

Emergency Nurses' Experiences of Caring for Patients with Dementia

by

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Abstract

There is evidence that older Canadians have a higher incidence of presenting to the emergency department (ED) than any other age group. These visits may be made more complex if individuals are also cognitively impaired or have dementia. The purpose of this study was to explore ED nurses' experiences of caring for adults with dementia in the ED. Using an interpretive descriptive approach, 12 registered nurses working in different EDs in an urban setting in Western Canada were interviewed about these experiences. Using the thematic analysis process described by Braun and Clarke, four themes were identified: 1) not a priority; 2) not the right place; 3) get them in, get them out; and 4) getting it wrong. The nurses identified that challenges in the care of persons with dementia in the ED are created by the fast-paced and chaotic environment of the ED, staffing, issues with disposition, and safety concerns. Suggestions for improving the care of persons with dementia were provided by the nurses.

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Chapter 1: Introduction and Background to Study

Globally, the population of older adults, defined here as adults with the chronological age of 65 years of age or older, is on the rise. In Canada, older adults are the fastest growing age group, with their numbers expected to double by 2036 (Center for Addiction and Mental Health, 2011). There is evidence that this group has a higher incidence of presenting to the emergency department (ED) than any other age group (Canadian Institute for Health Information, 2011; McCusker, Karp, Cardin, Durand, & Morin, 2003; Parke et al., 2013). These visits to EDs may be made more complex if individuals are also cognitively impaired or diagnosed with dementia. Of interest to this proposed study are nurses' experiences of caring for adults with dementia in the emergency department. Few studies to date have explored ED nurses' experiences and nurses are in an ideal position to provide interesting insights regarding the care of persons with dementia in emergency settings.

In this chapter, background information is presented about the environment of EDs, the care of people with dementia, and the experiences of persons with dementia in the ED. In addition, the study purpose, research questions, and significance are outlined.

Background to Study

In this section of the chapter, the background to the topic of interest, ED nurses' experiences of caring for adults with dementia, is explored. The environment of the ED is examined, dementia is defined, and knowledge related to ED nurses' experiences of caring for people with dementia is considered.

The environment of the ED. An ED is defined as a "24-hour location serving an unscheduled patient population with anticipated needs for emergency medical care, receiving emergency medical services (EMS) transports" (Welch et al., 2011, p. 541). Often a chaotic

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environment, many patients are being assessed, diagnosed, and treated swiftly due to demands in the environment. EDs must treat specific patient health issues as quickly as possible (Rollason, 2014), including carrying out diagnostic tests and caring for and treating multiple patients. These patients often cannot be managed by a family physician because of the gravity of the illness and situation or time of day (Greenlund, 2011). The ED is open 24 hours a day, seven days a week. Within the Winnipeg Regional Health Authority (WRHA), emergency services are provided at six acute care hospitals, including two tertiary and four community facilities, and one urgent care centre (WRHA, 2013). EDs typically have treatment spaces, resuscitation rooms, ambulance offload areas, a triage area, and a waiting room with staff of the emergency team caring for the patients in these spaces. The emergency team may include physicians, nurse practitioners, registered nurses, licensed practical nurses, social workers, occupational therapists, physiotherapists, psychiatric nurses, respiratory therapists, and support staff (WRHA, 2013).

Persons presenting to EDs in Canada are triaged according to the Canadian Triage and Acuity Scale (CTAS). The CTAS system consists of five categories: CTAS I, resuscitation; CTAS II, emergent; CTAS III, urgent; CTAS IV, less urgent; and CTAS V, non-urgent (Canadian Institute for Health Information [CIHI], n.d.). National Ambulatory Care Reporting System (NACRS) data from 2011-2012 in Canada revealed the following about the breakdown of patients presenting to EDs based on CTAS levels: 0.6% resuscitation; 13.5% emergent; 38.6% urgent; 37.1% less urgent; 8.5% non-urgent; 1.7% unknown (CIHI, 2013). Canadian Institute for Health Information (2014) data from 2012-2013 indicated that 55% of people presenting to EDs were categorized as CTAS levels I, II, and III.

The WRHA has identified that over 300,000 people visit emergency departments within the region each year (WRHA, 2014). EDs are known to be stressful and complex work

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environments (Healy & Tyrell, 2011; Redfern, Brown, & Vincent, 2009), and are described as fast-paced, chaotic, and crowded, with many interruptions. EDs are also known to be high-risk environments in terms of patient safety, increasing the potential for medication errors to occur (Berg et al., 2013). Crowding alone has been associated with compromised patient care (Handel et al., 2010), and frequent shift changes and poor communication by health care professionals in this area have also been linked to errors in the ED (Beach, Croskerry, & Shapiro, 2003).

Dementia. Dementia is a term which refers to a large number of progressive, debilitating cognitive disorders that impair a person's functioning. Degenerative brain disease leads to decreased ability to think and remember, and symptoms may include: short-term memory loss; confusion; changes in behavior, mood, personality; and impaired communication and judgment (Alzheimer Society of Canada, 2010; Dalhousie University, 2011; Sendecki, 2013). Dementia is caused by many conditions such as Lewy body disease, multi-infarct disease, fronto-temporal lobular degeneration, Parkinson's disease, and Alzheimer's disease (Maslow & Mezey, 2008). The most common form of dementia is Alzheimer's disease, and although the causes remain unclear, risk factors are believed to include lifestyle, environment, family history, high cholesterol, hypertension, and diabetes mellitus (Alzheimer Society of Canada, 2010). The risk of dementia is more prevalent with increased age, and doubles every five years after the age of 65 years, affecting more women than men (Alzheimer Society of Canada, 2010; Sendecki, 2013). Persons with dementia experience challenges with daily activities and their symptoms exacerbate over time. This disease robs the individual of independence and the ability to function due to the brain's failure to process information (Alzheimer Society of Canada, 2010; Dalhousie University, 2011; Sendecki, 2013).

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Dementia can be reversible or irreversible, reversible if the dementia is due to, for example, tumours or hormonal imbalances, or irreversible due to Alzheimer's disease, vascular dementia, or fronto-temporal dementia (Alzheimer Society of Canada, 2013). A diagnosis of dementia is made using the *Diagnostic and Statistical Manual of Mental Disorders IV* (DSM-IV) criteria, plus additional information gleaned from caregivers, family members, and hospital records (Watkin, Blanchard, Tookman, & Sampson, 2011). It is important to note that dementia is not delirium. Delirium is "a cognitive disorder characterized by acute onset, fluctuating course, and disturbances of attention, consciousness, thinking, perception, psychomotor activity, and sleep-wake cycle" (McCusker et al., 2011, p. 1152). One difference is that delirium is an acute change in cognition, while dementia usually appears and progresses at a slower rate.

