

Perspectives of Family Caregivers on Care of Hospitalized Relatives with Dementia

By

Dalbir (Dhillon) Mann

The University of British Columbia

SCHOLARLY PRACTICE ADVANCEMENT RESEARCH PROJECT

SUBMITTED IN PARTIAL FULFILLMENT OF

THE REQUIREMENT FOR THE DEGREE OF

MASTER OF SCIENCE IN NURSING

In

THE FACULTY OF GRADUATE STUDIES

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

August 24, 2016

© Dalbir (Dhillon) Mann

## Table of Contents

ABSTRACT.....	3
ACKNOWLEDGEMENTS.....	4
CHAPTER ONE: INTRODUCTION.....	5
Challenges for the hospitalized dementia patient.....	6
The Concept of Person-Centered Care.....	7
Purpose and Research Question.....	9
Methodology.....	10
CHAPTER TWO: FINDINGS FROM THE INTEGRATED LITERATURE REVIEW.....	15
Communication and information sharing.....	16
Knowledge and quality of care.....	21
The acute care environment.....	22
CHAPTER THREE: DISCUSSION OF THE FINDINGS.....	25
CHAPTER FOUR: LIMITATIONS, RECOMMENDATIONS AND CONCLUSION.....	35
Limitations.....	35
Recommendations.....	35
Conclusion.....	38
REFERENCES.....	40

## ABSTRACT

**Purpose** - To examine family caregivers' experiences of care provision for their hospitalized relative with dementia

**Methods** – An integrative literature review was conducted using healthcare databases to examine primary research that focused specifically on family caregivers' attitudes and experiences of care that was provided to their relatives with dementia in the acute care setting.

**Significance** – Family caregivers were overall dissatisfied with the care that was provided to their relatives with dementia in the acute care setting. As a result, family caregivers felt it was their responsibility to provide personal care to their relatives with dementia and ensure that they were safe. There were three major themes that emerged as barriers to providing optimal care and person-centered care (PCC) to the patient with dementia: communication, knowledge and the environment. The concept of (PCC) is identified as the gold standard approach to care for dementia patients. There is evidence of family caregivers' expressing satisfaction where this philosophy of care is applied in the acute care setting. It is imperative that all stakeholders involved in the care of the dementia patient to collaborate to ensure a change for the better in care provision. This will be possible with effective communication between all stakeholders, educating and training the nurses in dementia care and also making physical changes to the acute care environment and its process to create a culture of PCC for the dementia patient.

**Key Words** - dementia, relatives, family, caregivers, hospital, acute care, experience

## ACKNOWLEDGEMENTS

Thank you to Dr. Jennifer Baumbusch, PhD, RN, my supervisor, for your positive encouragement, support and guidance throughout this entire process. Your knowledgeable input and expert advice have been invaluable to me. Thank you for believing in me. I truly appreciate all you have done to help me develop this paper into what you see today.

I would also like to thank my committee member Dr. Alison Phinney, PhD, RN for taking interest in my SPAR project and providing me with your expert advice and perspectives in this particular topic. Thank you!

To my amazing friend Rina Dulku, thank you for your support and encouragement. I cannot thank you enough for the time that you dedicated in editing this final project for me. Thank you!

To my beautiful daughter, Sahana, thank you for being my personal cheerleader. You were my motivation to complete this SPAR project. I love you with all my heart!

Finally, to my mom and dad, without your ongoing support the completion of this SPAR Project would not have been possible. I love you both very much and I cannot thank you both enough for all that you have done for me. Thank you!

## CHAPTER 1: INTRODUCTION AND RESEARCH METHODS

Health care improvements in the last century have increased the life expectancy of men and women in Canada (CIHI, 2011). Advances in medical care, improved public health, higher educational attainment and per capita income, and increases in total health care spending are all factors that have contributed to the growth of our aging population (CIHI, 2011). According to Statistics Canada (2011) seniors make up the fastest growing age group and it has been estimated that by 2036 the number of seniors aged 65 and over will double to 10.4 million. With an aging population, the prevalence of age related health conditions such as dementia also increases (Alzheimer's Society of Canada, 2016). There were an estimated 747,000 people living with dementia in 2011 and the Alzheimer's Society of Canada purposes that by 2031, 1.4 million people will be living with dementia (Alzheimer's Society of Canada, 2016).

Dementia is characterized by a progressive decline in cognitive function (Alzheimer's Society of Canada, 2016). It affects "memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement" (World Health Organization, 2016, para 1). There are many diseases that cause dementia. Some causes of dementia include Lewy Body disease, head trauma, strokes, fronto-temporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease, and Huntington's disease (Alzheimer's Society of Canada, 2016). Alzheimer disease is the most common form of dementia – approximately 64 per cent of all Canadians who have dementia have Alzheimer disease (Alzheimer's Society of Canada, 2016). According to the Alzheimer's Society of Canada (2016), there are three stages to the progressive decline seen in patients with dementia: early stage, middle stage and late stage. In the early stage of dementia the person affected may have mild cognitive impairment, communication difficulties, behavior and mood changes, forgetfulness, and may need minimal assistance for Activities of Daily Living (ADLs).

In the middle stage, the person has greater decline in cognitive and functional activity and assistance with ADLs is necessary. In the late stage, the person is not able to communicate verbally or take care of themselves and is in need of 24 hour care.

While dementia is not a normal part of aging, the chance of developing dementia increases with age. According to the Chief Public Health Officer Report (2014), the prevalence of dementia increases significantly after age 65 and is higher in people age 85 or more. In 2009, dementia was the 4<sup>th</sup> leading cause of death in those persons aged 85 and above (Statistics Canada, 2015). Not only will the growing numbers of older people with dementia add strain to the already ill-equipped health care system, but the costs to manage all aspects of dementia care are estimated to increase to \$293 billion per year by 2040 (Alzheimer's Society of Canada, 2016).

### **Challenges for the hospitalized dementia patient**

Older adults are the largest consumers of health care services (CIHI, 2011). The diagnosis of dementia is usually not the primary reason for hospital admission. Comorbid conditions, such as coronary heart disease, hypertension, diabetes, and respiratory diseases can lead to the need for acute medical care for the patient with dementia (Alzheimer's Society of Canada, 2016).

The acute care setting is a busy and fast-paced environment. The push for rapid quantity and treatment in the acute care setting, "exacerbates the situation for people with dementia and they are not able to conform to such ethos" (Nolan, 2007, p.419). Hospitalized patients with dementia face considerable physical and psychological stressors, and are at increased risk of adverse events, psychological and behavioral symptoms, general deconditioning, falls, loss of mobility, functional decline and mortality (McCloskey et al., 2014; Sampson et al., 2013; Watkin

et al., 2012; Marengoni et al., 2011; Nolan, 2007). The hospitalization of patients with dementia can intensify their distress and dysfunctional behaviors. Stressors that contribute to the negative outcomes include changes in routine, environment, or caregiver (Alzheimer's Society of Canada, 2016; Nolan, 2007). It has been shown that these negative stressors may lead to challenging behaviors which are manifested through expressions of anxiety, delusions, aggression, agitation, wandering, restlessness, and other socially deviant behaviors (Alzheimer's Society of Canada, 2016; Nolan, 2007; Eriksson and Saveman, 2002). Unfortunately, in a hospital setting, these 'challenging behaviors' are most commonly managed through the use of physical restraints and psychotropic medications (Gerace et al., 2013; McCloskey, 2004). Further, they are associated with increased length of hospital stay (McCloskey et al., 2014; Nolan 2007), mortality (Sampson et al., 2013), post hospital institutionalization, and escalating health care costs (CIHI, 2011).

