation and disorientation during medical procedures. During the in-hospital stay, the CG's role as advocates ensured that the care needs of the PWD were identified and that, although not always successful, they ensured that the lines of communication with the health care team were open. At the time of discharge, the CGs wanted to be included in the planning process and also insisted they receive appropriate care instructions to reduce complications post-discharge. Despite their importance in every step of the hospitalization process, CGs were rarely included in the care plan, and were frequently forgotten or pushed

aside by care staff. This finding has also been reported in other qualitative studies that conducted semi-structured interviews with CGs of a PWD. Bauer, Fitzgerald & Koch, (2011) found similar themes such as failure of the care team to address the family's needs, as well as poor engagement with the family. Using focus groups, Donnelly et al. (2011) and Bauer et al. (2011) noted the importance of involving CGs in the care process.

Another important issue that was noted in this analysis is the added burden of acute hospitalization on the CG. It was evident from the transcripts that the pre-existing constant care provided by CGs was exacerbated at the time of admission with the onset of acute illness. This stress was compounded by the fear of possible consequences as a result of a change in environment, as well as the additional time commitment required to be a good advocate. Once admitted to hospital, there was fear of leaving the PWD alone. Caregivers alleviated this fear by ensuring constant supervision of the PWD. Jurgens et al. (2012) also reported that CGs perceived hospitalization as a stressful time as they attempted to adapt to a new routine. In some cases, CGs were even prevented to provide care, a finding not found in the current analysis. In this current study, CG burden did not appear to be recognized nor was it addressed in terms of support. This obstacle was even more pronounced for CGs who were elderly themselves, such as in the case of a PWD's spouse. Schultz and Martire (2004) report specifically on elderly CGs and on differences which may be particular to this population. As time spent in hospital increased, so did the fear experienced by the CGs for their loved ones. Our findings suggest that CGs felt they were expected to ensure supervision and safety of the PWD. It is also possible that the CG expected this of themselves as a means of alleviating their fear. On the other hand, this group of CGs was more appreciative of information shared by the health care team but were more hesitant to ask for information compared to younger CGs. The CGs reported a general sense of unease and fear of becoming a disruption for care by being "in the way" with a necessity to have their "independent" image preserved. Moreover, they were also very keen on providing key information about the PWD to the health care team and felt

valued when asked for their input. Discharge was even more difficult on the CG due to their fear of speaking up on their view of the care needs in addition to their own often frail health status. This made care provision to their loved one even more challenging. These concerns added to the challenges of caring for their spouse who had dementia. Nevertheless, CGs who were more affirmative in advocating for better discharge plans found it easier to access services and prevent inappropriate and unsafe care plans. The more solid and stronger advocates were frequently the child CG, or the CG with a health care background, rather than a CG who was an elderly spouse. Since nearly half of the CGs in this study were elderly spouses, their hospital experience as a whole seemed more stressful compared to the younger CGs.

The second important theme was communication. This theme was evident in all codes and categories and had a significant influence on the entire experience, from pre-hospital until discharge. The term “communication” refers to communication between health care professionals, communication with CG and family, and communication with PWD. The communication between the CG, family, PWD and health provider has been named the communication triad by Adams & Gardiner (2005). Cognitive changes associated with dementia affects the processes involved in perceiving, understanding, and responding to verbal and nonverbal information, thereby impairing communication, and consequently, interactions with others (Miller et al., 2009). Accordingly, health care professionals must be flexible in their communication techniques with PWD – an element that was not reported in our sample. Upon arrival to hospital, PWD were asked to provide a complete medical history, define symptoms (e.g. pain) and consent to medical investigations that most were unable to understand. During admission, PWD were provided with confusing medical information yet were expected to make independent decisions using the information given. This issue was noted as dangerous by CGs at the time of discharge, because CGs were often unaware of the discharge plan and the care needs that were required for the transition home. The communication was limited to the PWD – health care team dyad, highlighting the difficulties the CGs had to communicate with health care

professionals, as reported in the Jurgens et al. (2012) study. Failure to communicate with CGs can cause a great deal of unnecessary distress, and prevents the opportunity for the health care team to learn more about the PWD.

Another barrier to a good hospital experience that was identified in this study was the absence of communication between the health care team members, as well as the poor transfer of care information to the subsequent care provider. This issue may have had a negative impact on continuity of care, which is essential to quality of care provision and patient experience (Naylor & Keating, 2008). Continuity is also essential for integration, coordination and the sharing of information between health care providers (Gulliford, Naithani & Morgan, 2006). This lack of communication and faulty continuity of care led to unsatisfying experiences, lowered expectations and potentially unsafe decision-making. Kmietowicz (2009) commented that the communication triad is essential to better continuity of care, especially with regards to interprofessional communication.

Though the study did not specifically examine the health care professionals' communication styles or pre-conceived thoughts about PWD, it is not unlikely that ageism may have played a role in their approach to patients with dementia. Negative attitudes regarding older adults persist in our society and in the medical community (Institute of Medicine, 2008). It is possible that health care professionals' pre-existing age stereotypes and stereotypes about PWD may have led them to reinforce dependence. An ageist approach of disregard and lack of recognition would not be conducive to patient-centred care. These attitudes toward PWD could explain the suboptimal care provided in this study (Mellor, Chew & Greenhill, 2007).

The third theme reflects how the processes and environment of acute care hospitals are not an ideal place for PWD. Other studies have reported suboptimal care for PWD while in an acute care environment (Clissett et al., 2013a; Cowdell, 2010; Jurgens et al., 2012). The hospital processes were perceived as disruptive and the environment was perceived as unfit to manage PWD's distressed behaviours by Clissett (2013a). The interaction with staff in this group was

dominated by the delivery of essential routine physical care with absence of individualized care. Communication was minimal, adding to the PWD's uncertainty about their plans for the future. The emergency department environment was especially chaotic, slow, exhausting and uncomfortable for PWD and their CGs (Clissett, 2013a). The CGs' expectations about dignity, physical comfort, ensuring privacy, identity and safety were not met because the hospital did not have systems in place to manage PWD (Jurgens et al., 2012). These findings from previous literature were supported by the current study. It is evident that the layout and processes of various departments (e.g. emergency department, hospital wards, radiology department) in an acute care hospital have been developed to care for the general adult population and not necessarily the elderly or PWD. The participants in the current study noticed many obstacles in the acute care setting. First, the emergency department process was impersonal, fast-paced, had poorly designed physical environments, and staff lacked the ability to recognize symptoms of dementia. Clevenger et al. (2012) also reported a lack of dementia recognition by health care professionals in the acute care hospitals. This problem raises a system-level issue regarding the knowledge of health care professionals regarding dementia care. The lack of recognition was also reported by Hustley, Meldon, Smith & Lex (2003), who found that emergency physicians recognized impaired mental status in only 38% of patients who screened positive for cognitive impairment (Hustley, et al, 2003).

The emergency room waiting times significantly impacted the CGs and especially the PWD due to their cognitive deterioration. In the time leading up to admission, PWD may become more difficult to manage because of disorientation, challenging behaviours, and reduced function with co-existing delirium. The impact that the disease has on their ability to understand the reason for their hospitalization creates issues for appropriate care. The disorientation that results from the foreign, busy, and noisy environment, in combination with their memory deficits, and the requirement of constant repetition and redirection, all have the

potential to agitate and destabilize an already fragile patient. All these negative experiences were experienced by PWD and CGs in this study.

During their hospital stay, additional system-level issues contributed to inappropriate or suboptimal care for PWD. Similar to the experience with the emergency room personnel, a lack of dementia recognition by the health care personnel was reported, suggesting a lack of education for overall dementia care. These concerns were also reported in previous literature (Donnelly et al., 2011; Fessey, 2007; Lin, Hsieh, & Lin, 2012). In the current study, the acute care hospital environment was described as over-stimulating, cluttered, noisy and overcrowded. The rooms were described as confusing, without easy access to washrooms, without windows and did not have enough space for family members. Geriatric (including cognitive) assessments were rarely done for measures of mobility, continence, nutrition, fall prevention, polypharmacy, function and behaviour. Delirium recognition and management was also missing. There were precipitous discharges without discussion about care needs, as well as a lack of continuity of care with community services to prevent re-admissions. These findings were also reported in the literature (Bauer et al. 2011; Fitzgerald et al., 2011; Naylor, Hirschman, Bowles, Bixty, Konick-McMahan & Stephens, 2007).