The number of adults with dementia is staggering. Worldwide, it is estimated 24.3 million people have dementia (Cowdell, 2010). The Alzheimer Society of Canada estimates that in 2011, cognitive impairment, including dementia, affected 747,000 Canadians and it is anticipated that the numbers will continue to rise to 1.4 million by 2031 (Alzheimer Society of Canada, 2013). Stated another way, a total of 9% of Canadians older than 65 years had dementia in Canada in 2011, and by 2031 that number is projected to double (Sendecki, 2013). In 2015 statistics from the United States, it is estimated that 5.3 million Americans suffer from Alzheimer's disease, which means in people over the age of 65 years, one in nine have Alzheimer's disease in that country (Alzheimer's Association, 2015). Since age is an unchangeable risk factor, the growth of the population with dementia will increase in Canada as the population ages (Alzheimer Society of Canada, 2010). It is suggested that these numbers will have a dramatic impact on the Canadian health care system in the next few decades as costs of dementia care are predicted to rise from \$33 billion a year to \$293 billion a year by 2040

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(Alzheimer Society of Canada, 2013). Many Canadians with dementia still live in the community, while others reside in long-term care facilities. The Winnipeg Regional Health Authority (2012) reported that it sets aside \$348 million a year for the personal care homes in which approximately 80% of the residents living there have some form of cognitive impairment.

While some behaviours associated with dementia may be more readily addressed, such as impaired memory and short attention span, behaviours such as wandering, pacing, hoarding, changed sleep-wake cycles, poor balance, agitation, and hallucinations can create challenges when caring for people with dementia (Sparks, 2008). Best-practice guidelines related to the care of persons with dementia have been developed by different organizations (Alzheimer Society of Canada, 2011; National Collaborating Centre for Mental Health, 2007; Registered Nurses Association of Ontario [RNAO], 2004). Key principles underlying these guidelines include the Registered Nurses Association of Ontario (2004) tenets of care: know the person, relate effectively, recognize retained abilities, and manipulate the environment (p.18). Likewise, the document created by the Alzheimer's Society of Canada (2011) includes the following core concepts: "dignity and respect, information sharing, participation and collaboration" (p. 11). In the United Kingdom (U.K.), the guidelines set out by the National Collaborating Centre for Mental Health (2007) add to this by considering care in acute hospital settings, including the importance of assessment by a clinician with advanced knowledge in patients with dementia and collaboration between this expert clinician, hospital staff, and the patient with dementia and his/her family. The U.K. document identifies overcrowding, lack of privacy, and decreased attention from hospital staff as risks for increasing the challenging behaviours of patients with dementia. Current evidence provides information regarding the importance of meaningful relationships between persons with dementia and caregivers, which is described as person-

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centered care (Alzheimer's Society of Canada, 2011). Person-centered care allows dignified care and honours the personhood of the patient with dementia.

ED nurses and caring for people with dementia. EDs are open 24 hours a day and 7 days a week and function as a “gateway to healthcare” (Rintoul, Wynaden, & McGowan, 2009, p. 123). The ED nurse has traditionally been the first person you meet in the department, and nurses in ED will triage, assess, administer medication and treatments, and provide patient education. Manton (2004) suggests emergency nurses must be knowledgeable in every area of nursing, as the ED is unpredictable and every situation needs efficient and effective assessments followed by timely interventions. ED nurses work closely with physicians to provide care, treat injuries, and promote health (Shoquirat, 2013). Staff in emergency departments (EDs) have felt the impact of long patient wait times and overcrowding (Rollason, 2014), both of which can significantly influence the care ED nurses provide to patients (Bond et al., 2007; Olshaker, 2009).

Given that the occurrence of dementia is on the rise, the number of people with dementia presenting to an ED is also on the rise. It has been shown in one study that the prevalence of patients with cognitive impairment in ED is 40%, and, alone, cognitive impairment is a predictor of ED visits (Parke, Beaith, Slater, & Clarke, 2011). Researchers have identified that persons with dementia have twice as many visits to EDs as older adults without dementia (Ng et al., 2014; Parke et al., 2011). If persons with dementia present to EDs, they may exhibit challenging behaviours that the staff in ED may not necessarily have the resources to respond to or manage. The ED is hectic, loud and overcrowded making it an inappropriate environment for persons with dementia (James & Hodnett, 2009) as they may become stressed in an unfamiliar environment and wander, become agitated, or become aggressive, putting themselves, staff and

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other patients at risk in terms of safety. Being cognitively impaired increases the risk of adverse events in hospitals as patients may be unable to provide an accurate medical history. In addition, the bright lights and long wait times make this environment extremely difficult for persons with dementia, as they may get increasingly confused under these circumstances (Nolan, 2009; Shanley, Sutherland, Tumeth, Stott, & Whitmore, 2009).

Studies have found that nurses perceive that they lack the knowledge needed to care for persons with dementia (Nolan, 2006; Parke et al., 2013). Nurses may also experience frustration when caring for persons with dementia (Parke et al., 2013) for reasons that include the complexity of the care required and the frequent interruptions in the ED environment (Clevenger, Chu, Yang, & Hepburn, 2012). Although the literature highlights the need to improve current practice and staff training to the specific needs of people with dementia and their families (Alzheimer Society of Canada, 2010; Cowdell, 2010; Watkin et al., 2011), current educational opportunities in EDs are usually limited to caring for patients in emergency situations, with limited attention to the complexities of patients with dementia in those situations. It has been reported that few ED nurses have adequate training in caring for geriatric patients (Roethler, Adelman, & Parsons, 2011; Rogers, 2009). Within the Winnipeg Regional Health Authority, for example, there is a significant amount of education for ED nurses in orthopaedic, neurological, cardiac, gynaecological, trauma, respiratory and ear, nose, and throat emergencies, but limited education on cognitive impairment and dementia.

It has been suggested that system changes are needed to support nurses to carry out best practices when caring for patients with dementia (Borbasi, Jones, Lockwood, & Emden, 2006; Bray, Evans, Bruce et al., 2015a; Bray, Evans, Bruce et al., 2015b; Bray, Evans, Bruce et al., 2015c; Bray, Evans, Thompson et al., 2015). In a series of articles that emerged from a national

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project in the United Kingdom to improve care for people with dementia in hospitals, Bray and colleagues proposed a number of strategies to enhance person-centered care for persons with dementia and their family carers. These strategies included: using patient and carer passports and engaging family caregivers to better understand what their needs are (Bray, Evans, Thompson et al., 2015); improving signage in hospitals and departments (Bray, Evans, Bruce et al., 2015a); having staff trained in dementia care and having a secure area for persons with dementia (Bray, Evans, Bruce et al., 2015b); and developing a tool to improve pain assessment in patients with dementia (Bray, Evans, Bruce et al., 2015c). In Scotland, a program was developed for ED nurses to promote best practice in dementia care, as they found while some nurses are confident in caring for this group, many struggle (Howie, 2012). Eriksson and Saveman (2002) found acute care nurses in Sweden lack specialized training in caring for patients with dementia, and staff shared feelings of inadequacy and powerlessness. James and Hodnett (2009) identified that ED nurses in the United Kingdom have asked for training to manage patients with dementia.