### **The Concept of Person-Centered Care in Dementia Care**

Person-centered care (PCC) is identified as the ideal approach and best practice concept in providing health care services for older people with dementia (Alzheimer's Society of Canada, 2016; Clissett et al., 2013b; Maslow, 2013; Nilsson et al., 2013; Love & Pinkowitz, 2013; Edvardsson, Feathstonhaugh & Nay, 2010; McCormack, 2004; Kitwood, 1997). The concept of PCC has its origins in the work of Carl Rogers, who developed the approach in the field of psychology (McCormack & McCance, 2006). Later it was Tom Kitwood who encouraged PCC for persons with dementia. Specifically, Kitwood (1997) argued that behavioral and psychological symptoms, such as agitation and wandering, that people with dementia at times displayed, were not just a consequence of changes in the brain. He argued that these difficulties that people with dementia experienced were a consequence of a complex interaction between neuropathology and the person's psychosocial environment (Kitwood, 1997). Within this

conceptualization, the reason that people with dementia have difficult experiences is because they fear threats to their personhood that are brought about through negative interactions with others (Kitwood, 1997). This occurs as a result of negative care practices such as infantilization, intimidation, stigmatization and objectification, which create what Kitwood described as ‘malignant social psychology’ (Kitwood, 1997). It is very important to incorporate psychosocial needs with medical needs for people with dementia to establish PCC in the acute care setting (Maslow, 2013; Nilsson et al., 2013). Overall, the goal of person-centered approaches to care is to respect and value personhood. (Skaalvik, Normann & Henriksen, 2010).

There has been evidence in the literature that supports positive patient outcomes as a result of PCC approaches. The literature indicates positive outcomes such as decreased use of restraints (Fossey, 2006), less agitation (Sloane et al., 2004), decreased falls (Chenoweth et al., 2009) with persons with dementia in the long-term care setting. Unfortunately, there is a dearth of research on PCC outcomes evaluated in the acute care setting. The acute care setting prioritizes medical needs and discharging patients once their medical condition is stable; thus, it risks giving patients’ biopsychosocial needs lower priority and resulting in dissatisfaction with care (Moyle et al., 2011; Tadd et al., 2011). Further, the disease-orientated unit that lacks the PCC approach has been linked to several additional complications during hospitalization such as pressure sores, incontinence, and falls (Mecocci et al., 2005). It has been shown that the disease-orientated and efficiency-driven ward structure work against the provision of PCC (Preyde & Brassard, 2011).

Kitwood (1997) used PCC to describe ideas and the methods that emphasized communication and relationships between the person with dementia, the caregiver and the health care team. In Canada, 6 in 10 caregivers provided care to their spouse, parent, or grandparent



who had a diagnosis of dementia (Alzheimer's Society of Canada, 2016). According to a recent study by McCloskey et al. (2014), it was identified that patients with dementia tend to have longer hospital day stays than those with non-cognitive impairment. She further identified that these patients are usually classified as 'Alternate Level of Care' patients that do not need acute care but are occupying an acute care bed awaiting to be cared for elsewhere. (McCloskey et al., 2014). However, while waiting in the hospital these patients tend to have increased changes or other mishaps, such as falls that lead to other complications and even death (McCloskey et al., 2014).

It is important to apply PCC approaches to people with dementia in the acute care setting. Nurses and other healthcare professionals should focus on the individual needs of the person with dementia and build upon their strengths; and honor their values, choices, and preferences (Edvardsson, Feathstonhaugh & Nay, 2010; McCormack & McCance, 2006; McCormack, 2004; Kitwood, 1997).

### **Purpose and Research Question**

The purpose of this Scholarly Practice Advancement Research (SPAR) Project is to complete an integrated literature review of the healthcare literature to examine family caregivers' perceptions of care provision for their hospitalized relative with dementia. According to the Alzheimer's Society of Canada (2016) greater than 70% of patients who have dementia are cared for by family members. Though the ever increasing numbers of dementia patients in our aging Canadian population may not be able to verbalize their experiences in acute care, tapping into the thoughts of their family members and caregivers is a valuable source of information. I hope the

information that is gathered from this review will provide recommendations for achieving person-centered care for the hospitalized patient with dementia, particularly as they relate to the domains of the discipline of nursing. The research question for this SPAR project is: What are family caregivers' perspectives on care of patients with dementia in the acute care setting?

## **Methodology**

An integrative literature review approach was employed to examine the research question. An integrative literature review is a research strategy that involves reviewing, summarizing, critiquing, and synthesizing primary research evidence on a specific subject in a way that produces a comprehensive understanding of what is known and has the capacity to identify gaps in knowledge (Torraco, 2005). This integrative literature approach allowed me to view and incorporate both the empirical and theoretical research (Torraco, 2005), which focused on my research question. The integrative literature review approach is important to nursing science and nursing practice. It generates new insights, informs future research priorities and permits the inclusion of diverse methodologies (ie. experimental and non-experimental research) and levels of data (Torraco, 2005). This approach thus allows for a better understanding of how family caregivers perceive the care that is provided to their loved with dementia in the acute care setting.

Information for this integrative literature review was gathered from five databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) plus with Full Text, Medline, PubMed, PsycINFO, and Ageline and hand searches of reference lists of papers. The search included all relevant primary studies from all countries that focused specifically on family caregivers' attitudes and experiences of care that was provided to their relative who had dementia in the acute care setting. Articles were excluded if they were not written in English,

were published prior to 2005, and focused on caregivers other than family. Special consideration was taken to examine the key words for the search. Key search terms included: *dementia*, *relatives*, *family*, *caregivers*, *hospital*, *acute care\**, *experience*; these words were used alone and in various combinations using Booleans *AND* or *OR*.

The various combinations of search words generated 153 articles in all databases. After scanning the titles of the articles, removing all duplicates and then reading the abstracts of the studies, only eleven studies met the inclusion criteria. After reading the eleven studies in more depth, another six studies were further eliminated. Five of the articles (Shanely et al., 2011; Bradshaw et al., 2012; Clissett et al., 2013b; Boltz et al., 2015; Whittamore et al., 2014) were eliminated because the common themes in these studies were caregiver needs and well-being and did not focus on their perspectives of care of the patient with dementia. Another study by Bauer et al., 2011 was also eliminated because it explored family caregiver needs and well-being in preparation for receiving the patient with dementia after discharge. So overall, there were only five studies that met the inclusion criteria. A summary of findings from each search strategy is provided in Table 1 and an overview of the studies included in the literature review is included in Table 2.

Table 1: Literature Search Strategy

Database Searched	Search Strategy	# of Articles Found	# of Relevant Articles
CINAHL plus with full text	(MH “family caregivers”) OR (MH “relatives”) AND (MH “acute care setting”) OR (MH “hospital”) AND (MH “dementia”) or dementia* AND (MH “experience”)	15	2
Medline	(MH “dementia”) AND (MH “acute	30	7

	care”) AND (MH “family caregivers”) OR (MH “relatives”)		
PubMed	(MH “dementia”) AND (MH “acute care” OR “hospital”) AND (MH “caregivers” OR “relatives”) AND experiences	62	13
PsycINFO	(MH “dementia”) AND (MH “family”) OR (MH “relatives”) AND (MH “acute care”)	26	2
AgeLine	(MH “dementia”) AND (MH “family”) AND (MH “acute care” AND (MH “experiences”))	17	2

Table 2: Overview of the Studies included in the Literature Review

Article	Country	Purpose/Aim	Sample Size/ Study design/ Study method	Key Findings
“Support for carers of people with dementia during hospital admission”  M. Douglas-Dunbar & P. Gardiner (2007)	United Kingdom (U.K)	To explore the experiences of family carers’ of people with cognitive impairment during hospital admission	Family caregivers (n=9)  Qualitative Study: semi-structured interviews	Negative hospital experiences  Themes that emerged: communication; Nurses’ poor understanding of dementia; Carer vulnerability; The need for advocacy; Long term effects of being in hospital; Therapeutic relationship
“Why are family carers	U.K	To describe an analysis of	Family caregivers	Negative hospital experiences