These three themes (caregivers, communication and hospital environment) are consistent with themes that Douglas-Dunbar & Gardiner (2007) found in their study that examined care areas that required improvement. These themes were: communication, nurses' understanding of dementia and how to care for PWD, and the long-term effects of being in hospital. In their study, care providers felt that communication was poor in both directions (CGs - health professionals), which was also observed in the current study. Hospitalization significantly impacted CGs, as evidenced by feelings of vulnerability and disempowerment in the hospital setting. Caregivers also felt the need to stay with the PWD to provide a voice for them and assure their needs were met (Douglas-Dunbar & Gardiner, 2007), which is a finding that was replicated in this study as well.

5.3 Meeting the needs and expectations

Participants were asked if the hospital stay met their needs and expectations. In order to interpret this information, it was important to compare participant satisfaction to their expectations. Participants responded overwhelmingly with the answer that their needs were met. Surprisingly, their initial affirmative answers were followed by numerous examples of negative experiences. Though the reasons for this observed phenomenon were not explored with participants, some hypothesis can be made about this occurred. First, it is not unreasonable to suppose that the CGs wanted to avoid displeasing and being too critical of the care received because of the perceived hierarchy between the interviewer and/or the social stature of health care professionals. There may have been a fear of deception, of being judged and a fear of jeopardizing future care encounters with the health care system. Second, as the interviews took place after discharge from hospital, the general experience may have been perceived as “positive” as the desired outcome of being out of hospital was attained.

Despite this overwhelmingly affirmative answer, their interviews were filled with evidence of many unmet needs and expectations. One of the unmet expectations was to have continuity of care. There was an expectation that health care professionals would know their patients well and care for them in a personalized fashion. It was also expected that CGs would be included in the care plans in order to ensure continuity of care from the home, to the emergency room, to the in-patient wards, to discharge planning and post-discharge. Caregivers expected to be involved in the communication of important personal and medical information about the PWD, as well as assist with decision-making. This did not occur. When CGs were able to provide valuable health related information, it was often futile due to the breakdown in the flow of communication between health providers and other care areas.

Despite these challenges, some facilitators can be identified in the CGs' need to access information and to better communicate with the health care team. An interesting finding in the current project was the benefit of sharing a room with other patients. Caregivers received assistance from the PWD's roommates, especially in terms of sharing information about medical care and the functioning of the PWD. An observant roommate helped the CGs and partially compensated for the lack of communication by the nurses and physicians. The roommate was able to provide details of events as well as nursing and medical reports to the CG. They were also able to provide a form of supervision for the PWD while the CG was away. This assistance decreased the worry the CG had about leaving their loved ones unsupervised. No evidence of this finding has been found in the literature.

Contrary to popular belief, a private room was deemed by the CG as a barrier to care. Caregivers believed it created more confusion, more anxiety and more stress for the PWD. Isolation could predispose the PWD to fewer interactions with staff and patients, leading to social isolation, decreased mobilization and potentially functional decline.

Study participants also noted expectations that the health care team would have basic knowledge about dementia and dementia care. Results showed that CGs perceived that the health care staff's knowledge about dementia was minimal and was considered a barrier to care. The failure to recognize dementia led to difficulties identifying delirium – a condition that frequently occurs in this population. Care was suboptimal because lack of recognition resulted in absent or inadequate treatment. The importance of maintaining the PWDs functional status while in hospital (e.g. continence, mobility, nutrition) was not a priority for health care staff, which unfortunately led to a functional decline by the time of discharge.

On the other hand, a multidisciplinary approach to care was found to be very helpful in addressing the multiple needs of both PWD and CG. Good communication regarding the explanation of care goals upon admission to a care unit, as well as identifying individual needs was considered very beneficial to CGs. Good communication was most evident in post-acute

care units (e.g. geriatrics and rehabilitation units) where the focus was geared towards a holistic approach to caring for the elderly.

Lastly, the advocacy provided by the CGs on the behalf of the PWD was invaluable to the hospital stay and made a positive impact on the care received. Assertive CGs appeared to be able to access more information. These CGs were also able to access more services and even prevent inappropriate, poorly planned discharges from hospital. Caregivers with a health care background were even more resolute as they had more knowledge of the system and were aware of how to successfully navigate the system. They were aware of standards of care, and they expected optimal care. They knew the skills and knowledge to care for a PWD, and they were more skilled at identifying care gaps. They were also better able to interpret medical information and transmit important information to the health care team. Unfortunately, not many CGs in this sample had these characteristics, as half of the CGs were elderly themselves and did not have a health care background.

5.4 Person-centred care

In this last section of the discussion, the results will be interpreted as a function of Person Centred Care (PCC) principles. From the participants' reports, it is possible to identify areas of application of the PCC principles and some areas where improvements are needed. Unfortunately, the information provided during the interviews reported on areas of care that would not be considered person centered care for PWD.

Throughout the hospital stay, it was difficult to identify if personhood was maintained regardless of the cognitive impairment. Gaining an understanding of an individual's values base is central to PCC. Yet, in the transcripts, there was no mention of an individualized approach, as participants did not perceive any attempts by health care professionals to promote identity and value uniqueness of the PWD. The care was perceived to be as per "usual protocol", and not

specifically adapted to PWD. This finding was most striking upon arrival to the emergency department when PWD were triaged in the same manner as other patients. The PWD was not given special attention to their underlying cognitive impairment and often, their impairment was not recognized. This lack of individualized approach to care led to more confusion and agitation and was compounded by long wait times. The CGs were not included in the decision-making, and were not provided the opportunity to share valuable information about the PWD (e.g. preferences, values, beliefs, and behaviour issues) which could have facilitated the provision of PCC. Consequently, PWD were treated similarly to other patients during their in-hospital stay. Their strengths were not taken into account (e.g. if they were able to feed themselves and walk independently) nor were their disabilities (e.g. their ability to retain medical information and make significant decisions about care). The PWD and CGs' views and wishes were not heard because they were not verbalized to the appropriate care team members, they were not verbalized at all, or because they were simply not heard or acknowledged.

We did however have one report of a PCC approach that took place upon admission to a transitional care area. In this case, the health care team met with the PWD and the CG to provide them with information about the unit that they were transferred to, and they took the time to get to know the PWD and their family in order to ensure that the goals of care would be met. This was an area of care that was perceived as person-centred as it valued the person as an individual and included the CG in the process. Unfortunately, this case was an exception, and it was not experienced in an acute care setting.

In general, the care provided was task-oriented. It was not perceived as moving beyond a focus of technical competence, because the priorities were to do procedures and investigations and discharge patients quickly. There were no reports of engagement in authentic caring practices that embrace the patient and their family; thus there was no opportunity for the PWD and their CGs to make their own choices or feel that they were partners in the decision-making process. This decision-making process often took place in isolation,

without the involvement of the PWD or the CG, and it was especially prevalent in discharge planning. This problem raises issues about the absence of PCC approaches in acute care, and potential safety hazards as a result of the gaps in care. Proper discharge planning processes are considered evidence-based interventions to improve outcomes (Bauer, Fitzgerald, Haesler & Manfrin, 2009). Poor discharge planning, as reported by the participants, put the PWD and the family members at risk of poor outcomes.

Even within the environment itself, the acute care hospital was not considered an environment in which to experience relative well-being. Since the health care professionals did not always have all the appropriate information about the PWD, it was difficult for them to adapt the environment to make it more suitable for the PWD. There is a need for an enriched environment that compensates for the PWDs impairments and fosters opportunities for personal growth. Participants did not report this. The emergency room was the environment most frequently reported by participants as a negative environment due to excessive noise, long wait times and anxiety-provoking medical procedures.

One of the most frequently reported experiences was lack of communication between health care professionals, which is problematic because a previous study (Hickman et al. 2007) suggested that communication is of prime importance for continuity of care. Communication also plays a central role in PCC. History taking, which requires communication, is one of the key activities for appropriate care provision. Collecting histories from the PWD without the CG's involvement can lead to errors with inappropriate care decisions, which are based on incomplete information and data. PCC, as applied to PWD, should preferably be seen as including the CG.

Unfortunately, information about the philosophy of care and dementia initiatives of each hospital involved in this project was not collected. This information would have been useful in attempting to link the different care experiences. After analyzing the information collected from CGs and PWD, there was no mention of a holistic approach to health care. Relationships between PWD, CGs and health care personnel were often not based on trust. There was only

one instance where specialist care (e.g. geriatric medicine) was involved in order to assist with patient care, despite the overwhelming evidence of the positive impact it has on patient outcomes (Ellis, Whitehead, O'Neil, Langhorne & Robinson, 2011).