While some studies have been done on nurses' experiences of caring for patients with dementia in acute care and long-term care settings (Eriksson & Saveman, 2002), limited research has been carried out on the experiences of nurses caring for these patients in an emergency setting. The purpose of this proposed qualitative study was to explore and describe emergency nurses' experiences of caring for patients with dementia in the ED. The research questions were:

1. What are emergency nurses' experiences of caring for patients with dementia in the ED?
2. What factors facilitate providing good care to persons with dementia in the ED?

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3. What factors act as barriers to providing good care to persons with dementia in the ED?

Assumptions

As a former emergency department nurse, I began this study with some assumptions based on my own experiences. As a qualitative researcher and the interviewer for this study, it is important to articulate those assumptions. I assumed that ED nurses would have opinions about what constituted appropriate and inappropriate visits to the ED. I also assumed that ED nurses would likely have encountered persons with dementia in the EDs in which they worked on an almost daily basis. Given my own experiences, I felt that EDs are difficult environments to provide care for persons with dementia, and I anticipated that ED nurses would identify challenges in this aspect of their practice. I hoped that ED nurses from both community and teaching hospitals would volunteer to be interviewed for this study, and assumed that the experiences of ED nurses would be similar across these settings. Finally, based on my own experiences working with people with dementia, I anticipated that ED nurses would identify a need for additional education in this area.

Significance

As is suggested by the Department of Health, State of Western Australia (2011), “nurses are well placed to facilitate best practice ‘at the coalface’ in the clinical processes of early identification of risk factors, baseline cognitive screening, promoting the foundations of essential care and adhering to clinical standards required for dementia care” (p. 20). ED personnel, particularly nurses, are likely to encounter persons with dementia seeking health care. Given the paucity of research on the topic and the very real potential for increasing numbers of interactions with individuals with dementia, there is a need to better understand the experiences of ED nurses

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caring for patients with dementia and the facilitators of and barriers to providing good care. The knowledge arising from such studies provides much needed information about what promotes or hinders the provision of safe, meaningful, quality, ethical care for patients with dementia in EDs and the educational needs of nurses working in EDs. This research increases our understanding of nurses' experiences of caring for persons with dementia in the ED and provided opportunity to develop recommendations for education, practice, and future studies aimed at supporting ED nurses in offering quality care for patients with dementia.

Summary

Increasing numbers of older adults with dementia are presenting to emergency departments for care. EDs are very hectic and many challenges can arise when providing care to these individuals and their families. Education provided to nurses in ED is tailored to emergencies, with limited to no content on caring for patients with dementia included in their training. This raises concerns about the quality of care these individuals are receiving in EDs. To date, few studies have explored ED nurses' experiences of caring for patients with dementia. This is an important area to study to improve the quality of care provided in EDs and patients', families', and nurses' satisfaction with the care provided. The information provided in this background section has illuminated the need to explore and describe emergency department nurses' experiences of caring for patients with dementia. The significance and purpose of the study have also been identified. In the next chapter the literature on this topic will be reviewed.

Chapter 2: Literature Review

In this chapter, the current knowledge related to the experiences of emergency nurses' caring for persons with dementia in emergency departments is examined. Other areas of the literature explored for this chapter are the context and culture of the ED, challenges related to the care of persons with dementia in the ED, and education related to caring for persons with dementia. Databases used for this search included PubMed, CINAHL and the Cochrane Library, with a focus on literature published between 1999 and 2016. Search terms used included dementia, emergency, nurses, and experience.

Persons with Dementia and ED Use

It has been identified that older adults visit the emergency department (ED) more than any other age group, and typically with serious illnesses (Parke et al., 2011). In Winnipeg, for example, 29.6% of citizens between the ages of 75 and 84 years and 41.7% of citizens 85 years of age and older visited an ED at least once in 2004/2005 (Doupe et al., 2008). Older adults coming to the ED are at increased risk for return visits, hospital admissions, and even death (LaMantia, Stump, Messina, Miller, & Callahan, 2015; Samaras, Chevalley, Samaras, & Gold, 2010).

In a review of the literature on the topic of care of persons with dementia in the ED, Clevenger et al. (2012) identified that in the United States "between 21% and 40% of older adults who present to the ED are cognitively impaired, 21.8% screen positive for dementia without delirium" (p. 1743). Data collected in Winnipeg (Doupe et al., 2008) showed that 6.5% of people who visited the ED in 2004/2005 had a previous diagnosis of dementia and this group accounted for 23.7% of the individuals categorized as frequent ED users (i.e., seven or more visits in one year). In one study, cognitive assessment of older adults in ED revealed that 39.4%

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(n = 220) were found to have undiagnosed dementia (Dyer, Nabeel, Briggs, O'Neill, & Kennelly, 2016). In Indianapolis, Indiana, researchers examined 175,652 ED visits over an 11 year period of persons over the age of 65 years (10,354 individuals with dementia and 15,020 individuals without dementia) and found that persons with dementia attended to the ED more frequently and were hospitalized more often than persons without dementia (LaMantia et al., 2015).

A cross sectional study in France (175 nursing homes and n = 5684 residents) conducted by De Souto Barreto et al. (2013) looked at the impact of possible dementia without a formal diagnosis in nursing home residents on rates of ED visits. The researchers identified that their results suggest that undiagnosed dementia increases the likelihood of an ED visit for residents as staff in the nursing home, if confronted with symptoms of delirium and hallucinations in a resident, felt the resident required urgent treatment for an undetermined underlying illness.

Context and Culture in the ED

To understand the complexities of caring for persons with dementia in EDs, it is important to consider the culture of these environments. Cultures arise in organizations and reflect the occupations and experiences of their members who share the same views (Schein, 1996). Schein (1996) defined culture as “the set of shared, taken-for-granted implicit assumptions that a group holds and that determines how it perceives, thinks about, and reacts to its various environments” (p. 231). Colleagues in an organization share ways of thinking and perceiving events and this creates shared norms, principles, and expectations of other members that guide and shape the culture (Person, Spiva, & Hart, 2012; Schein, 1996). People who share a culture often are not aware that they do so until a different culture is encountered (Schein, 1996). Not unlike other cultures, the ED is unique and complex.