<p>of people with dementia dissatisfied with general hospital care? A qualitative study”</p> <p>F. Jurgens, P.Clissett, J. Gladman &amp; R. Harwood (2012)</p>		<p>interviews with family carers’ conducted after discharge, and then to present a model which aims to explain dissatisfaction</p>	<p>(n=35)</p> <p>Qualitative Design: semi-structured interviews</p>	<p>carer expectations were usually unexplored by staff and largely unmet; relationship with staff include poor communication and conflict over care</p>
<p>“Delivering dementia care differently-evaluating the differences and similarities between a specialist medical and mental health unit and standard acute care wards: A qualitative study of family carers’ perceptions of quality of care</p> <p>K. Spencer, P. Foster, K. Whittamore, S.E.,Goldberg and R.H. Harwood (2013)</p>	U.K	<p>To examine in depth carers’ views and experiences of the delivery of patient care for people with dementia or delirium in an acute general hospital</p> <p>Specialist Medical and mental health unit (MMHU) Versus standard acute wards</p>	<p>Family caregivers (n=40)</p> <p>Qualitative semi-structured interviews</p>	<p>Negative hospital experiences</p> <p>Main themes related to family carers’ met of unmet expectations and included activities of boredom, staff knowledge, dignity and fundamental care, the ward environment and communication between staff and carers’</p> <p>Overall, care was perceived satisfactory on MMHU, however communication and engagement of family carers’ was still perceived as insufficient on both units</p>

<p>“Treatment of older people with dementia in surgical wards for the viewpoints of the patients and close relatives”</p> <p>N. Hynninen, R. Saarnio, A. Isola (2015)</p>	Finland	To describe the treatment of older people with dementia in surgical wards from the viewpoints of the patients and their close relatives	<p>Family caregivers (n=5); Patients with dementia (n=7)</p> <p>A qualitative, descriptive design was used and data was collected using unstructured interviews</p>	<p>Negative hospital experiences</p> <p>Main areas of dissatisfaction: lack of communication and information sharing; medical management (the use of chemical and physical restraints);lack of dignified care and task-orientated approach; infrastructure (small, busy environment)</p>
<p>“ ‘They rush you and push you too much... and you can’t really get any good response off them’: A qualitative examination of family involvement in care of</p>	Australia	To explore the family caregivers role and their level of involvement in the care of their relative with dementia in the acute setting	<p>Family caregivers (n=30)</p> <p>A pragmatic, exploratory descriptive qualitative approach. Data was collected through semi-structured</p>	<p>Negative hospital experiences</p> <p>Lack of communication and information sharing; the need for a central source of information; lack of continuing care by same nurse; the need for staff</p>

people with dementia in acute care”  W. Moyle, M. Bramble, M. Bauer, W. Smith, E. Beattie (2015)			interviews from three different sites	to be educated about dementia care; lack of acknowledgement of the family caregivers knowledge of the patient and their needs; the need for guidelines on the roles and processes for the family caregiver
---	--	--	---------------------------------------	--

## **CHAPTER TWO: FINDINGS FROM THE LITERATURE REVIEW**

This chapter will describe the findings from the five studies used in this integrative literature review. All five of the articles were qualitative studies that addressed the experiences, attitudes, or viewpoints of family caregivers in respects to the care that was provided to their family member with dementia in the acute care setting. In this paper, the relatives (spouse, child, grandchild, sibling, niece or nephew) of the person with dementia are described as “family caregivers.” In all five of the studies it was clear that family caregivers had negative attitudes, experiences or viewpoints of the overall care that was provided to their family members with dementia in the acute care setting (Dunbar & Gardiner, 2007; Jurgens, Clissett, Gladman, & Harwood, 2012; Spencer, Foster, Whittamore, Goldberg & Harwood, 2013; Hynninen, Saarnio, & Isola, 2015; Moyle, Bramble, Bauer, Smyth, Beattie, 2016). There were many factors that were identified by family caregivers as contributing to the sub-optimal care provided to patients with dementia in acute care. The factors discussed in the selected studies were associated with the health care professionals and the ward and each of the factors impacted how patients with dementia were cared for. These factors included: communication, information sharing, therapeutic relationships, knowledge, education, experience, physical and chemical restraints, the ward environment, and the family caregiver role. For the purposes of this literature review, the aforementioned topics have been combined and presented under three major subheadings: Communication and information-sharing; knowledge and quality of care; and the acute care environment.

### **Communication and information sharing**

A lack of communication and a lack of information sharing between healthcare professionals and family caregivers, from the admission process through to the time of discharge,



were recognized as barriers by family caregivers in all five of the studies. From the family caregivers' perspectives, poor communication and information sharing led to sub-optimal care of their family members with dementia in the acute care setting.

The Dunbar and Gardiner (2007) study took place in the U.K. and individual semi-structured interviews were conducted of nine family caregivers of patients who had dementia. The interviews occurred after discharge and were conducted in a place that suited the caregiver. Poor communication was the most enduring theme amongst the caregivers in this study. Caregivers felt that the information that they shared with healthcare professionals in relation to the needs of their family members with dementia was often dismissed. Furthermore, these caregivers felt they were excluded from the decision-making and discussion on prognosis and diagnosis, especially for those patients that displayed short term memory loss (Dunbar & Gardiner, 2007). These family caregivers resided with these patients prior to their hospital stay and thus had invaluable insight into their everyday functioning and needs. However, health care professionals seemed to ignore the shared information and managed care at their own discretion, usually resulting in challenging patient behaviors and resulting in poor patient outcomes (Dunbar & Gardiner, 2007). In the cases of those patients for whom communication had become difficult, family caregivers felt they needed to be with them to ensure their needs were being met. However, at times family caregivers felt abandoned since they did not know or were not made aware of the level of involvement in their relative's care that they were expected to have. As a result, this lead to dissatisfaction and uncertainty (Dunbar & Gardiner, 2007).

Jurgens et al., (2012) study also took place in the U.K., where 35 family caregivers of 34 patients with dementia were recruited from one of 12 general medical or trauma orthopedic wards on two sites of a large teaching hospital. Semi-structured interviews were conducted to

capture the experiences of the family caregivers approximately six to eight weeks after patient discharge at a setting convenient for the participant. Many of the caregivers expressed frustration with regards to the lack of communication with health care professionals. Family caregivers mentioned that the needs of the patients with dementia were not met and health care professionals failed to reach out to the caregivers for information, some feeling a lack of opportunity to share their knowledge. The concerns focused on the delivery or appropriateness of the interventions and the increased deterioration in the health of the patient with dementia. In some examples, caregivers felt that the information that was collected by the health care professionals upon admission was not directed towards better care, but towards discharge. However, when it came to the actual discharge planning, caregivers felt they were never actually consulted or included as a part of the discharge planning process. The family caregivers felt that the decisions were made entirely by the health care professionals. For instance, one example from the article revealed a patient was readmitted within 12 hours of discharge which could have been avoided had the family caregiver been consulted.