As person-centred care has been found to be important for care of all patients, it has taken a more dominant role in the dementia literature. Guided by the principles that encourage health care professionals to get to know their patients well, provide care that is specific to their needs and promote and facilitate CG involvement in decision-making, it is clear that the consequences of not doing so is disastrous to the population with dementia. Because of the cognitive fragility and ensuing confusion, not providing patient-centred care for PWD and their families can lead to medical complications like delirium, prolonged hospitalization, cognitive and functional decline, behavioural disturbances and increased caregiver burden. Evidence shows that person-centred care practices can make a positive difference to health outcomes and patient satisfaction and can also improve health care workers' sense of professional worth (Dow, Haralambous, Bremner & Fearn, 2006). Adapting the PCC model to the unique population of PWD becomes even more important when they are admitted to an acute care hospital, as they face considerable physical and psychological stressors superimposed on their underlying fragility. This complexity can lead to a higher risk of numerous complications that could be avoided with the use of PCC (Edvardsson & Nay, 2009).

CHAPTER 6: LIMITATIONS

While rich in data, there are some limitations of this study that are worth mentioning. First, since the larger research project from which the current data was extracted was not originally designed as a qualitative project, the semi-structured interviews conducted have less depth. It is only a posteriori that it was clear that some of the data was rich with information about their experiences and could be analyzed qualitatively. The participants were likely influenced to be very open and divulge a wealth of information about their experiences by the trusting relationship that was established with monthly telephone contacts between the interviewer and the interviewee over the two year study. The nature of this project, which required participants to recall events, leads to the possibility of a second limitation known as recall bias. In order to optimize accurate recall of the event, all interviews were conducted within one month of hospitalization. However, had each event been recorded as it was unfolding, we would have more robust and valid information to analyze. A third limitation of the study was that objective information such as administrative data related to admission to hospital, diagnosis, length of stay, course in hospital and hospital care initiatives were not collected. Other than the demographic information that was collected about the participants, only subjective information was collected which pertains to the participants' perceptions of their experiences in an acute care hospital setting. Regardless, the perceptions are examples of real experiences to the interviewees, and it is evident that these experiences were not limited to only one case, suggesting that perhaps these experiences are very common in the acute care setting. Lastly, despite the presence of a reasonable number of total participants, there were fewer dyads (only four). This limited the interpretation of the PWD experience and would have been better captured through a prospective study.

CHAPTER 7: CONCLUSION

This study discusses the experiences of CGs and PWDs during their stay at an acute care hospital. Their reports support findings made in prior research that state that the acute care hospital is not adapted to care for PWD. From their reports, it is evident that the care that was received is not considered to be person-centred. Participants described their experiences in the acute care setting as negative, and they felt that they experienced many challenges and even felt deceived at times. Positive experiences were the exception. Most of these positive experiences occurred in post-acute care settings where the care philosophy is different. In those environments, they operate at a slower pace and have a focus on geriatrics and rehabilitation.

It is possible that the negative care experiences are generated by acute care philosophies that are not adapted to PWD. It may also be possible that person-centred care models are not put in place in these fast-paced care centers. Our findings also suggest that a lack of knowledge about dementia in the acute care setting results in the inability to recognize symptoms of dementia. Failure to recognize these signs can mean that an adapted model for acute dementia care will not be initiated, resulting in inappropriate patient care as well as dissatisfaction on behalf of the PWD and CG.

It is not a surprise that the population is aging; this increase in age is matched by the exponential increase in the number of PWD. It is unsettling to know that even though this problem exists, the acute care setting is unable to provide appropriate care to this population. It is imperative that the health care system develops strategies to bridge the gaps that are highlighted in this analysis. The findings of this project could influence the development of further initiatives for care improvement. Specific initiatives for acute hospital care improvement should first target educational initiatives directed at health care workers to improve their knowledge about dementia, recognition of the signs and symptoms as well as its potential impact on the person and their families. By increasing this knowledge, recognition should be easier upon admission, leading to a better alignment of care provision, influenced by PCC

principles. A more direct initiative that could be instituted would be early identification of PWD in acute care as they enter the system – in the emergency department. Once rapid identification had occurred, special care teams with geriatric expertise could be mobilized to assist with care and leadership in educating others to achieve better outcomes including better care experiences. Likewise, a similar knowledge translation initiative should occur at the higher hospital administrative level. This would be in their best interest since a large proportion of the acute care hospital's population is comprised of PWD (Department of Health, 2001; Silverstein and Maslow, 2006). This would hopefully lead to support for policy and organizational changes that need to occur to better align with PCC philosophies.

Additional studies in this area could correlate care practices with quantitative outcomes such as length of stay, re-admission, diagnosis, co-morbid conditions, and in-hospital complications. A detailed economic analysis would also be extremely beneficial in terms of determining improved outcomes and the costs associated with PCC.

As a health care professional who works in acute care with PWD and CGs, the findings did not come as a surprise. Unfortunately, the examples given by participants are seen in daily practice. The net result of this analysis suggests that the experiences of PWD and their CGs in acute care hospitals are mostly negative and that the care given is not person-centred. It is imperative that health care professionals be better equipped to care for this population because their actions have a significant impact on each PWD and CG. Intervention studies are required to prove the benefits of PCC care strategies. In order to develop care philosophies that promote person centred care, it is imperative that recognition of this issue occurs at the organizational level as well. This will ensure that health care professionals will adopt this care philosophy, which will ultimately create a change for the better in care provision.

CHAPTER 8: REFERENCES

Adams, T. & Gardiner, P. (2005). Communication and interaction within dementia care triads:

Developing a theory for relationship-centred care. *Dementia*, 4(2), 185-205.

Alzheimer's Australia. (2004). Dementia care and the built environment. Position paper 3.

Canberra: Alzheimer's Australia.

Alzheimer's Society of Canada. (2012). A new way of looking at the impact of dementia in

Canada, September 27, Toronto, Ontario.

Alzheimer's Society of Ontario. (2012). Dementia evidence brief; Central West Local Health

Integration Network, July 2012.

Alzheimer Society of Canada, (2010). *Rising Tide: The Impact of Dementia on Canadian*

Society, Toronto, Ontario.

Alzheimer's Society (2009). "Counting the cost: caring for people with dementia on hospital

wards", Alzheimer's Society, London, UK. Retrieved from

http://alzheimers.org.uk/site/scripts/download_info.php?fileID1/4787

Almberg, B., Jansson, W., Grafstrom, M., Winblad, B. (1998). Differences between and within

genders in caregiving strain a comparison between caregivers of demented and non-

caregivers of non-demented elderly people. *Journal of Advanced Nursing*, 28(4), 849-58.

- Andrieu, S., Reynish, E., Nourhashemi, F., Shakespeare, A., Moulias, S., Ousset, P.J., ...
Vellas, B. (2002). Predictive factors of acute hospitalization in 134 patients with Alzheimer's disease: A one year prospective study. *International Journal of Geriatric Psychiatry*, 17(5), 422-426.
- Archibald C. (2003). *People with Dementia in Acute Hospitals*. Sterling: Dementia Services Development Centre.
- Balardy, L., Voisin, T., Cantet, C. & Vellas, B. (2005). Predictive factors of emergency hospitalization in Alzheimer's patients: results of one-year follow-up in the REAL FR Cohort. *Journal of Nutrition Health Aging*, 9(2),112-116.
- Bauer, M., Fitzgerald, L., Haesler, E., Manfrin, M. (2009). Hospital discharge for frail older adults and their family. Are we delivering best practice? A review of the literature. *Journal of Clinical Nursing*, 18(18), 2539-46.
- Bauer, M., Fitzgerald & Koch, S. (2011). Hospital discharge as Experienced by Family Carers of People with Dementia: A Case for Quality Improvement. *Journal for Healthcare Quality*, 33 (6), 9-16.
- Beeri, M.S., Wener, P., Davidson, M.& Noy, S. (2002). The cost of behavioral and psychological symptoms of dementia in community dwelling Alzheimer's disease patients. *International Journal of Geriatric Psychiatry*, 17, 403-408.
- Blennow, K., de Leon, MJ. & Zetterberg, H. (2006). Alzheimer's Disease, *Lancet*, 368, 387-403.