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The culture of the ED was examined in an ethnographic study involving 120 observation periods in an ED in a level two trauma center in the United States (Person et al., 2012). The researchers identified four categories related to ED culture: cognitive attributes of the work (e.g., rewarding, making a difference, multi-tasking); environmental influences (e.g., high volumes of patients, unpredictable, stressful); linguistic attributes – communication (e.g., effective and ineffective); and social attributes (e.g., importance of teamwork, competence). Person et al. (2012) highlighted that “stress associated with the ED environment included frequent interruptions, overcrowding, inter-staff conflict, and technology barriers” (p. 5).

Infamous for being stressful and chaotic environments, the ED is the primary access point or the “front door” (Nugus & Brathwaite, 2009, p.512) of the hospital for many patients. The ED provides the initial care to patients, from minor injuries to life-threatening illness. The ED is a “unique environment due to the volume of work and the need for accuracy under pressure” (Kilner & Sheppard, 2010, p.135). Physically, staff members are dispersed between resuscitation, triage, ambulance offload area, minor treatments, and more acute areas. Other departments, such as the laboratory, x-ray, admitting, and respiratory, are linked with emergency departments and help with treatment and diagnosis of these patients. Multiple providers are involved in providing care in a crowded space, and this adds to the chaos of “unscheduled, complex, acutely ill patients” who visit the department (Rosenstein & Naylor, 2012, p.140). It is noted that often there are challenges with the ED and other departments having conflicting opinions of each other’s responsibilities and workload (Person et al., 2012). This could be due to “role ambiguity” of the disciplines and can lead to poor communication (Yeager, 2005, p.145). The tendency to focus on one’s own task and lose team perspective has been identified as a

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problem when individuals work in a high stress area (Flowerdew, Brown, Russ, Vincent, & Woloshynowych, 2012).

In addition to the volume of work and the conflicts that may arise between the various players in emergency settings, EDs are fast-paced environments with high patient acuity, and health care providers working there must always be ready for a crisis. Lack of resources and time to deal with overcrowded EDs pose major threats to patient and staff safety (Birrer, Singh, & Kumar, 1999; O'Mahony, 2011; Schein, 1996). For example, research has demonstrated that EDs are high-risk settings for aggression and violence directed towards staff for reasons that may include patient or family member anger related to waiting for attention or treatment, stress levels, mental health issues, or intoxication (Kowalenko et al., 2012). It is also the case that the chaotic nature of the work environment can lead to frequent interruptions for staff members in EDs. Berg et al. (2013), in an observational study in an ED in Sweden, found an interruption rate for staff of 5.1 per hour, based on observations of 18 clinicians over a two-hour period. Interruptions while preparing medications occurred most commonly. This has implications for patient safety. A number of research studies have been done on the environment of EDs and have identified various issues that can arise there, but it is argued that EDs continue to be efficient at treating and diagnosing patients (Levin et al., 2006).

Due to the nature of EDs with increased emphasis on patient flow, they are not programmed for responding to chronic health problems, and staff members are not trained in comprehensive assessments of the elderly (Birrer et al., 1999). Patient flow and ED wait times are topics of interest nationally, and emergency nurses and doctors assume the responsibilities of achieving high standards of care while reducing the long wait times (Handel et al., 2010). Because there is a heightened awareness of ED wait times, the potential exists for patients

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leaving without being seen and ambulances to be redirected to other facilities. This can have a negative impact on quality of care.

A mandatory benchmark in the near future set by the WRHA (2013) involves a commitment of four hours to see, assess, and find alternate dispositions for patients. This makes looking after patients with dementia challenging as they tend to present with higher acuity and are known to have increased lengths of stay and more admissions to hospital (Desy & Prohaska, 2008). Decline in function and poor experiences of persons with dementia and their families may be part and parcel of the ED experience. Looking at nursing in general, the Royal College of Nurses (RCN) in the United Kingdom (2008) conducted a survey to explore the attitudes of nurses about caring for patients. The RCN (2008) found that 65% of respondents (N = 2000) reported there was not enough time to provide dignified care for their patients, and eight out of ten nurses were unhappy with the care they were able to give due to overcrowded wards, distractions, and the limited time available to spend with patients. In that survey, emergency care was one of the “activities” (RCN, 2008, p. 34) identified as potentially compromising patient dignity.

Persons with Dementia and Care in the ED

Dementia is complex, bringing multiple challenges to patient safety and quality of care, assessment, and treatment in the ED (Parke et al., 2013). Complicating care is the reality that dementia lowers people’s threshold for sensory overload and distress and may result in difficult behaviors (Clevenger et al., 2012; Kang, Moyle, & Venturato, 2010). The literature shows that the care of persons with a diagnosis of dementia can be affected negatively in acute care settings by any number of factors, including: workload issues; health care providers’ lack of knowledge of dementia; inadequate assessments; inappropriate interventions; the structure of health care

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environments; health care providers' attitudes; and hospital work routines (George, Long, & Vincent, 2013; Kang et al., 2010; Watkin et al., 2011). These factors can also lead to stress and dissatisfaction for the health care providers involved (Kang et al., 2010). Patients with dementia often present to the ED with acute illness or deterioration and their dementia may not have been diagnosed previously (Dyer et al., 2016; Lagomasino, Daly, & Stoudemire, 1999). In addition, there is a significant lack of consistent quality of care for this population (Cowdell, 2010) and, due to the increased prevalence of dementia, it has been identified that appropriate action is needed to improve care of these patients (Cowdell, 2010; Eriksson & Saveman, 2002). George et al. (2013) found there is a need to increase nurses' knowledge and awareness of the potential adverse events that happen to patients with dementia such as falls, delirium and functional decline.

A particular concern in quality of care is the role cognitive impairment plays in adverse events of older patients (Salen, Heller, Oller, & Reed, 2009). The literature confirms there is a significant association between diagnosis of dementia and unintentional adverse events to patients, such as falls or medication errors, but few studies have explored the risk factors for reported adverse events (Watkin et al., 2011). Adverse events are not only costly for healthcare, but can be detrimental to patient morbidity and mortality and length of stay.

In a systematic review exploring studies that identified practices found to be effective in meeting the care needs of older adults with cognitive impairment in EDs, Schnitker, Martin-Khan, Beattie, and Gray (2013) located 43 articles relevant to their review. Of that number, only 10 studies were carried out in emergency settings, with the remainder carried out in acute care settings (31) or a combination of emergency and acute care settings (2). The types of interventions described in the articles reviewed included those designed to improve recognition

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of impairment, reduce falls, and prevent delirium. These authors noted that “studies carried out in EDs regarding care practices that meet the specific care needs of the older ED population with cognitive impairment were scarce” (Schnitker et al., 2013, p. 163).