The study by Spencer et al., (2013), also took place in the U.K. There were 40 caregivers of dementia patients recruited to a randomized controlled trial comparing the Medical and mental health unit (MMHU) with a standard care ward. The MMHU is an acute geriatric medical ward aiming to provide the best practice care for patients with dementia and delirium. Semi-structured interviews took place at the caregiver's home; there were 20 participants from the MMHU and 20 participants from the standard care wards. All of the family caregivers, from both the MMHU and the standard care ward, expressed feelings of neglect and indicated that they felt they were not kept informed about their family member's status. The family caregivers insisted that the staff should voluntarily provide information on patient care and progress rather than the family

feeling obligated to initiate interactions. The participants on the standard ward expressed that there was no information sharing about the needs of the dementia patient, and any communication that did take place was solely based on the medical history. Nurses did not have much interaction or communication with the family caregivers or the patients. The family caregivers mentioned that the nurses would interact with patients for general tasks and not engage in conversation. In contrast, the participants from the MMHU stated that the nurses collected detailed information about patient's background and specific dementia needs on admission from the caregiver. However, one caregiver from the MMHU speculated whether or not the information collected was actually being used. Overall, although the family caregivers from the MMHU were more satisfied with the overall care for their family member with dementia than those on the standard care unit, family caregivers from both units expressed the need for more communication and information sharing.

The Hynninen et al., (2015) study took place in Finland. Participants for this study included five family caregivers who visited with the patients and seemed to have the most knowledge about their dementia. These family caregivers were recruited from four surgical wards at a Finnish university hospital. Data was collected using unstructured interviews which took place on the surgical ward during the patients hospital stay. Three of these interviews were conducted in the presence of the patient and two were conducted individually with the family caregiver. The aim of this study was to describe the treatment of elderly people with dementia from both the viewpoint of the patient and the viewpoint of close relatives. This study highlighted the lack of communication and information sharing between the healthcare professionals and the patient and family caregiver dyad. Family caregivers in this study observed that nurses did not report everything that happened with the patients and felt that getting

adequate information depended on asking the right questions. Similar to the study by Spencer and colleagues, family caregivers also commented on how nurses were task focused and attended solely to the physical well-being of the patient. For example, one caregiver stated “the nurse would come to clean the wound but would have no conversation” (Hynninen et al., 2015, pg. 3696). Furthermore, the relatives complained about the hardships of communicating with doctors. They explained that they would be at the patient’s bedside “many hours out of the day without seeing a doctor, in spite of the repeated requests” (Hynninen et al., 2015, pg. 3696). Both the family members and the patients felt ignored when there was no discussion between them and the healthcare professionals.

Finally the study by Moyle et al., (2016) aimed to explore the role and needs of the family caregiver across different acute care settings and their level of involvement in the care of their relatives with dementia. In this study, a convenience sample of 30 family caregivers directly involved in the care of a relative with dementia across three different acute care sites in Australia completed semi-structured interviews. As in the studies mentioned above, this study also found that the lack of information sharing and communication from nurses and doctors led to feelings of disappointment in family caregivers. A majority of the family caregivers “indicated information sharing as the highest priority need” ( pg.31) for them, since the person with dementia was not able to independently or reliably relay any information to the family member regarding what healthcare providers may have discussed with the patient. Family caregivers reported that they wanted to be kept informed at all times in regard to the person’s medical condition, plan of care and discharge; however, they believed that access to such information was made more difficult due to the lack of access to medical staff. Family caregivers expressed frustration as they were not able to coordinate times to meet with doctors and when they did they

felt rushed and their questions were never really answered. One caregiver stated that the information that was shared by doctors was in complicated medical terms that were incomprehensible, which further hindered the family caregiver's sharing of that information with the patient and with other family members. When it came to meeting the psychosocial needs of the patient, family caregivers expressed the need for "medical staff to value and treat the patient as a person, rather than a medical diagnosis" (pg.32). Similar to the other studies, the family caregivers voiced the importance of making conversation with the patients when completing physical tasks. Overall, family caregivers felt they had an important role to play in providing advocacy, companionship, support and information sharing for the patient with dementia (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016).

### **Knowledge and quality of care**

In all five of the studies, family caregivers identified that nurses working in the medical or surgical units had poor understanding of dementia and were inexperienced with the needs of patients with dementia, which led to poor patient outcomes (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016).

In the Dunbar & Gardiner (2007) study, family caregivers expressed that the nurses lacked understanding of dementia. For example, one caregiver expressed that "nurses did not understand her mother's condition or her specific needs and they were totally at a loss to understand how to treat her" (pg. 29). Another caregiver described how a nurse pulled the family aside to tell them that their father was a "little muddled" when they already knew about his dementia, further showing a lack of her understanding of the condition (pg. 29). Care staff frequently failed to recognize and also draw on the expertise of the family caregivers when

planning and implementing care. Consequently, those patients with dementia who were once independent with their care and mobilization became dependent on all aspects of care while in the hospital.

In the Jurgens' et al. (2012) study, family caregivers questioned the staff's training, attitudes and accountability. They commented on how the nursing staff seemed young and inexperienced. For example, one caregiver described how the nursing staff appeared to avoid the older patients and, "they seemed scared of them because they didn't know how to handle them" (pg.4). As a result of this neglect, family caregivers voiced the need to be present with their family members to assure that they were cared for appropriately. Some of the indicators of poor care were soiled sheets, catheter insertions, cracked lips, and physical isolation and loneliness. Further, the professionals' ability to manage patient agitation and pain were used by family caregivers to judge the competence of healthcare professionals. Interestingly, in this particular study family caregivers also viewed poor communication as an indication of inexperienced staff.

In the study by Spencer et al., family caregivers from the standard medical units expressed that the staff had limited understanding and training of dementia, which resulted in patients being ignored, shouted at, or threatened when staff were faced with uncooperative or challenging situations. To explain the actions of some nurses on the ward, a nurse commented that it was a 'mixed medical ward that was not equipped to deal with dementia patient' (pg. 4). Family members complained about the quality of care that their loved ones were receiving. For example, some patients were found by family caregivers with excrement under their fingernails, in wet beds or unwashed. Others witnessed patients being undressed in public bays and also bathroom doors being left open, exposing female patients to male patients. These actions were attributed to staff inexperience in delivering care to confused patients. Hence, family caregivers

felt the need to provide one to one care to their family members and act as advocates to assure their family member's needs were being met. In contrast, the family caregivers from the MMHU described staff as being well prepared for dealing with confused patients, and as displaying patience and compassion.

Similar to the Jurgens et al., (2012) study, the Hynninen et al., (2015) study also found that family caregivers associated poor pain management of patients with dementia as an indication of a lack of understanding from the health care professionals. In the Hynninen et al., study, family caregivers indicated that their family members required assistance with basic needs such as bathing and feeding. The nurses often provided verbal instructions to the family members which were often insufficient, and most of the time the nurses were not available for additional 'hands on' guidance. Furthermore, in the absence of family caregivers, when these patients would present with challenging behaviors, nurses were quick to use physical and chemical restraints. Family caregivers explained how the use of physical and chemical restraints further limited the patient's mobility and cognitive function, leading to other complications. In most cases, family caregivers expressed frustration with and distrust of the healthcare professionals caring for their loved ones. The family caregivers felt they needed to be with the patient for long hours leading to their own exhaustion.

Finally, the study by Moyle et al., (2016) echoed the findings of the previously discussed studies in that family caregivers noted that staff had poor understanding of dementia and, therefore, failed to provide appropriate support to the patients. One indicator of the lack of knowledge about dementia that was unique to this study was that some of those working on the ward made negative and hurtful statements about the patients to the family caregivers.

It was evident that when family caregivers identified gaps in care or observed poor clinical practices they felt obligated to be with their relatives during the course of their hospitalization. Family caregivers participated in assuring the psychosocial needs of their relatives were being met by actively communicating with them and doing the various activities that they enjoyed (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Hynninen et al., 2015; Moyle et al., 2016). Other family caregivers were directly involved in providing direct physical care to their relatives, by assisting them with washes and keeping their surrounding bedside area clean (Spencer et al., 2013).

### **The acute care environment**

The acute care setting is identified as a busy and fast paced environment with a constant shift in staff that has a negative impact on patients with dementia (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Family caregivers described the acute care setting as a strange environment with unfamiliar faces that was frightening for patients, which contributed to negative effects such as refusal to eat or drink leading to further deterioration in well-being (Dunbar & Gardiner, 2007).