Borbasi, S., Jones, J., Lockwood, C. & Emden, C. (2006). Health Professionals' perspectives of providing care to people with dementia in the acute setting: Toward better practice. *Geriatric Nursing*, 27 (5), 300-8.

Boyd, C.M., Landefeld, C.S., Counsell, S.R., Palmer, R.M., Fortinsky, R.H., Kresevic, D., Burant, C & Covinsky, K.E. (2008). Recovery of Activities of Daily Living in Older Adults After Hospitalization for Acute Medical Illness. *Journal of American Geriatric Society*, 56, 2171-79.

Bradley, J. (1993). Methodological issues and practices in qualitative research. *Library Quarterly*, 63(4), 431-449.

Brody, H. & Donkin, M. (2009). Family Caregiver of People with Dementia. *Dialogues Clin Neuroscience*, 11(2), 217-228.

Brooker, D. (2004). What is person centred care in dementia? *Reviews in Clinical Gerontology*, 13, 215-222.

Bynum, J.P., Rabins, P.V., Weller, W., Niefeld, M., Anderson, G.F. & Wu, A.W. (2004). The Relationship Between a Dementia Diagnosis, Chronic Illness, Medicare Expenditures, and Hospital Use. *Journal of American Geriatrics Society*, (52), 187-194.

Campbell, P., Wright, J., Oyebode, J., Job, D., Crome, P., Bentham, P... Lendon, C. (2008). Determinants of burden in those who care for someone with dementia. *International Journal of Geriatric Psychiatry*, 23(10), 1078-1085.

Cavanagh, S. (1997). Content analysis: concepts, methods and applications. *Nurse Researcher*, 4, 5-16.

Chenoweth, L., King, M., Jeon, Y-H., Brodaty, H, Stein-Parbury, J., Norman, R... Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology*, 8(4), 317-325.

Chief Public Health Officer, (2010). *Report on the State of Public Health Care in Canada*, Ottawa, Ont.

Clevenger, C.K., Chu, T.A., Yang, Z. & Hepburn, K.W. (2012). Clinical Care of Persons with Dementia in the Emergency Department: A Review of the Literature and Agenda for Research, *Journal of American Geriatric Society*, 60(9), 1742-1748.

Clipp, EC. & George, LK. (1993). Dementia and Cancer: A Comparison of Spouse Caregivers. *The Gerontologist*, 33(4), 534-541.

Clissett P., Porock D., Harwood RH., & Gladman J.R.F. (2013a). Experiences of family carers of older people with mental health problems in the acute general hospital: a qualitative study. *Journal of Advanced Nursing*, 69(12), 2707-16. doi: 10.1111/jan.12159.

Clissett, P., Porock, D., Harwood, R.H.& Gladman, J.R.F. (2013b). The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families. *International Journal of Nursing Studies*, 50, 1495-1503.

- Clyburn, L.D., Stones, M.J., Hadjistavropoulos, T. & Tuokko, H. (2000). Predicting caregiver burden and depression in Alzheimer's disease. *Journals of Gerontology Series B*, 55 (1) S2-S13.
- Cohen, CA., Gold, CP., Shulman, DI., Wortley, JT., McDonald, G. & Wargon, M., (1993). Factors determining the decision to institutionalize dementing individuals: a prospective study. *Gerontologist*, 33(6), 714-720.
- Cohen, Z. (2003). The single assessment process: an opportunity for collaboration or a threat to the profession of occupational therapy? *British Journal of Occupational Therapy*, 66(5), 201-7.
- Cowdell, F. (2010). Care of older people with dementia in an acute hospital setting. *Nursing Standard*, 24(23), 42-48.
- Cox, C. (1997). Findings from a statewide program of respite care: a comparison of service users, stoppers and nonusers. *Gerontologist*, 37(4), 511-517.
- Dahlke, S., Phinney, A. (2008). Caring for hospitalized older adults at risk of delirium: the silent unspoken piece of nursing practice. *Journal of Gerontological Nursing*, 34(6); 41-47.
- Day, K., Carreon, D. & Stump, C. (2000). The therapeutic design of environments for people with dementia: a review of the literature. *The Gerontologist*, 40, 397-416.
- Department of Health. (2001). National Service Framework for Older People, The Stationary Office, London.

Department of Health of the United Kingdom (2009). Living well with Dementia: A National Strategy, Department of Health, London.

Devere, R. (2012). Short-and Long-Term Cognitive Consequences of Acute non-neurological Hospitalization. *Practical Neurology*, Jan., 30-35.

Digby R, Bloomer, MJ. (2014). People with dementia and the hospital environment: the view of patients and family carers. *International Journal of Older People Nursing*, 9(1), 34-43.

Digby, R., Moss, C., & Bloomer, M. (2012). Transferring from an acute hospital and settling into a subacute facility: The experience of patients with dementia. *International Journal of Older People Nursing*, 7(1), 57-64.

Donnelly, M., McElhaney, J., Carr, M. (2011). Improving BC's Care for People with Dementia in the Emergency Department and Acute Hospital. Retrieved from <http://www2.gov.bc.ca/assets/gov/topic/AE132538BBF7FAA2EF5129B860EFAA4E/pdf/improvingcaredementiareport2011.pdf>

Douglas-Dunbar, M., & Gardiner, P. (2007). Support for carers of people with dementia during hospital admission. *Nursing Older People*, 19(8), 27-30.

Dow, B., Haralambous, B., Bremner, F. & Fearn, M. (2006). What is person-centred health care? A literature review, Victorian Government Department of Human Services.

Downe-Wamboldt, B. (1992). Content Analysis: Method, applications and issues. *Health Care for Women International*, 13, 313-321.

Draper, B., Karmel, R., Gibson, D., Peut, A., & Anderson, P. (2011). The hospital dementia services project: Age differences in hospital stays for older people with and without dementia. *International Psychogeriatrics*, 23(10), 1649-1658.

Dunkin, JJ., Anderson-Hanley, C. (1998). Dementia caregiving burden: a review of the literature and guidelines for assessment and intervention. *Neurology*, 51 (Suppl.1), S53-S60.

Edvardsson, D., & Nordvall, K. (2008). Lost in the present but confident of the past: Experiences of being in a psycho-geriatric unit as narrated by persons with dementia. *Journal of Clinical Nursing*, 17(4), 491-498.

Edvardsson D, Nay R. (2009). Acute care and older people: challenges and ways forward. *Australian Journal of Advanced Nursing*, 27(2); 63-69.

Edvardsson D, Fetherstonhaugh D, Nay R. (2010). Promoting a continuation of self and normality: person centered care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing*, 19, 2611-2618.

Edvardsson, D., Winblad, B. & Sandman, PO. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7, 362-367.

Ellis, G., Whitehead, MA., O'Neil, D., Langhorne, P., Robinson, D. (2011). Comprehensive Geriatric Assessment for older adults admitted to hospital (Review). *The Cochrane Collaboration*, Issue 7.

- Elo, S. & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1),107-115.
- Epstein-Lubow, G., Gaudiano, B., Darling, E., Hinckley, M., Tremont, G., Kohn, R., ... & Miller, I. W. (2012). Differences in depression severity in family caregivers of hospitalized individuals with dementia and family caregivers of outpatients with dementia. *The American Journal of Geriatric Psychiatry*, 20(9), 815-819.
- Etters, L., Goodall, D., Harrison, B.E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20, 423-428.
- Fessey, V. (2007). Patients who present with dementia: exploring the knowledge of hospital nurses. *Nursing Older People*, 19 (10), 29-33.
- Fick, DM, Kolanowski AM, Waller JL, Inouye SK. (2005). Delirium superimposed on dementia in a community-dwelling managed care population: A 3 year retrospective study of occurrence, costs and utilization. *Journal of Gerontology Series A Biological Sciences and Medical Sciences*, 60, 748-53. (PMID:15983178)
- Filembaum G, Heyman A, Peterson B, Pieper C, Weiman AL. (2000). Frequency and duration of hospitalizations of patients with AD based on Medicare data; CERAD XX, *Neurology*, 54, 740-743.

Fitzgerald, L.R., Bauer, M., Koch, M., King, S.J. (2011). Hospital discharge: recommendations for performance improvement for family carers of people with dementia. *Australian Health Review, 35*, 364-370.

Flatley M, Bridges J. (2008). Promoting the art of caring for older people. *International Journal of Nursing Studies, 45* (3), 333-334.