Rhodes et al. (2016) conducted a retrospective electronic health record review that studied risk factors that increased length of stay and the occurrence of adverse events for people 65 years of age and older who visited the ED with behavioural health issues (n = 213). They found that more than 90% of the patients had a prolonged length of stay, with being restrained and/or unable to return to their previous living arrangements increasing length of stay. Increased length of stay in the ED was associated with an increased risk for adverse events. Rhodes et al. (2016) concluded that “although not ideal, selective use of the ‘social admit’ for patients with a failed discharge, necessitating restraint or involuntary legal status may be the safest temporary plan” (p. 150).

Nurses and caring for persons with dementia in the ED. The literature illustrates that the ED is an unsuitable environment for any patient with confusion and that the complex needs of these patients may prove challenging to meet in this environment (Eriksson & Saveman, 2002; James & Hodnett, 2009). The ED has been described as the “dumping ground” (Bache, 2005, p.257) of the hospital. This, in part, refers to the reality that people requiring complex, but non-emergent, care in the hospital may find that the ED provides their only access to care from the community or other facilities (e.g., long-term care). This can be true, for example, for people experiencing social issues, such as persons with cognitive decline and their families who are struggling to cope in the community. As noted earlier, persons with cognitive impairment may face challenges in the ED, with possible issues arising related to safety, effectiveness of care, and quality of care (Parke et al., 2011; Parke et al. 2013). Emergency staff members may feel

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anxious when caring for patients with dementia due to the time it takes to care for these patients and the interruptions in the department, both of which make it difficult for the staff to give good care (Clevenger et al., 2012). These challenges are problematic, yet limited research has been done on needed system changes to support nurses caring for this vulnerable group (Parke et al., 2013) or on quality initiatives to examine the context of ED and environmental modifiable factors such as physical design and staffing resources (Parke et al., 2011).

Research has been done with nurses in acute care generally in relation to caring for persons with dementia. Challenges and concerns highlighted in this research include: the safety of patients and staff, poor nursing reactions to patients with dementia and their families which can exacerbate problems, environmental limitations, multiple demands on nurses' time leading to a lack of time to provide care, high workload and stress for nurses, and increased restraint use with patients with dementia (Eriksson & Saveman, 2002; Nolan, 2006). In emergency departments, nurses have reported challenges associated with caring for elderly clients, particularly those individuals with cognitive impairments. These include: poor quality of care, safety concerns, incomplete histories, time constraints, and heavy workloads (Parke et al., 2013).

Barriers to quality care in the ED are present for persons with dementia. In a systematic review on evidence to guide practice in the ED in the care of older persons with cognitive impairment, it was identified that "emergency care providers are challenged to combine gerontological knowledge with the skills of dealing with emergency situations" (Schnitker et al., 2013, p. 164). In a review of the studies on the pharmacological management of agitation in the ED, Baker (2012) identified that at times only limited information was sent with patients coming to ED from long-term care settings putting workers and patients at risk, especially if patients were cognitively impaired and/or agitated.

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Schnitker et al. (2013) have identified that the literature indicates that older patients interacting with the hospital system are at risk for poor outcomes and adverse events such as functional decline, readmissions, and also death; patients with cognitive impairment have an even higher risk for this. Poor outcomes for patients include being restrained, poor quality of care, and unintentional adverse events (Parke et al., 2013). These experiences or events are heightened when patients have difficulty with communication and pain verbalization, preventing safe discharge planning (Schnitker et al., 2013). Restraint use, both physical and pharmacological, has been reported to increase when concern for safety is an issue and appears to be used more when there is limited physical space and limited knowledge about dementia (Parke et al., 2013). Staff in the ED are not always trained in appropriate management of patients who become aggressive or violent (Baker, 2012), and without a different approach to care a visit to the ED can become harmful or an unintentional life-changing event for an older adult (Parke et al., 2011).

Studies from acute care settings may provide some insight in relation to the care of persons with dementia in EDs. A qualitative study carried out by Eriksson and Saveman (2002), and involving interviews with twelve nurses, sought to describe nurses' experiences of "difficulties" (p. 79) related to caring for patients with dementia in an acute care setting in Sweden. Themes identified through thematic content analysis were: difficulties associated with ethical situations and concerns for possible abuse of patients, disorderly behaviors among patients, and difficulties with the organization of care preventing good nursing care. Ethical situations included the nurses giving medications to patients against their will and wondering if they were "actually helping or hurting patients" (Eriksson & Saveman, 2002, p. 79). The organization of care, such as the pressures from administration to decrease patient care times,

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compounded the nurses' feelings of not having enough time for these patients. These patients with dementia were also found to "disturb" the routines on the ward given the time required to care for such patients (p. 82). Nurses found the routines and setting prevent good care, and the researchers identified a need to improve care and attend to the risk of neglect and abuse of people with dementia cared for in acute care settings.

Cowdell (2010) and Nolan (2006) also studied nurses working in acute care settings. Using an ethnographic approach, Cowdell (2010) observed and interviewed 25 nurses and 33 health care aides working with older people with dementia in an acute care hospital setting in the United Kingdom. The study participants "appeared to attach little value to the care they provided", indicating that it was viewed by others as "unskilled in nature" (p. 44). The care provided to patients focused on physical needs and staff appeared to lack confidence in their abilities to provide care generally, but most particularly in relation to psychosocial care, with many identifying that they felt unprepared for this work. In a study aimed at exploring nurses' experiences of caring for persons with dementia, Nolan (2006) interviewed seven nurses in an acute hospital setting in Ireland. In the interviews, nurses identified challenges to caring related to the layout of the unit and the lack of available time to provide quality care and described the importance of being vigilant to ensure safety. Nolan also found that nurses felt safer when caring for non-aggressive patients and that personhood of the patient with dementia was significant to the nurses.

Very few studies were found examining the experiences of ED nurses. Kihlgren, Nilsson, and Sorlie (2005) conducted a study in Sweden to explore ED nurses' perceptions of the nature of good nursing care for patients 75 years of age or older. Ten ED nurses were interviewed in this study and their experience in ED ranged from 10 to 17 years. The researchers

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identified factors that promoted or prevented good nursing care. For example, nurses commented on the importance of being knowledgeable about the older patients' complex medical problems and a variety of illnesses, having knowledge of the particular patient's situation, being responsible for the care provided, and the significance of organizing their time. The types of factors identified as preventing good nursing care included lack of time, heavy workload, long wait times to be assessed by a physician, and inadequate knowledge and training related to the care of persons with dementia. The study authors comment on the limitations of a small convenience sample. They also noted that "several of the emergency room nurses found it difficult to describe a good situation" of care (p. 603) related to older patients.