Jurgens et al., (2012) reported the stresses of the emergency room and the admission process. Some family members reported that because of their experience from previous admissions, they purposely delayed admission, “worrying that the process would be more harmful than the physical illness” (pg.3). The emergency room was described to be an extremely busy and noisy environment with long waiting periods that not only created distress for the patients leading to challenging behaviors, but also resulted in the exhaustion of caregivers who were trying to keep their loved ones feeling protected and safe (Jurgens et al., 2012). Family caregivers from studies by Spencer et al., (2013) and Hynninen et al., (2015) indicated that the



physical environment, and specifically the noise, lack of privacy and quiet space, and décor of the general medical and surgical ward were not appropriate for their family members with dementia. In addition, some family caregivers from the standard wards believed that behaviors displayed by the patients, such as wandering and vocalization, could have been prevented if activities were available to alleviate their boredom and give options other than being confined to their room (Spencer et al., 2013). The family caregivers from the MMHU were appreciative of the availability of a large room and the coordination of activities, but some stated that their family members were too ill to attend (Spencer et al., 2012). Finally, family caregivers from the Moyle et al., (2016) study commented that the busy environment of the hospital was confusing and overwhelming. The constant shifts in staff were not only disruptive to the patients' well-being, but also made the transfer of information and communication between the patient or family caregiver and the healthcare professionals very challenging.

### **CHAPTER THREE: DISCUSSION OF FINDINGS**

The aim of this integrative literature review was to explore the family caregiver's perspectives on the care that was being provided for their relatives with dementia in the acute care setting. From the literature that was reviewed, the findings indicate that family caregivers perceived hospitalization to be an overall negative experience for their family members with dementia. There were three major themes that emerged as barriers to providing optimal care and PCC to the patient with dementia: communication, knowledge and the environment.

In the studies reviewed in this paper, it was clear that there was a lack of communication occurring either between the patient and healthcare professional dyad; the patient, healthcare professional and family caregiver triad (Adams and Gardiner, 2005); or between the interdisciplinary team members themselves, which led to poor patient outcomes. For nurses,

knowing how to communicate with patients with dementia is vital to every intervention (Weitzel et al., 2011). Dementia impairs normal communication due to changes in receptive and expressive language (Alzheimer's Society of Canada, 2016; Weitzel et al., 2011). Affected patients exhibit memory loss, decreased attention span, impaired judgement, decreased insight, impaired abstraction and diminished visual/spatial abilities (Weitzel et al., 2011). Therefore, it is imperative for nurses to use appropriate communication techniques to interact effectively with dementia patients and provide quality care (Weitzel et al., 2011). However, this was far from what was stated by family caregivers from the studies reviewed in this paper. Family caregivers reported nurses to be task orientated, with minimal to no conversation at all with the dementia patients; and to be distant from the patient, making no effort towards building a therapeutic relationship (Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Nurses would focus on and complete the physical task related to the medical illness and then move on, leaving patients with a sense of loneliness and even neglect (Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). The Alzheimer's Association (2016) stresses that ongoing communication is important no matter how confused the patient with dementia becomes. Communication is basic to the development of relationships, and being responsive to another person involves listening to that person in order to understand the message they are trying to relay (Grover, 2005). Poor communication gives rise to misunderstandings and conflict that can further compromise the provision of care. Valuing a person as an individual is essential in providing PCC to the person with dementia (Kitwood, 1997). Depersonalization of patients and treating them like objects or seeing them merely as the medical diagnosis they have been given does not demonstrate PCC; nonetheless, such objectification by healthcare professionals is an observation prevalent in the studies reviewed in this paper.

Family caregivers viewed themselves as patient advocates in all of the studies reviewed in this paper (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). In light of the fact that patients with dementia have a progressive decline in cognitive function, the central role of family caregivers as stakeholders in the care of people with dementia has been emphasized (Adams & Gardiner, 2005). In addition to the communication impairments discussed above, people with dementia may also have memory loss, changes in mood and personality, problems with language and abstract thinking and also a loss of initiative (Alzheimer's Society of Canada, 2016). The role of the family caregiver is to act as an advocate for the patient with dementia, specifically in terms of exchanging knowledge and sharing information about the patient with the healthcare professionals, in order to have shared decision making in the provision of their relative's care (Lindhardt, Nyber & Hallberg, 2008). Sharing information about the patient's needs and abilities related to their dementia promotes understanding and individualized care for the patient in an effort to achieve PCC. However, the studies reviewed in this paper identified a lack of communication and information sharing amongst family caregivers and health care professionals (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Family caregivers have invaluable information about their relatives that would assist health care providers in efficiently providing individualized care. However, it was evident that the nurses did not collect personal information about the patients with dementia in the emergency room or on the standard medical or surgical wards. The information that was collected focused on the medical history or was used only towards discharge planning (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). There was only one instance identified in this review, namely the MMHU, where patient's biographical information was

shared between the family caregivers and the nurses and used by nursing staff in implementing individualized care (Spencer et al., 2013). The specific aim of this particular unit was to provide PCC for patients with dementia (Spencer et al., 2013). Overall, the family caregivers were satisfied with the care that their relatives received on the MMHU (Spencer et al., 2013). The family caregivers from the standard medical and surgical wards voiced concerns for their relatives' well-being, since there was a lack of communication and information sharing. Family caregivers believed that if the nurses had incorporated the shared information about the needs of their relatives with dementia into the nursing care plan it could have prevented the challenging behaviors displayed by their relatives (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016).

Communication between the doctors and family caregivers seemed to be next to impossible. Family caregivers would spend long hours at the patient's bedside or go days without seeing a doctor (Jurgens et al., 2012; Spencer et al., 2013; Moyle et al., 2016). Family caregivers expressed the need to have shared decision making in regards to the care provision for their relatives. As discussed above, with their cognitive decline, patients with dementia might not be competent in making decisions in regards to their own care, so it would be imperative for family caregivers to collaborate with healthcare professionals in making such decisions (Lindhart et al., 2008). Family caregivers questioned the exchange of information between the nurses and doctors, indicating that there was a lack of communication between the healthcare professionals themselves that further limited the communication ties between the triad and contributed to poor patient outcomes (Jurgens et al., 2012; Spencer et al., 2013; Moyle et al., 2016). Those family caregivers that managed to meet with the doctor felt rushed and dissatisfied overall with the entire experience (Moyle et al., 2016). For example, family caregivers mentioned that the

language that was used by the physicians to explain the relative's condition was incomprehensible (Moyle et al., 2016). It is important for health care professionals to communicate in layman's terms, rather than using medical jargon, so that family caregivers can comprehend the information that is being provided, pass on the information accurately to the patient and other relatives involved, and so that there can be effective decision making and sharing of information in the provision of care for their relatives with dementia (Lindhart et al., 2008).

When the family caregivers felt that there was a lack of information being shared about their relatives, they felt a need and responsibility to be present with their relatives in the hospital and be involved in their overall care. (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Some family caregivers became suspicious of the quality of care that was being provided to their patients and felt they needed to be with their relatives to assure that their personal needs were being met and that they were safe, since they were not able to communicate effectively on their own due to their dementia (Jurgens et al., 2012).