Fleming, R., Purandare, N. (2010). Long-term care for people with dementia: Environmental design guidelines. *International Psychogeriatrics, 22*(7), 1084-1096.

Fong, T.G., Jones, R.N., Marcantonio, E.R., Tommet, D., Gross, A.L., Habtemariam, D., et. al. (2012). Adverse outcomes after hospitalization and delirium in persons with Alzheimer disease. *Annals of Internal Medicine, 156*(12), 848-856.

Gallicchio, L., Siddiqi, N., Langenberg, P., Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *Internal Journal Geriatric Psychiatry, 2*, 154-63.

Gaugler, J.E., Leach, CR., Clary, T., Newcomer, RC. (2004). Predictors of Nursing Home placement in African Americans with dementia. *Journal of American Geriatric Society, 52*(3), 445-452.

Gaugler, J.E., Kane, R.L. Kane, R.A. & Newcomer, R. (2005). Unmet care needs and key outcomes in dementia. *Journal of American Geriatrics Society, 53*, 2098-2105.

- Gaugler, J.E., Wall, MM., Kane, RL., Menk, JS., Sarsour, K., Johnston, JA ... Newcomer, R. (2010). The effects of incident and persistent behavioral problems on change in caregiver burden and nursing home admission of persons with dementia. *Medical Care*, 48, 875-883.
- George, J., Long, S. & Vincent, C. (2013). How can we keep dementia safe in our acute hospital? A review of challenges and solutions. *Journal of the Royal Society of Medicine*. 106(9), 355-361.
- Gill SS, Camacho X, Poss JW. (2011). Community Dwelling Adults with Dementia: Tracking Encounters with the Health System. In: Bronskill SE, Camacho X, Gruneir A, Ho MM, editors. Health System Use by Frail Ontario Seniors: An In-Depth Examination of Four Vulnerable Cohorts. Toronto, ON: Institute for Clinical Evaluative Sciences.
- Gill, FM., Allore, HG., Holford, TR. & Guo, Z. (2004). Hospitalization, restricted activity, and the development of disability among older persons. *JAMA*, 292, 2115-2124.
- Glaser, B.G., & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine.
- Golant, SM. (2003). Conceptualizing time and behavior in environmental gerontology: a pair of old issues deserving new thought. *Gerontologist*, 43, 638-650.
- Goodall, D. (2006). Environmental Changes Increase Hospital Safety for Dementia Patients. *Holistic Nursing Practice*, 20(2), 80-84.

Grossberg G.T. (2003). Diagnosis and treatment of Alzheimer's disease, *Journal of Clinical Psychiatry*, 64 (Suppl. 9):3-6

Guijarro, R., San Roman, C.M., Gomez-Huelgas, R., Villalobos, A., Martin, M., Guil, M., et. al. (2010). Impact of dementia on hospitalization. *Neuroepidemiology*, 35(2), 101-108.

Gulliford, M., Naithani, S., Morgan, M. (2006). What is 'continuity of care'?. *Journal Health Services Research Policy*. 11(4), 248-250.

Hennelly, D. & Lawlor, (2008). Management of dementia in a general hospital setting. *CME Geriatric Medicine*, 10(1), 14-19.

Heru, A.M. & Ryan, C.E. (2006). Family functioning in the caregivers of patients with dementia: One-year follow-up. *Bulletin of the Menninger Clinic*, 70, 222-231.

Hickey, A., Clinch, D. and Groarke, E.P. (1997). 'Prevalence of cognitive impairment in the hospitalised elderly', *International Journal of Geriatric Psychiatry*, 12(1) 27-33.

Hickman L, Newton P, Halcomb EJ, Chang, Davidson P. (2007). Best practice interventions to improve the management of older people in acute care settings: a literature review. *Journal of Advanced Nursing*, 60(2), 113-126.

Hsieh, HF., Shannon, SE. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research*, 15(9), 1277-1288.

- Hustey FM, Meldon SW, Smith MD, Lex CK. (2003). The effect of mental status screening on the care of elderly emergency department patients. *Annals of Emergency Medicine*, 41(5), 678–684.
- Inouye SK, Bogardus ST Jr, Charpentier PA, Leo-Summers L, Acampora D, Holford TR, Cooney LM Jr.. (1999). A multicomponent intervention to prevent delirium in hospitalized older patients. *New England Journal of Medicine*, 340(9), 669-676.
- Inouye SK. & Charpentier, PA. (1996). Precipitating factors for delirium in hospitalized elderly persons: predictive model and interrelationship with baseline vulnerability. *JAMA*, 275(11), 852-857.
- Institute of Medicine. (2008). Retooling for an aging America: Building the health care workforce.
- Jacques A, Jackson G. (1999). Understanding dementia. Third Edition. Churchill Livingstone. Edinburgh.
- Jurgens, F.J., Clissett, P., Gladman, J.RF., Harwood, R.H. (2012). Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. *BMC Geriatrics*, 12(57). doi:10.1186/1471-2318-12-57
- Kim, H., Chang, M., Rose, K. & Kim, S. (2011). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846-855.
- Kitwood T. (1988). The technical, the personal, and the framing of dementia. *Social Behaviour*, 3, 161–79.

Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham.

Kmietowicz, Z. (2009). Poor care in hospital is delaying discharge of patients with dementia, charity says. *British Medical Journal*, 339, b4907.

Krippendorff, K. (1980). *Content Analysis: An introduction to its Methodology*. Sage Publications, Newbury Park.

Light, E., Niederehe, G., & Lebowitz, B. D. (1994). *Stress effects on family caregivers of Alzheimer's patients: Research and interventions*. New York: Springer.

Lin, P-C., Hsieh, M-H. & Lin, LC. (2012). Hospital Nurse Knowledge of and Approach to Dementia Care. *The Journal of Nursing Research*, 20(3), 197-206.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications.

Malone, D.C., McLaughlin, T.P., Wahl, P.M., Leibman, C., Arrighi, H.M., Cziraky, M.J. & Mucha, L.M. (2009). Burden of Alzheimer's disease and association with negative health outcomes. *American Journal of Managed Care*, 15(8), 481-488.

Marquardt G (2011). Wayfinding for people with dementia: the role of architectural design. *Health Environments Research & Design*, 4, 22-37.

- McBrien, B. (2009). Translating change: the development of a person-centred triage training programme for emergency nurses. *International Emergency Nursing*, 17(1), 31-37.
- McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *International Journal of Older People Nursing*, 13,31-38.
- McKhann GM, Snopman DS, Chertkow H, Hyman BT, Jack CR, Kawas CH, Klunk WE... Phelps CH. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroup. *Alzheimer's & Dementia*, 1-7.
- Mellor, P., Chew, D., & Greenhill, J. (2007). Nurses' attitudes toward elderly people and knowledge of gerontic care in a multi-purpose health service. *Australian Journal of Advanced Nursing*, 24(3), 37-41.
- Miles M.B., & Huberman, A.M. (1994). *Qualitative Data Analysis: An expanded Sourcebook*. Thousand Oaks, CA; Sage.
- Miller, E.A., Allen, SM. & Mor, V. (2009). Commentary: Navigating the labyrinth of long-term care: Shoring up informal caregiving in a home- and community-based world. *Journal of Aging Society Policy*, 21(1), 1-16.
- Miller, E.A., Rosenheck, R.A., Schneider, L.S. (2010). Caregiver burden, health utilities, and institutional service costs among community-dwelling patients with Alzheimer disease. *Alzheimer Disease Associated Disorders*, 24(4), 380-389.

Miller, E. A., Rosenheck, R. A. and Schneider, L. S. (2012). Caregiver burden, health utilities, and institutional service use in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 27, 382–393.

Molyneux G.J., McCarthy G.M., McEniff S., Cryan M. & Conroy R.M. (2008). Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. *International Psychogeriatrics*, 20(6), 1193–1202.

Morgan, DL. (1993). Qualitative Content Analysis: A guide to Paths not Taken. *Qualitative Health Research*, 3, 112-121.

Morrisson, RS. & Siu, AL. (2000). Survival in end-stage dementia following acute illness. *JAMA*, 284, 47-52.

Morse J.M. & Field P.A. (1995). *Qualitative Research Methods for Health Professionals* (2nd Edition) Thousand Oaks, CA: Sage.

Moyle W., Borbasi, S., Wallis M., Olorenshaw R. & Gracia N. (2011). Acute care management of older people with dementia: a qualitative perspective. *Journal of Clinical Nursing*, 20(34), 420-428.