Three related studies carried out by Gallagher and colleagues explored nurses' experiences of caring for older persons in the ED. Four focus groups were carried out with Australian ED nurses, with a total sample of 27 nurses. Two themes were identified in relation to nurses' perceptions and experiences of caring for older people: 1) "clash of expectations between nurses and family carers related to safety and quality nursing care" (Gallagher, Fry, Chenowith, Gallagher, & Stein-Parbury, 2014, p. 449); and 2) "nurses' perception that family/carers could provide a safety net for the older person in the ED in times of high workload" (p. 449). The ED nurses expressed frustration with being unable to provide quality care to older patients due to time constraints and "other priorities" (p. 451). The study found that support was needed to enable ED nurses to both provide quality care and keep patients safe (Gallagher et al., 2014).

Fry, Gallagher, Chenoweth, and Stein-Parbury (2014) used the same data from these focus groups to examine ED nurses' expectations of family carers attending the ED with older patients. Three themes were identified: 1) "the importance of time; 2) the family/carer as an

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informant; 3) getting in the way” (Fry et al., 2014, p. 32). Family members were viewed as supportive and helpful if they saved nurses time and viewed as demanding or obstructive if they “cost” nurses time (p. 33). It was also identified that if carers had unrealistic expectations of the nurses in ED, conflict and stress between the two parties would occur.

In the third related study, emergency nurses’ perceptions regarding which groups of older people use the most nursing resources were explored (Gallagher et al., 2015). The data from the previously mentioned focus groups were used, along with data from an audit of 13 ED patients’ medical records. The groups of patients identified as requiring the most time and resources were: repeat or cluster presenters; patients with multiple co-morbidities, including dementia; and the complicated patients that were waiting for a physician to admit them to a medical unit.

Parke et al. (2013) used an interpretive, descriptive exploratory design with 10 registered nurses (RN), 4 nurse practitioners (NPs), and 10 patient-family caregiver dyads in a setting in Western Canada. Focus groups and interviews were conducted to identify factors that expedited or delayed safe care for older adults with dementia who came to the ED from the community and to explore practice solutions. The study uncovered four “reinforcing consequences”: patients being under-triaged; the waiting and fear for patients and families about what was wrong with the patient; time constraints and lack of attention to patients’ basic needs; and interactions with patients and families that led to feelings of being overlooked and forgotten (p.1206). Nurses identified that basic needs such as toileting, mobilizing, feeding, and hydrating patients were often not being met. Parke et al. (2013) concluded that negative consequences can be “interrupted” through relationship-centred care, enhanced communication, and the building of trust with patients and their families and that to support nurses, and their ability to carry out best practices, system changes are needed (p.1206). The study authors suggested it was important

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that interventions to improve care of persons with dementia target the nurses (e.g., through education) as well as the organization (e.g., staffing changes, the addition of clinical resource nurses).

Boltz, Parke, Shuluk, Capezuti, and Galvin (2013) carried out a study in the United States examining ED nurses' perspectives on issues that need to be addressed to improve care for older people presenting to EDs. Secondary analysis was done on data from a survey entitled "Nurses Improving Care for Health system Elders (NICHE) Geriatric Institutional Profile (GIAP)". This survey was completed by staff in hospitals participating in the NICHE program. An open-ended question was included on the survey: "What are the most pressing issues you currently face in caring for older adults" (p. 443)? Content analysis was used to assess the responses of 527 nurses who answered this question (out of 1,191 ED registered nurses who responded to the survey). The mean age of the nurses who responded to the question was 42.7 years, with a mean of 15.8 years of experience as a nurse. Boltz et al. (2013) identified five themes summarizing the issues that need to be addressed: "a) respect for the older adult and carers; b) correct and best procedures and treatment, c) time and staff to do things right, d) transitions, and e) a safe and enabling environment" (pp. 444-445). Nurses identified issues that included poor communication, negative staff attitudes, a lack of compassion, information flow problems, inadequate support of the older adult when making decisions, and a lack of acknowledgement of families. The study found nurses need evidence-based protocols to guide their assessments of patients with cognitive impairment and to learn ways to care for these patients without physical and chemical restraints. Boltz et al. (2013) also found nurses were concerned with not having time to address the needs of older patients, and concerned both nurses and physicians knew too little about this client group.

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In geriatric care, behaviors of patients with dementia have been highlighted as possible reasons for staff burnout, as caring for these patients can prove to be both physically and emotionally difficult (Eriksson & Saveman, 2002). Though not specifically linked to any particular types of patients, there is evidence that ED nurses experience burnout, compassion fatigue, and a desire to leave their positions (Browning, Ryan, Thomas, Greenberg, & Rolniak, 2007; Duffin, 2013; Hooper, Craig, Janvrin, Wetsel, & Reimeis, 2010). Using Maslach and Jackson's work, O'Mahony (2011) defined burnout as "a syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment" (p.30). Her research study examined levels of burnout experienced by emergency nurses and the relationship between burnout and emergency department work environments. Of the 64 emergency department nurses who filled out the survey, 61% reported they had experienced burnout, and 67% reported high levels of emotional exhaustion (O'Mahony, 2011). ED nurses felt disregarded and overburdened, with the staffing and resource adequacy subscale emerging as the most unfavourable for the nurses (O'Mahony, 2011). Overcrowding and lack of control over their practice left them emotionally exhausted, which increased turnover and decreased quality care. The study revealed that improvements to the work environment and education are needed to decrease the risk of nurses developing burnout and its sequelae, including low morale, increased sick time, decreased job performance, and high turnover. Browning et al. (2007) found that emergency nurses (n=100) experienced more emotional exhaustion and depersonalization, based on Maslach Burnout Inventory scores, than nurse practitioners (n = 88) or nurse managers (n = 40). The lack of time to provide care was identified as a concern for nurses in both of the studies just described.

Education for nurses in ED. In their review of the literature on practices designed to meet the care needs of patients in the ED with cognitive impairment, Schnitker et al. (2013)

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identified four categories of interventions to improve quality of care for this population: those designed to improve cognitive impairment recognition (e.g., screening tools); those designed to prevent acute confusion (e.g., primary delirium prevention using specialized geriatric nurses, secondary delirium prevention through psychiatric consults); those designed to better manage symptoms; and other interventions (e.g., falls prevention; nutritional intake). These authors concluded that “caring for people with dementia and their families demands special skills to improve comfort, to prevent adverse outcomes, and to achieve optimal outcomes” (Schnitker et al., 2013, p.165).