The second important theme that emerged as a barrier to optimal care of patients with dementia was knowledge. Family caregivers identified that nurses working on the standard medical and surgical wards had poor understanding of dementia and were inexperienced with the needs of the patients with dementia (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Care of older adults within the acute care setting has consistently been criticized for being inadequate because of the lack of experience of the nurses in accurately assessing the needs of this population (Tadd et al., 2011; Clissett et al., 2013b; Baumbusch et al., 2016). Family caregivers associated gaps in care and poor nursing

practices as a lack of knowledge in dementia care. First, poor management of pain was an identifier by family caregivers as poor nursing practice (Jurgens et al., 2012; Hynninen, et al., 2013). For example, pain assessments were not performed by the nurses, which contributed to the patient's reluctance to move. These findings are supported by other studies that have identified that pain is often left untreated for patients with dementia (Zwakhalen et al., 2012). The lack of ability to recognize pain or use appropriate pain scales to assess pain effectively for the patient was demonstrated as a poor nursing practice (Zwakhalen et al., 2012). As well, the nurses' expectation of the patients' involvement in their own care or understanding of actions was unacceptable to the family caregivers and further demonstrated the lack of understanding about dementia. In some studies reviewed in this paper, a few nurses assumed patients with dementia would be able to care for themselves when it came to bathing and eating, so they would provide verbal instructions with minimal to no physical guidance (Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Patients with dementia may not be effective at following verbal instructions and there is often a need for them to have physical guidance or assistance in completing tasks, especially if their dementia is in moderate to advanced stages (Alzheimer's Association of Canada, 2016). Lastly, family caregivers expressed that the use of physical restraints and chemical restraints by the nurses further demonstrated their inability to effectively communicate or recognize the dementia patient's needs (Hynninen et al., 2015). Consequently, the needs of patients were discredited and disregarded, which in turn has the potential to lead to inadequate health assessments and resulted in delirium, falls, dehydration, inadequate nutrition and untreated pain (Weitzel et al., 2011).

Although family caregivers from the standard medical and surgical wards expressed dissatisfaction with the quality of care for their relatives; the family caregivers on the Medical

and Mental Health Unit (MMHU) were satisfied with the nursing staff's knowledge and the delivery of professional care (Spencer et al., 2013). They further stated that the nurses were well prepared for dealing with confused patients, displaying patience and compassion (Spencer et al., 2013). The MMHU is a specialized medical unit where nurses have special education and training to provide care to patients with dementia and delirium (Spencer et al., 2013). The model of having a specialized unit on which healthcare professionals are equipped with the knowledge and training needed to effectively provide care to patients with dementia is likely a step in the right direction. Similarly, the Acute Care for the Elderly (ACE) unit, while not specific to dementia, is a specialized unit that addresses the needs of hospitalized older adults. Research has shown that older adults on ACE units have improved outcomes compared to the older adults on the standard medical units because of the specialized education and training that staff members receive (Krall et al., 2012). Evidence shows that there are decreased fall rates, UTIs and pressure ulcers on ACE units with an overall improvement in the older adult's functional ability (Krall et al., 2012).

The final theme focuses on the acute care environment itself as a barrier to appropriate service provision to patients with dementia. The acute care setting is not seen as an ideal place for patients with dementia and the studies reviewed in this paper have reported suboptimal care for patients with dementia while in the acute care environment (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). The acute care setting was identified as a busy and fast-paced environment with constant staff changes (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Consequently, the unfamiliar and unpredictable environment puts these patients in particular at risk for delirium, falls, dehydration, inadequate nutrition, untreated pain

and unmet spiritual needs (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). In the study by Nolan (2007), nurses indicated that the acute care setting is suitable for those without cognitive impairment, indicating that patients with dementia, which involves cognitive deterioration, are not perceived as a homogenous group for this environment. In addition, other studies have indicated that the acute care settings physical layout is not suitable for the care needs of the older adults in general (Tadd et al., 2011; Baumbusch et al., 2016).

As a result of the cognitive impairment, patients with dementia are highly vulnerable to changes in their environment (Alzheimer's Association, 2016). The acute care setting consists of multiple stimuli that can be bewildering for the patients with dementia. For example, there are many acoustic stimuli alone which can be alarming to a dementia patient, such as the ringing of call bells and phones, noises from televisions and medical equipment, the scuffle of conversations between the various hospital staff, visitors, other patients, the constant closing of doors, and the sounds of patients being transported. It has been identified that behavioral issues associated with dementia are increased with changes to their environment (Alzheimer's Association, 2016; Weitzel et al., 2011; Nolan, 2007). The expectations of the acute care environment to push for higher numbers of patients and rapid treatment exacerbates the situation for people with dementia as they are not able to conform to such ethos (Nolan, 2007, p.419). The delivery of care in this setting focuses on medical diagnoses and physical assessments in the absence of consideration for the emotional and psychological needs of the patients with dementia (Dunbar & Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016).



The emergency room also negatively impacted the patients with dementia. Specifically, the long wait times and busy environment frightened and agitated the patient with dementia (Jurgens et al., 2012). In addition, the open concept design of the emergency department is ineffective for care of the acutely ill patient, a design that produces a bustling, overcrowded, noisy space adds additional stress to the dementia patient and contributes to the agitated and aggressive behaviors that may result (Clevenger et al., 2012). Interestingly, when nurses placed these patients in the same common waiting area as the general patient population, family caregivers identified this as the nurse's lack of knowledge in recognizing the negative effects that the patient with dementia would experience being in this type of setting (Jurgens et al., 2012).

The physical and poorly designed environment of the standard medical and surgical wards seemed to meet the needs of the general adult population, but not those of older adults with dementia (Dunbar and Gardiner, 2007; Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). Family caregivers voiced dissatisfaction with the patient rooms and the physical design of the ward that was not ideal for the cognitively impaired patient. They described the rooms to be small and plain which limited privacy and personal space for the patients and they described the wards to be cluttered and noisy with a poor layout (Spencer et al., 2013; Hynninen et al., 2015; Moyle et al., 2016). There was a lack of privacy in the rooms and there was a lack of dignified care being provided to patients. From the studies reviewed in this paper, family caregivers provided anecdotal evidence indicating that their family members with dementia were being exposed to other patients while using the bathroom or being changed in public areas in front of other patients, visitors and hospital personnel (Spencer et al., 2013). The patient with dementia thrives in a positive environment. This positive environment consist of minimal noises, warm colors on the wall, large, clean and tidy halls, large patient rooms that are

personalized with familiar pictures, and open areas in which to safely walk and do various activities (Alzheimer's Australia, 2004; Weitzel et al., 2011; Baumbusch et al., 2016). It is important for the acute care setting to adapt their physical environment to make it one that will promote individualized and dignified care for dementia patients.

## **CHAPTER FOUR: LIMITATIONS, RECOMMENDATIONS AND CONCLUSION**

### **Limitations**

There are limitations in this integrative literature review. First, only five studies were included in this integrative literature review, which were conducted in countries other than Canada. Three of the studies were from the United Kingdom, one was from Finland and another from Australia. The finding from these studies may not be generalizable to the acute care system in Canada due to the differences in the health care systems. Second, the sample sizes from the Dunbar & Gardiner (2007) study and the Hynninen et al., (2015) study were relatively small. Third, in three of the qualitative studies, family caregivers were interviewed four to six weeks after the hospitalization of their relative with dementia which might influence perceptions and interpretations of their experiences in the hospital (Jurgens et al., 2012; Spencer et al., 2013; Hynninen et al., 2015). Finally, in one of the qualitative studies, some family caregivers were interviewed while their relative with dementia was present which might have limited what was said openly by the family caregiver (Jurgens et al., 2012).

### **Recommendations**

#### **Research**

In this paper studies conducted in the United Kingdom, Finland and Australia have been reviewed. This literature review has shown that there are a number of common barriers to quality care of patients with dementia in the acute care setting across locations. However, it is necessary to conduct qualitative studies to explore family caregiver perspectives on the delivery of care to patients with dementia in the acute care setting specifically within Canada. Only after such studies have been conducted can the findings then be transferable within the Canadian health care system. It is important to have a

large sample size of participants from different hospitals in Canada and varying acute care units (for example, the emergency departments, the surgical units and medical units, the sub-acute units and the rehabilitation units) to further encourage transferability of findings. In addition, it would be ideal to conduct interviews with family caregivers at different times during the hospitalization of their relative with dementia, in an effort to increase maximum variation in narratives (Moyle et al., 2016). In addition, it is essential to conduct intervention studies on the various acute care units to prove the benefits of PCC care strategies.