Mukadam, N. & Sampson, E.L. (2011). A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *International. Psychogeriatrics*, 23(3), 344-355.

- Nasreddine, ZS., Phillips, NA., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, JL. & Chertkow, H. (2005). The Montreal Cognitive Assessment (MoCA): A brief screening tool for mild cognitive impairment. *Journal of American Geriatric Society*, 53, 695-699.
- Naylor, M.D., Keating, S.A. (2008). Transitional Care: Moving patient from one care setting to another. *American Journal of Nursing*, 108(9), Suppl, 58-63.
- Naylor, M.D., Stephens, C., Bowles, K.H., Bixty, M.B. (2005). Cognitively Impaired Older Adults: From Hospital to Home. *American Journal of Nursing*, 105(2), 52-61.
- Naylor, M.D., Hirschman, K.B., Bowles, K.H., Bixby, M.B., Konick-McMahan, J., Stephens, C. (2007). Care Coordination for Cognitively Impaired Older Adults and Their Caregivers. *Home Health Care Service Quality*, 26(4), 57-78.
- Nichols, J.N., & Heller, K.S. (2002). Windows to the heart: Creating an acute care dementia unit. *Journal of Palliative Medicine*, 5(1), 181-192.
- Ory, MG., Hoffman, RR., Yee, JL., Tennstedt, S., Schulz, R.(1999). Prevalence and impact of caregiving: a detailed comparison between dementia and non-dementia caregivers. *Gerontologist*, 39, 177-185.
- Papastavrou, E., Kalokerinou, A., Papacostas, S.S., Tsangari, H. & Sourtzi, P. (2007). Caring for a relative with dementia family caregiver burden. *Journal of Advanced Nursing*, 58(5), 446-457.

Pearlin, L.I., Mullan, J., Semple, S. & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30, 583-594.

Pedone C, Ercolani S, Catani M, Maggio D, Ruggiero C, Quartesan R et al. GIFA Study Group. (2005). Elderly patients with cognitive impairment have a high risk for functional decline during hospitalizations: the GIRA Study. *Journal Gerontology A Biological Sciences Medical Sciences*, 60, 1578-80. PMID: 16424291

Phelan, EA, Borson, S, Grothaus, L, Balch, S., Larson, EB. (2012). *Journal of the American Medical Association*, 307(2), 165-172.

Prichard, E., Dewing, J. (2001). Older people with dementia in acute settings. *Nursing Older People*, 12(10), 21-25.

Prince M., Jackson, J. (2009). World Alzheimer's Report, London. Alzheimer's Disease International.

Prorok JC, Horgan S, Seitz DP. (2013). Health Care Experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. *CMAJ*, 185(4) E669-E680.

QSR International, NVivo qualitative data analysis software. Version 10, 2012.

Raivio, M.M., Laakkonen, M-L.& Pitkala, K.H. (2011). Alzheimer's Patients' Spouses Critiques of the Support Services, *International Scholarly Research Network*, Vol. 2011, 1-8.

Richard, KC. & Beck, CK. (2004). Progressively lowered stress threshold model: understanding behavioral symptoms of dementia. *Journal of American Geriatric Society*, 52, 1774-1775.

Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M. C., ... & Mecocci, P. (2005). Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study. *International journal of geriatric psychiatry*, 20(2), 168-174.

Royal College of Psychiatrists (2011). Report of the national audit of dementia care in general hospitals. Editors: Young J, Hood C, Woolley R, Gandesha A and Souza R. London: Healthcare Quality Improvement Partnership.

Sampson, E.L., Blanchard, M.R., Jones, L., Tookman, A., & King, M. (2009). Dementia in the acute hospital: Prospective cohort study of prevalence and mortality. *British Journal of Psychiatry*, 195(1), 61-66.

Sampson, E.L., Leurent, B., Blanchard, M.R., Jones, L. & King, M. (2013). Survival of people with dementia after unplanned acute hospital admission: a prospective cohort study. *International Journal of Geriatric Psychiatry*, 10, 1015-22.

Sandelowski, M. (1995). Qualitative Analysis: what it is and how to begin? *Research in Nursing & Health*, 18, 371-375.

Schilling, J. (2006). On the pragmatics of qualitative assessment: Designing the process for content analysis. *European Journal of Psychological Assessment*, 22(1), 28-37.

Schulz, R., Martire, L.M. (2004). Family Caregiving of Persons with Dementia. *American Journal of Geriatric Psychiatry*, 12(3), 240-249.

Shankar, K.N., Hirschman, K.B., Hanlon, A.L., Naylor, M.D. (2014). Burden in Caregivers of Cognitively Impaired Elderly Adults at Time of Hospitalization: A Cross-Sectional Analysis. *Journal of American Geriatric Society*, 62, 276-284.

Silverstein, M. & Maslow, K. (2006). *Improving Hospital Care for People with Dementia*, Springer Publishing Co, New York, USA.

Simpson, R.G., Scothern, G., & Vincent, M. (1995). Survey of carer satisfaction with the quality of care delivered to in-patients suffering from dementia. *Journal of Advanced Nursing*. 22(3), 517-527.

Sink, K.M., Holden, K.F., Yaffe, K. (2005). Pharmacological treatment of neuropsychiatric symptoms of dementia: a review of the evidence. *JAMA*. 293(5), 596-608.

Skaalvik, M.W., Normann, H.K., Henriksen, N. (2010). Student experiences in learning person-centred care of patients with Alzheimer's disease as perceived by nursing students and supervising nurses. *Journal of Clinical Nursing*, 19 (17/18), 2639–2648.

Sloane, P.D., Mitchell, C.M., Wiesman, G., Zimmerman, S., Foley, K.M.L., Lynn, M., ... Montgomery R (2002). The therapeutic environment screening survey for nursing homes (TESS-NH): An observational instrument for assessing the physical environment of institutional settings for persons with dementia. *Journal of Gerontology*, 57B, 69-78.

the Swedish Council on Technology Assessment in Health Care (2008). Dementia—Etiology and Epidemiology, A Systematic Review Vol.1, June.

Tadd, W. Hillman, A., Calnan, M., Bayer, T. Read, S. (2011). Right-place – wrong person: dignity in the acute care of older people. *Quality in Ageing and Older Adults*, 12(1), 33-43.

Tesch, R. (1990). *Qualitative Research: Analysis Types & Software Tools*. Bristol, PA: Falmer Press.

Tierney MC, Herrmann N, Geslani DM, et al. (2003). Contribution of informant and patient ratings to the accuracy of the Mini-Mental State Exam in prediction probable Alzheimer's disease. *Journal of American Geriatric Society*, 51,813-818.

Thompson, F., Girling, D., Green, S. and Wai, C. (2010). 'Care of people with dementia in the general hospital' in Downes, M. and Bowers (eds.) *Excellence in Dementia Care: Research into Practice*, Open University Press, Maidenhead, 310-18.

Traynor, V., Brisco, S. & Coventry, T. (2005). Developing person-centred dementia care in acute settings: findings from a study tour in Australia. *Nursing Older People*, 8, 16-19.

Turcotte, M., & Schellenberg, G. (2007). *A portrait of seniors in Canada*. Retrieved January 23, 2014. (Catalogue no. 89-519-XIE). Ottawa, Ontario: Statistics Canada.

Voisin, T., Andrieu, S., Cantet, C., Vellas, B., & REAL.FR, G. (2010). Predictive factors of hospitalizations in Alzheimer's disease: A two-year prospective study in 686 patients of the REAL.FR study. *Journal of Nutrition, Health & Aging*, 14(4), 288-291.

Wait Times Alliance. (2012). Shedding Light on Canadians', Report Card on Wait Times in Canada, 2012.

Waller, S. (2012). Redesigning wards to support people with dementia in hospital. *Nursing Older People*, 24(2), 16-21.

Watkin, L., Blarehard, MR., Tookman, A., Sampson, EL. (2012). Prospective cohort study of adverse events in older people admitted to acute general hospital: risk factors and the impact of dementia. *International Journal of Geriatric Psychiatry*. 27(1), 76-82.

Weber, R.P. (1990). Basic Content Analysis. Newbury Park, CA: Sage Publications.

Webster, J. (2011). Improving care for people with dementia in acute hospital: the role of person-centred assessment. *Quality in Ageing and Older Adults*, 12(2), 86-94.