It has been argued that acute care nurses generally (Eriksson & Saveman, 2002), and ED nurses more specifically, lack education regarding caring for patients with dementia (James & Hodnett, 2009). The number and proportion of elderly people that visit the ED in higher income countries is sizeable, and in North America older adults visit emergency departments more than any other age group (Birrer et al., 1999; Brymer, Cavanagh, Denomy, Wells, & Cook, 2001; Hare, Wynaden, McGowan, & Speed, 2008; Parke et al., 2011), yet routine assessment of cognition is not typically done (Hare et al., 2008). Emergency nurses are able to care for minor injuries and illness through to critical life-threatening situations. These specialized nurses typically have training in Advanced Care Life Support (ACLS), trauma, medical and surgical treatments, and palliation. Within the WRHA these nurses receive training in the WRHA emergency program. This educational program includes content related to common minor illnesses and injuries often seen in the ED, to cardiac rhythms, resuscitation, and triaging. Little time is spent in that program on content related to older adults or dementia.

Cowdell (2010), Desy and Prohaska (2008), and Eriksson and Saveman (2002) have identified that there is a gap in knowledge of dementia and dementia care for nurses in the ED as

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they generally do not have advanced education in geriatric nursing. Nurses in the ED have been described as anxious about caring for patients with dementia due to the time required to do so and because of the pressures of department routines (James & Hodnett, 2009). It has been argued that all staff in the ED should be trained to communicate effectively with, manage behaviours in, and care for patients with dementia. Strategies other than sedation are needed to deal with wandering, falls, and challenging behaviours (Andrews & Christie, 2009).

The literature highlights difficulties in communication and a gap between the care nurses want to deliver and what they are able to provide as issues of concern in relation to caring for persons with dementia in the ED; these issues can lead to increased stress for nurses and risk of delirium for patients (Boltz et al., 2013; James & Hodnett, 2009). James and Hodnett (2009) have identified that nurses who lack specific knowledge of this type of care were interested in information on stress, communication, pain, and ethics when managing situations like wandering, aggression, and confusion.

Globally, the need is recognized to be able to care for persons with dementia at a higher level of quality care than is currently being provided. The English National Dementia Strategy and the Alzheimer Society have both highlighted the need to improve staff training, patient advice, and liaison services (Watkin et al., 2011). In Scotland, dementia was declared a national clinical priority (Crabtree & Mack, 2010). The University of Scotland suggested the staff in EDs had needs unlike any other setting and developed an online resource called “Dementia Care in the Emergency Department” (Howie, 2012, p. 12). This resource was developed to help staff increase knowledge and skills in the care and treatment of patients with dementia and included content related to initial contact, assessment, and interventions (Howie, 2012). The National Health Service (NHS) of Scotland developed an online learning resource for clinicians with a

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range of experience and to accommodate their workload and the pace of the ED. This resource has proved useful in promoting best practice in the care of patients with dementia, increasing and bettering outcomes and experiences (Howie, 2012).

There is a course that has been developed for nurses in the ED that focuses on geriatrics. The Geriatric Emergency Nursing Education (GENE) Course, developed in 2004 by the Emergency Nurses Association (ENA) in the United States, is an eight-hour course that has been used in North America to increase ED nurses' skills and abilities to provide good quality nursing care to the geriatric population. Desy and Prohaska (2008) evaluated the impact of the GENE course on ED nurses in the United States. A total of 102 ED nurses from various cities in the country attending an ENA conference took part in the course. One hundred nurses completed the post-course questionnaire and 63 completed the 3-month post-course questionnaire. The researchers found a significant difference between pre- (23.9) and immediate post-course knowledge scores (27.2) ($p < .000$). Over one quarter of the nurses reported an increased ability to assess patients related to activities of daily living, functional status, depression, delirium, and dementia, and 20% of respondents reported increased use of referrals for services for patients. In addition, there was evidence of a significant increase in the proportion of nurses who used geriatric assessment tools at the three-month data collection point.

Brymer et al. (2001) conducted a study in Canada to measure the impact of a one-day workshop for ED nurses addressing the following topics: delirium, dementia, and depression; physical assessment of an older adult; and the application of a cognition assessment tool. Of the 101 nurses who took the workshop, 51 nurses completed the pre- and post-workshop questionnaires. The researchers found the nurses reported increased screening for depression (p

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< .001) and cognition ($p < .01$) status post-workshop, with an increase of referrals to the geriatric team noted in the unit studied.

The literature provides important information regarding geriatric educational programs, which can have an impact on the practice of ED nurses to improve their assessments and discharge planning of older patients (Brymer et al., 2001). Andrews and Christie (2009) suggest that a number of staff in the ED experience difficulty caring for patients with cognitive impairment and are fearful and lack confidence when caring for them. They suggest that staff attitudes towards dementia can be changed through educational programs. For interventions to be effective, knowledge of dementia along with the nursing process can influence outcomes for these patients (Parke et al., 2011). Education can impact discharge planning and improve practice, decrease the amount of burden of staff, and increase patient, family, and ED nurse satisfaction.

Created as a comprehensive Alzheimer Strategy in Canada, the P.I.E.C.E.S approach to care was created. The Ontario government invested millions of dollars to improve the quality of life of patients with dementia and provided a common approach to caring for patients with dementia targeting staff in long-term care (Alzheimer Knowledge Exchange Resource Centre, n.d.). In 2008, Manitoba Health publicized that 1.2 million dollars had been set aside for dementia care for personal care homes. Since the rollout in 2008, Manitoba Health has been providing dementia education to Winnipeg's 39 personal care homes using a framework (Alzheimer Society of Manitoba, 2013) that provides an organized and efficient approach to caring for patients with dementia (P.I.E.C.E.S., n.d.). The P.I.E.C.E.S acronym embodies the physical, intellectual, emotional, capabilities, environment, and social needs of the individual (P.I.E.C.E.S., n.d.). The P.I.E.C.E.S. philosophy teaches the staff how to deal with challenges of

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difficult behaviours and treat the patient holistically. McAiney et al. (2006) assessed the value of P.I.E.C.E.S and found that training enough staff to support each other may increase staff satisfaction and decrease turnover. Their evaluation of this quality improvement initiative suggests the significance of a supportive work environment. This information is offered to staff in long-term care, but is not presently being offered to staff members within the WRHA's EDs.