### **Practice**

It is vital to encourage collaboration between nurses and family caregivers and to build relationships in an effort to provide PCC for the patients with dementia. First, it is imperative to create a culture of effective communication, where open dialogue between the family caregivers and nurses is encouraged so that beneficial relationships can be formed in an effort to improve patient care. In addition to promoting PCC, nurses need to facilitate more hands on care by family caregivers that may provide the *quid pro quo* to improve outcomes patient outcomes within a resource-constrained health care system (Spencer et al., 2013). Furthermore, effective communication between the nurses themselves is necessary to encourage a continuum of care that promotes effective and safe nursing practices. A unit culture that promotes PCC to patients is essential; however, it cannot be accomplished by the nurses and family caregivers alone. It is critical that all stakeholders involved in the care of the patient with dementia, including those at the organizational level, be on par with making better care provision the goal and assuring

that the unit culture and environment is equipped with the essential resources that will make a PCC philosophy possible.

### **Education**

All nurses working in the various acute care environments need to be educated and trained to work with dementia patients and to effectively communicate with family caregivers. They should be trained to recognize signs of agitation and anxiety that may be displayed by the dementia patient and also to communicate effectively and in a calm manner with a patient demonstrating such signs. Nurses will need to recognize that family caregivers have invaluable insight into the care needs of the patient with dementia which can provide guidance to them in completing all the medical, physical and psychosocial needs for the patient effectively and efficiently. Seeing the family caregivers as the first point of contact for information gathering, rather than solely conducting a medical assessment and assessing and questioning the patients themselves is unique to this diagnosis and may not have been part of traditional nursing training. Family caregivers and nurses will need to collaborate and create a plan of care that best fits the dementia patient's needs. In addition, it is essential to have a geriatric nurse specialist on the unit to continue mentoring nurses and to be actively involved in the care planning of dementia patients to ensure that the PCC philosophy is being applied effectively. Finally, unit managers need to be proactive about assuring that all essential education and training is available to the nurses on the unit to promote this care philosophy.

## Conclusion

It is clear from the studies reviewed in this paper that family caregivers were dissatisfied with the overall care being provided to their relatives with dementia during their admission to the acute care setting. It has been identified that Person-Centered Care (PCC) is the best practice for older patients with dementia (Alzheimer's Society of Canada, 2016; Spencer et al., 2013).

However, it has been shown that the acute care setting's strong medical focus built on medical and organizational efficiency is at odds with the core concepts of PCC, which center around respecting and valuing personhood despite cognitive impairment (Skaalvik, Normann & Henriksen, 2010). This dichotomy between two medical models makes it difficult to balance and incorporate the psychosocial needs and medical needs for the dementia patients in the acute care setting and leads to poor patient outcomes. Family caregivers have identified three main barriers within the acute care setting that contributed to their dissatisfaction with the overall care for their relatives with dementia. First, the lack of communication and information sharing between the patient, family care giver and healthcare professional; second, the healthcare professional's lack of knowledge about dementia and the care needs of patients with dementia; and third, the acute care environment structure and processes. As a result, family caregivers expressed the need to be present with their relatives that have dementia to assure their safety and well-being.

On the other hand, there is evidence amongst family caregivers who have expressed overall satisfaction for the care of their relatives with dementia on units, such as the MMHU, which have incorporated the PCC philosophy into their physical environment and functionality (Spencer et al., 2013). The family caregivers expressed overall satisfaction with the communication and information sharing on this particular unit; the healthcare professionals were knowledgeable about dementia and were trained to effectively deal with challenging behaviors

efficiently; and the physical environment was large, open and inviting. The MMHU model should be used as a model for other acute care units to follow when it comes to the provision of ideal care for individuals with dementia.

It is important for healthcare providers to take into consideration the gaps identified by the family caregivers, as detailed in this paper, and try to eliminate these gaps in order to promote and provide PCC for patients with dementia. As our population continues to age, the prevalence of older adults with dementia admitted to the acute care setting will also increase. It is crucial for all stakeholders involved in the care of older adults with dementia to collaborate in creating conditions fostering a culture of PCC in the acute care setting. The nursing profession needs to become more adaptable to the changing needs of these aging adults with dementia. Specifically, this would require the unit managers to create and promote a culture of PCC by having the resources available for nurses to be able to effectively provide PCC to their patients with dementia. It is essential for family caregivers to be actively involved and included in patient care and decision making; therefore, an open dialogue is imperative between the healthcare team and the family caregivers. Applying the PCC philosophy in caring for patients with dementia will promote a positive environment that will promote overall well-being for the patients with dementia and all stakeholders involved in their care.

## 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*. Retrieved July 17,

2016, from [https://fightdementia.org.au/files/20040600\\_Nat\\_NP\\_3DemCareBuiltEnv.pdf](https://fightdementia.org.au/files/20040600_Nat_NP_3DemCareBuiltEnv.pdf)

Alzheimer's Association (2016). *Communication and Alzheimer's*. Retrieved July 17, 2016, from

<https://www.alz.org/care/dementia-communication-tips.asp>

Alzheimer's Society of Canada (2016). *What is Dementia?* Retrieved on April 15, 2016, from

[http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Dementia-numbers#DynamicId\\_2](http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Dementia-numbers#DynamicId_2)

Alzheimer's Society of Canada (2016). *Types of Dementia*. Retrieved on April 15, 2016, from

<http://www.alzheimer.ca/en/About-dementia/Dementias>

Alzheimer's Society of British Columbia (2016). Retrieved on April 15, 2016, from

<http://www.alzheimer.ca/en/bc/About-dementia/What-is-dementia/Dementia-numbers-BC>

Baumbusch, J., Leblanc, M., Shaw, M., & Kjørven, M. (2016). Factors influencing nurses'

readiness to care for hospitalized older people. *International Journal of Older People*

*Nursing*, 11(2), 149-159. doi:10.1111/opn.12109

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

Canadian Institute for Health Information (CIHI) (2011). *A Focus on Senior's and Aging*.

Retrieved on May 1, 2016, from

[https://secure.cihi.ca/free\\_products/HCIC\\_2011\\_seniors\\_report\\_en.pdf](https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf)

Canadian Nurses Association (2016). *Dementia in Canada: Recommendations to support care*

*for Canada's Aging Population*. Retrieved on July 18, 2016, from [https://www.cna-](https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/dementia-in-canada_recommendations-to-support-care-for-canadas-aging-population.pdf?la=en)

[aiic.ca/~media/cna/page-content/pdf-en/dementia-in-canada\\_recommendations-to-support-care-for-canadas-aging-population.pdf?la=en](https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/dementia-in-canada_recommendations-to-support-care-for-canadas-aging-population.pdf?la=en)

Chenoweth, L. (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. *Lancet Neurol*, 8(4), 317-325. doi:10.1016/S1474-4422(09)70045-6

Chief Public Health Officer (2014). *Report on the State of Public Health in Canada: Public*

*Health in the Future*. Retrieved on May 1, 2016 from [http://www.phac-](http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2014/chang-eng.php)

[aspc.gc.ca/cphorsphc-respcacsp/2014/chang-eng.php](http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2014/chang-eng.php)

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 the American Geriatrics Society*, 60(9), 1742-1748. doi:10.1111/j.1532-

5415.2012.04108.x

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
- Douglas-Dunbar, M., & Gardiner, P. (2007). Support for carers of people with dementia during hospital admission. *Nursing Older People*, 19(8), 27.
- 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.
- Eriksson, C., & Saveman, B. (2002). Nurses' experiences of abusive/non-abusive caring for demented patients in acute care settings. *Scandinavian Journal of Caring Sciences*, 16(1), 79-85. doi:10.1046/j.1471-6712.2002.00061.x
- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: Cluster randomised trial. *BMJ: British Medical Journal*, 332(7544), 756-758. doi:10.1136/bmj.38782.575868.7C
- Gerace, A., Mosel, K., Oster, C., & Muir-Cochrane, E. (2013). Restraint use in acute and extended mental health services for older persons. *International Journal of Mental Health Nursing*, 22(6), 545-557 13p. doi:10.1111/j.1447-0349.2012.00872.x
- Grover, S. M. (2005). Shaping effective communication skills and therapeutic relationships at work: The foundation of collaboration. *AAOHN Journal : Official Journal of the American Association of Occupational Health Nurses*, 53(4), 177.