Wills, T. and Ford, P. (2001). "Assessing older people – contemporary issues for nursing", *Nursing Older People*, 12(9),16-20.

Witlox J, Eurelings LM, de Jonghe JM, Kalisvaart KJ, Eikelenboom P, van Gool WA. (2010). Delirium in Elderly Patients and the Risk of Postdischarge Mortality, Institutionalization, and Dementia: A Meta-analysis. *JAMA*, 304(4), 443-451.

World Health Organization. (2012). Dementia: a Public Health Priority.

Zhang, Y. & Wildemuth, BM. (2012). Qualitative Analysis of Content. Retrieved from <http://7702-f13.design4complexity.com/qualitative-research/content-analysis.pdf>

Ziegert, K., Fridlund, B.& Lidell, E. (2006). Health in everyday life among spouses of haemodialysis patients: a content analysis. *Scandinavian Journal of Caring Science*, 20, 223-228.

Table 1: Participant characteristics

| Participant ID | Age | Gender | Caregiver Age | Caregiver Gender | Care relationship | Education PWD | Education CG |
|----------------|----------------|-------------|----------------|------------------|-------------------|-------------------------|---------------------------|
| 1001 | 83 | F | 63 | F | Child | E | P |
| 1003 | 65 | M | 64 | F | Spouse | P | P |
| 1010 | 82 | F | 50 | F | Daughter in law | P | P |
| 1014 | 80 | M | 54 | M | Child | P | H |
| 1021 | 71 | F | 76 | M | Spouse | P | P |
| 1024 | 78 | M | 79 | F | Spouse | H | H |
| 2007 | 76 | F | 79 | M | Spouse | H | H |
| 2008 | 87 | F | 62 | F | Child | P | P |
| 2012 | 89 | M | 67 | F | Child | H | H |
| 2013 | 71 | F | 48 | F | Child | P | P |
| 2016 | 86 | F | 87 | M | Cousin | P | P |
| 2017 | 72 | M | 75 | F | Spouse | H | H |
| 2019 | 85 | F | 48 | F | Child | P | P |
| 2025 | 74 | M | 60 | F | Spouse | H | H |
| 2026 | 86 | F | 45 | F | Child | P | P |
| 2027 | 80 | F | 77 | M | Spouse | H | H |
| 2032 | 78 | M | 77 | F | Spouse | H | P |
| 2035 | 80 | F | 42 | F | Child | E | H |
| 3001 | 78 | F | 71 | M | Spouse | P | P |
| 3002 | 79 | M | 74 | F | Spouse | E | H |
| 3003 | 94 | M | 87 | F | Spouse | P | H |
| 3011 | 76 | M | 40 | F | Niece | H | H |
| 3015 | 77 | F | 58 | F | Child | H | H |
| 3017 | 84 | F | 94 | M | Spouse | H | P |
| 3026 | 84 | F | 50 | F | Child | H | P |
| 3030 | 90 | F | 45 | M | Child | H | P |
| 3031 | 89 | M | 83 | F | Spouse | P | P |
| 3033 | 85 | F | 51 | F | Child | H | H |
| 3035 | 78 | F | 41 | M | Child | H | P |
| Summary | Average: 80 | 38% male | Average: 64 | 34% male | 45% spouse | E: 0 H: 43% P:37% | E: 10% H: 47% P:43% |

Legend

E= \leq grade 8

H=grade 12

P=post-secondary

Table 2: Coding frequency

| Codes | Code description | # Participants | # Quotes |
|---|--|-----------------------|-----------------|
| Trigger to hospitalization | The precipitating event that led to hospitalization and admission diagnosis as per the caregiver's understanding. | 25 | 35 |
| Pre-hospitalization facilitators | All external events leading to seeking care at hospital other than the actual admission. All events that facilitated the process of seeking care in an acute care hospital. | 4 | 5 |
| Emergency Department Process | The series of actions or steps taken from the point of entry at the emergency department at triage in an acute care hospital to the emergency department discharge. | 8 | 18 |
| Discharge Process | The point at which the discharge planning process is initiated for the PWD to be able to leave the hospital. Plans are made for the PWD to return home or to be transferred to another facility such as a rehabilitation center or a nursing home. | 5 | 6 |
| Post-acute care environment | All events occurring after the acute care hospitalization in a different health care setting like a rehabilitation center. | 3 | 7 |
| Care continuity and coordination | Encompassing the uninterrupted succession of flow of care. Providing a logical sequence of coherent, connected care. It relates to the level with which services are provided in an integrated, coordinated fashion and through which information is shared amongst providers. | 8 | 8 |
| In-hospital cognitive trajectory | The path or course while in hospital that relates specifically to the cognitive symptoms of dementia. Focuses on the events related to the cognitive, behavioral and functional changes of dementia and delirium. | 13 | 36 |
| In-hospital medical trajectory | Relates specifically to the medical/surgical course associated to the underlying illness. It includes pain, medical complications and interventions done by the health care team. | 7 | 10 |
| In-hospital environment | All factors external to the PWD and the CG that relate to the | 8 | 17 |

| | | | |
|--|---|----|----|
| | environment during the acute hospital stay. Included room transfers, presence of noise, cleanliness, nutrition, loss of personal valuables and the impact of isolation precaution measures. | | |
| Communication with Physician | The activity of conveying meaningful information through the exchange of thoughts, messages, or information, by speech, visuals, signals, writing, or behavior specifically by physicians. | 10 | 19 |
| Communication with Caregiver/family | Statements where the exchange of information occurred with or about the CG. | 6 | 12 |
| Communication – PWD as an agent | When complex medical information is shared with the PWD without the CG being present. | 7 | 13 |
| Physician satisfaction/dissatisfaction | General comments about physicians not directly related to communication. | 4 | 9 |
| Nurse satisfaction/dissatisfaction | -Comments on the perceived skills of nurses and knowledge defined as the proficiency, ability or dexterity that is acquired or developed through training or experience in the nursing profession. -Nursing systemic factors defined as issues pertaining to the health care system that have a direct impact on nursing care. | 12 | 20 |
| Other health care professional satisfaction/dissatisfaction | The act of being satisfied, content, with allied healthcare professionals (social worker, physiotherapist, occupational therapist). | 2 | 3 |
| Caregiver-General Opinion about hospitalization | A view or judgment formed about the hospitalization. It refers to a general description of the hospitalization as a whole rather than considering its details or exceptions. | 14 | 32 |
| PWD-recollection about hospitalization-telling their story | PWD's recollection and memory of their acute hospitalization experience. | 5 | 6 |
| Caregiver – Stress and Burden | A multidimensional response to the negative appraisal and perceived stress resulting from taking care of an individual who is ill. Includes physical strain, emotional stress and financial hardship. Pertains to | 10 | 21 |

| | | | |
|----------------------------------|---|---|---|
| | the restructuring required from the whole family to assure supervision and visitations while in hospital. | | |
| Caregiver Fear and Worry | A distressing emotion felt by the caregiver set off by impending danger whether the threat is real or imagined. It is an apprehension, a concern, anxiety or a fear for their loved one's safety. It can be felt when the CG will not be able to assure protection and constant presence. during the hospital stay. | 3 | 3 |
| Caregiver Time Commitment | The caregiver's act or the pledge to assure constant supervision and presence for the PWD. It is the engagement and state of being bound emotionally, intellectually and physically to the PWD at the expense of time. | 8 | 8 |

Table 3: Coding scheme including categories

| Categories | Codes |
|--|---|
| Process | |
| Part 1 | Trigger to hospitalization Pre-hospitalization facilitators Emergency Department Process |
| Part 2 | Discharge Process Post-acute care environment Care continuity and coordination |
| Trajectory | In-hospital Cognitive Trajectory In-hospital Medical Trajectory In-hospital Environmental Factors |
| Impact on Caregiver | Caregiver Fear and worry Caregiver Stress/Burden Caregiver Time Commitment |
| Communication | Physician Communication Communication with Caregiver/family Communication – Person with dementia as an agent |
| Health Care Professional Satisfaction | Satisfaction/dissatisfaction with Physicians Satisfaction/Dissatisfaction with Nurses Satisfaction/dissatisfaction with other health care professionals |
| General Opinion/Recollection | Caregiver – General Opinion about hospitalization Person with dementia – Recollection about hospitalization – telling their stories |

Figure 1: Coding process

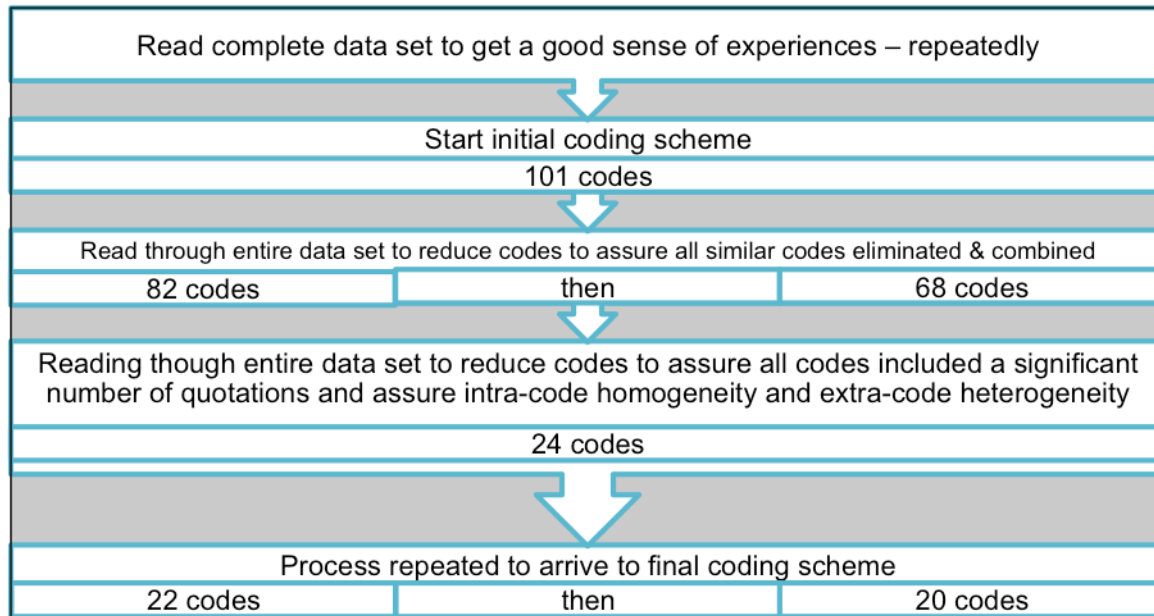
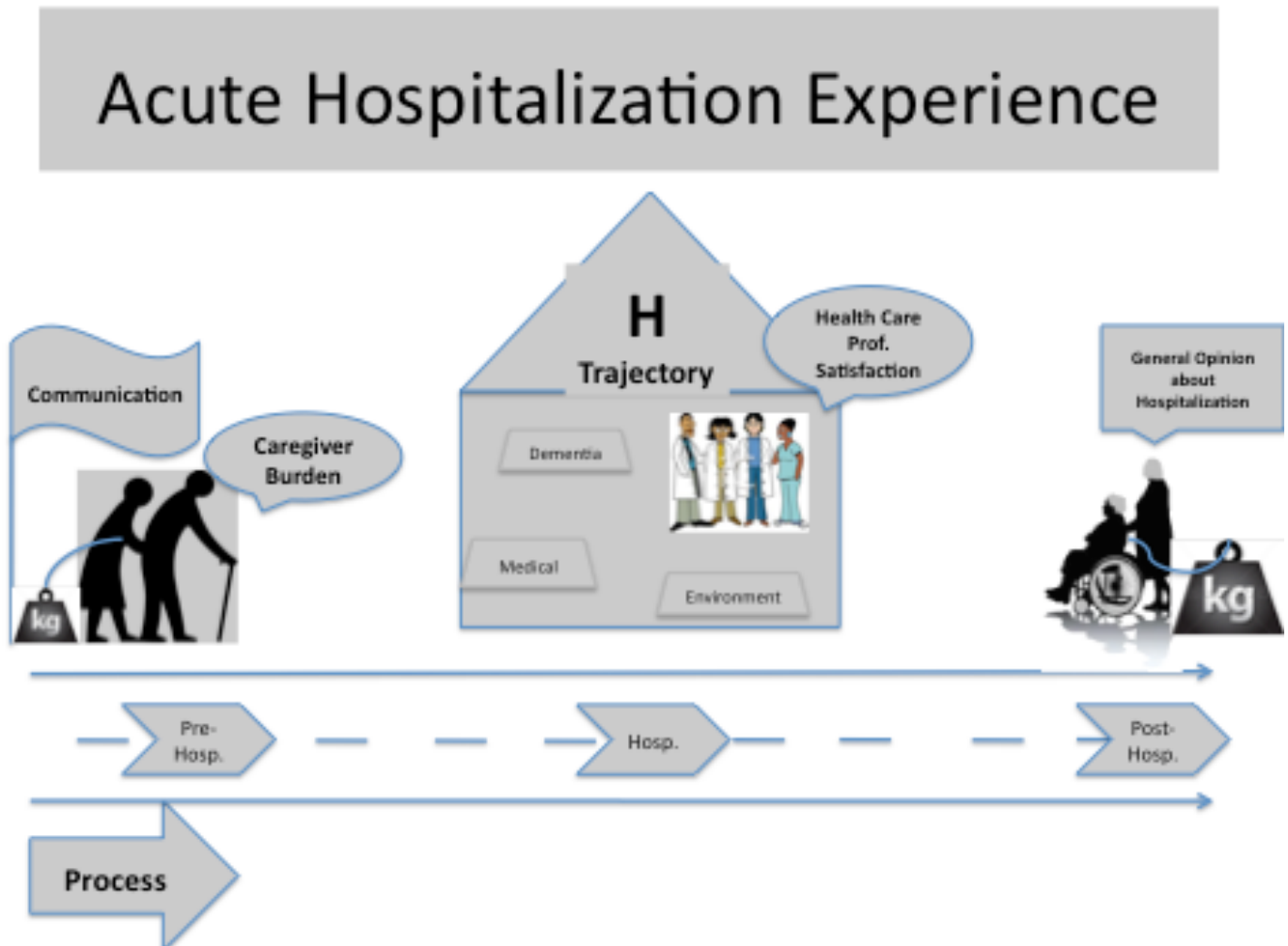


Figure 2: Schematic representation of the hospitalization experience



Appendix A: Research Ethics Board approval



Université d'Ottawa **University of Ottawa**
 Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

Ethics Approval Notice
Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

| <u>First Name</u> | <u>Last Name</u> | <u>Affiliation</u> | <u>Role</u> |
|-------------------|------------------|----------------------------------|---------------------------|
| Linda J. | Garcia | Health Sciences / Others | Principal Investigator |
| William | Dalziel | | Co-Principal Investigator |
| Neil | Drummond | | Co-investigator |
| Michael | Eliasziw | | Co-investigator |
| Jennifer | Hesketh | Health Sciences / Others | Co-investigator |
| Frank | Molnar | Medicine / Medicine | Co-investigator |
| Tracey | O'Sullivan | Health Sciences / Human Kinetics | Co-investigator |
| Tracy Jing | Xu | Medicine / Medicine | Co-investigator |
| Adi | Kartolo | Health Sciences / Others | Research Assistant |
| Farwa | Malik | Health Sciences / Others | Research Assistant |

File Number: H12-09-05

Type of Project: Other

Title: Dementia Services and Health Outcomes during Transitions

| Renewal Date (mm/dd/yyyy) | Expiry Date (mm/dd/yyyy) | Approval Type |
|----------------------------------|---------------------------------|----------------------|
| 01/21/2011 | 01/20/2012 | Ia |

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
 N/A



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

Please submit an annual status report to the Protocol Officer 4 weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at:
http://www.rges.uottawa.ca/ethics/application_dwn.asp

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5841 or by e-mail at: ethics@uOttawa.ca.

Appendix B: Research Ethics Board termination

From: Ethics [REDACTED]

Sent: December-14-12 10:55 AM

To: [REDACTED]

Subject: RE: Ethics file #H12-09-05: Dementia Services and Health Outcomes during Transitions

Bonjour Mme [REDACTED],

Ce dossier a été fermé et archive au mois d'avril 2012, donc il n'est pas nécessaire de soumettre un rapport annuel, puisqu'il n'y a plus de contact avec les participants.

Si vous avez des questions ou des commentaires, n'hésitez pas à communiquer avec nous par courriel ou à l'extension [REDACTED].

Bonne journée,

[REDACTED]

Coordonnatrice de l'éthique
Bureau d'éthique et d'intégrité à la recherche
Université d'Ottawa

[REDACTED]