- Hynninen. (2015). Treatment of older people with dementia in surgical wards from the viewpoints of the patients and close relatives. *Journal of Clinical Nursing*, 24(23-24), 3691; 3691-3699; 3699.
- Jurgens, F. J., Clissett, P., Gladman, J. R. F., & Harwood, R. H. (2012). Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. *BMC Geriatrics*, 12(1), 57-57. doi:10.1186/1471-2318-12-57
- Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham
- Krall, E., Close, J., Parker, J., Sudak, M., Lampert, S., & Colonnelli, K. (2012). Innovation pilot study: Acute care for elderly (ACE) unit- promoting patient-centric care. *Herd-Health Environments Research & Design Journal*, 5(3), 90-98.  
doi:10.1177/193758671200500309
- Lindhardt, T., Hallberg, I. R., Poulsen, I., Medicinska fakulteten, Department of Health Sciences, Faculty of Medicine, . . . Lund University. (2008). Nurses' experience of collaboration with relatives of frail elderly patients in acute hospital wards: A qualitative study. *International Journal of Nursing Studies*, 45(5), 668-681.  
doi:10.1016/j.ijnurstu.2007.01.010
- Love, K., & Pinkowitz, J. (2013). Person-centered care for people with dementia : A theoretical And conceptual framework. *Generations*, 37(3), 23-29 7p.
- Marengoni, A., Corrao, S., Nobili, A., Tettamanti, M., Pasina, L., Salerno, F., . . . Mannucci, P.

- M. (2011). In-hospital death according to dementia diagnosis in acutely ill elderly patients: The REPOSI study. *International Journal of Geriatric Psychiatry*, 26(9), 930-936 7p. doi:10.1002/gps.2627
- Maslow, K. (2013). Person centered care for people with dementia: Opportunities and challenges. *Generations*, 37(3), 8-15 8p.
- McCloskey, R. M. (2004). Caring for patients with dementia in an acute care environment. *Geriatric Nursing*, 25(3), 139-144. doi:10.1016/j.gerinurse.2004.04.006
- McCloskey, R., Jarrett, P., Stewart, C., & Nicholson, P. (2014). Alternate level of care patients in hospitals: What does dementia have to do with this? *Canadian Geriatrics Journal*, 17(3), 88-94 7p. doi:10.5770/cgj.17.106
- McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *International Journal of Older People Nursing*, 13,31-38.
- McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, 56(5), 472-479 8p. doi:10.1111/j.1365-2648.2006.04042.x
- Mecocci, P., von Strauss, E., Cherubini, A., Ercolani, S., Mariani, E., Senin, U., . . . Fratiglioni, L. (2005). Cognitive impairment is the major risk factor for development of geriatric syndromes during hospitalization: Results from the GIFA study. *Dementia and Geriatric Cognitive Disorders*, 20(4), 262-269. doi:10.1159/000087440
- 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
- Moyle, W., Bramble, M., Bauer, M., Smyth, W., & Beattie, E. (2016). ‘They rush you and push you too much ... and you can't really get any good response off them’: A qualitative examination of family involvement in care of people with dementia in acute care. *Australasian Journal on Ageing*, 35(2), E30-E34. doi:10.1111/ajag.12251
- Nilsson, A., Lindkvist, M., Rasmussen, B. H., & Edvardsson, D. (2013). Measuring levels of person-centeredness in acute care of older people with cognitive impairment: Evaluation of the POPAC scale. *BMC Health Services Research*, 13(1), 327-327. doi:10.1186/1472-6963-13-327
- Nolan, L. (2007). Mental health. Caring for people with dementia in the acute setting: study of nurses' views. *British Journal Of Nursing*, 16(7), 419-422.
- Preyde, M., & Brassard, K. (2011). Evidence-based risk factors for adverse health outcomes in older patients after discharge home and assessment tools: A systematic review. *Journal of Evidence-Based Social Work*, 8(5), 445-468. doi:10.1080/15433714.2011.542330
- 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.
- Skaalvik, M.W., Normann, H.K., Henriksen, N. (2010). Student experiences in learning personcentred 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., Hoeffler, B., Mitchell, C. M., McKenzie, D. A., Barrick, A. L., Rader, J., . . . Koch,

- G. G. (2004). Effect of Person-Centered showering and the towel bath on Bathing-Associated aggression, agitation, and discomfort in nursing home residents with dementia: A randomized, controlled trial. *Journal of the American Geriatrics Society*, 52(11), 1795-1804. doi:10.1111/j.1532-5415.2004.52501.x
- Spencer, K., Foster, P., Whittamore, K. H., Goldberg, S. E., & Harwood, R. H. (2013). Delivering dementia care differently--evaluating the differences and similarities between a specialist medical and mental health unit and standard acute care wards: A qualitative study of family carers' perceptions of quality of care. *BMJ Open*, 3(12), e004198.
- Statistics Canada (2015). *Age standardized mortality rates for the 10 leading causes of death, Canada, 2000-2009*. Retrieved on May 1, 2016, from <http://www.statcan.gc.ca/pub/84-215-x/2012001/tbls-eng.htm>
- Statistics Canada (2011). *Canadians in context- Aging Population*. Retrieved May 1, 2016 from <http://well-being.esdc.gc.ca/misme-iowb/.3ndic.1t.4r@-eng.jsp?iid=33>
- Statistics Canada (2008). *Eldercare: What we know today*. Retrieved on May 1, 2016 from <http://www.statcan.gc.ca/pub/11-008-x/2008002/article/10689-eng.htm>
- 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.
- Torraco, R. J. (2005). Writing integrative literature reviews: Guidelines and examples. *Human Resource Development Review*, 4(3), 356-367.

Villars, H., Dupuy, C., Soler, P., Gardette, V., Soto, M. E., Gillette, S., . . . BrunoVellas. (2013).

A follow-up intervention in severely demented patients after discharge from a special alzheimer acute care unit: Impact on early emergency room re-hospitalization rate.

*International Journal of Geriatric Psychiatry*, 28(11), 1131-1140. doi:10.1002/gps.3932

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

Weitzel, T., Robinson, S., Barnes, M. R., Berry, T. A., Holmes, J. M., Mercer, S., . . . Kirkbride,

G. L. (2011). The special needs of the hospitalized patient with dementia. *Medsurg Nursing : Official Journal of the Academy of Medical-Surgical Nurses*, 20(1), 13- 18.

World Health Organization (2016). *Dementia*. Retrieved on April 15, 2016 from

<http://www.who.int/mediacentre/factsheets/fs362/en/>

Zwakhale, S. M., Hof, C. E., & Hamers, J. P. (2012). Systematic pain assessment using an observational scale in nursing home residents with dementia: Exploring feasibility and applied interventions. *Journal of Clinical Nursing*, 21(21-22), 3009-3017.  
doi:10.1111/j.1365-2702.2012.04313.x