Summary

In reviewing the literature, few studies were found related to the various aspects of nurses' experiences of caring for patients with dementia in acute care settings. The studies that have been carried out with ED nurses have explored nurses' perceptions of: a) the nature of good nursing care for patients 75 years of age or older; b) factors that facilitated or delayed care for older adults with dementia presenting to the ED; c) the types of older persons that require the most nursing resources in EDs; and d) the most pressing issues in relation to caring for older adults in the ED. A gap is identified in relation to nurses' perspectives on caring for persons with dementia in the ED. There is evidence that nurses are not consistently educated or trained to respond to the complex behaviours of patients with dementia and that the setting of ED is not conducive to quality care for these patients. In the next chapter, the methods used in this study will be described.

Chapter 3: Methods

In this chapter, the research methods used in this study are outlined. The particular research approach used is identified, the data collection and analysis strategies are described, and strategies used to ensure rigour are discussed. In addition, the conceptual model used in the study is described. The chapter ends with a discussion of the ethical considerations that served as a backdrop to the study.

The research objective, to explore and describe emergency nurses' experiences of caring for patients with dementia in the ED, was best addressed using a descriptive research approach. The specific approach selected for this study was interpretive description. This method has been described as inductive, "linked to grounded theory... and aligned with a constructivist and naturalistic orientation to inquiry" (Hunt, 2009, p. 1284). Interpretive description (ID) is a method that uses refined techniques pulled from traditional methodologies, and is used to generate and share knowledge to guide clinical practice in health disciplines (Hunt, 2009; Thorne, 2008). Guidelines for the use of ID include: a) beginning with a critical review of existing literature and knowledge related to the phenomenon of interest; b) paying attention to the experience of clinicians and/or patients and families; c) using some form of constant comparison in the analysis process; and d) reflecting throughout the data collection and analysis processes on patterns and relationships in the data (Hunt, 2009; Oliver, 2012; Thorne, 2008).

Thorne (2008) describes interpretive description as a methodology which requires a practice goal and an understanding of "what we do and don't know" (p.35) from empirical evidence. The understanding begins with theoretical scaffolding of a clinical problem we are concerned with. It has been suggested that theoretical scaffolding is a significant part of understanding the clinical question, the assumptions and beliefs underpinning the question, and

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what answers are sought. The literature review highlights the existing knowledge and/or gaps in research. The research plan provides a “solid foundation of the principles underlying the choices you are going to be making” (Thorne, 2008, p.103). Based on available evidence, two assumptions were made: a) it is not an uncommon experience for ED nurses to care for persons with dementia in the ED; and b) nurses are able to articulate their experiences, what facilitates good nursing care, and the barriers to good nursing care.

Interpretive description suggests interviewing is an effective data collection strategy to get at people’s experiences, and through sorting and organizing data, patterns in the data can be identified. As interview data are collected and confirmation of patterns in the data occurs, findings can be articulated. Tenets of interpretive description include: using a naturalistic context that respects the ethical rights of study participants; valuing first-hand knowledge and experience as a source of insight; using both common and individual expressions as they depict and explain the same or similar experiences; acknowledging that multiple realities are possible; and recognizing that the researcher and the participant influence one another in the data collection process (Thorne, 2008).

Conceptual Model

As the study was being developed, it became clear that the Donabedian model would prove helpful in examining this particular aspect of health services (i.e., the care of persons with dementia in the ED). Donabedian was interested in quality of medical care and its evaluation. The model he developed provided three key concepts: structure, process, and outcome (SPO). Donabedian described these concepts and the relationships between them. Kobayashi, Takemura, and Kanda (2010) have indicated that the SPO model has played a significant role in

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quality care and improvement in the health care field, and has been used in nursing quality evaluation.

Donabedian (1968, 1988) defined structure as the characteristics of the environment where a person receives care and includes things like administrative structures, staffing, and the facility environment. This can include financial resources, training or qualifications of staff, staff salaries, equipment, and the physical plant (Donabedian, 1968; Kajonius & Kazemi, 2015). In considering Donabedian's model, Gardner, Gardner, and O'Connell (2013) described structure as the physical, material, professional, and "collegial elements of clinical service" (p.152). Process is defined as how and when things are done or care is received (Donabedian, 1988), and although it relies on structure attributes to be successful, it is said to have the most influence on care (Naranjo & Kaimal, 2011). Process can include the procedures of diagnosis and treatment and health care provider-patient interactions (Kajonius & Kazemi, 2015). Donabedian (2005) described outcomes as being the effects of the care provided; outcomes are "amenable" to "measurement" (p.693), and include such factors as knowledge, satisfaction with care, and the effects of care, including health outcomes (Kajonius & Kazemi, 2015). When considering the relationships between structure, process, and outcome, it has been suggested that different structures combined with different processes will likely lead to different outcomes. Gardner et al. (2013) assert judgment of outcomes should not be made without taking structure and process into consideration.

The model does have limitations. Donabedian (2005) suggests that the quality of clinical care cannot be precisely measured and a number of factors may influence outcomes; therefore, it is suggested that limits should be placed on using outcomes alone to measure quality of care. It

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has also been proposed the “relationship between structure and process or structure and outcome is often not well established” (Donabedian, 2005, p. 695).

The value of viewing health services, including interactions between persons with dementia and ED nurses in the ED, from a structure, process, and outcome perspective was recognized early on in the study development. The framework of SPO proved helpful as it provided guidance at various stages of the study. The framework informed the development of the interview questions, was a consideration in the development of the categories used in data analysis, was applied to the suggestions for improvement made by the nurses in the interviews, and proved useful in understanding the findings.

Sample and Setting

A convenience sample of ED nurses working in Winnipeg and who self-identified the ED as their place of work were interviewed for this study. Thorne, Reimer- Kirkham, and MacDonald-Emes (1997) suggest that in the early stages of describing a phenomenon, using an easily accessible group of individuals can be a great source of understanding a shared experience. Through initial inquiries through the WRHA, it was identified that at the time of the study there were approximately 400 nurses employed in the EDs within the WRHA. After research ethics board approval was obtained (Appendix A), permission was obtained (Appendix B) from the College of Registered Nurses of Manitoba (CRNM) for them to send out an email message on my behalf to nurses registered with the CRNM who, upon re-registration, had selected the ED as the area in which they were currently employed. The recruitment email (Appendix C) provided an outline of the purpose of the study, what was required of the participants, examples of the types of questions that would be asked, and the researcher’s contact information. The email message also directed ED nurses to contact the researcher via email or

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phone within two weeks if they were interested in discussing the study and possible participation.

Inclusion criteria for study participants were: full-time or part-time employment as an ED nurse registered with the CRNM, minimum of 6 months of nursing experience in ED, experience working with persons with dementia in the ED, and willingness to be interviewed and participate in the study. Excluded from the study were ED nurses working at Misericordia Urgent Care, as they do not keep patients that need admission. The email message sent by the CRNM on my behalf began with a few sentences explaining that the message was sent by CRNM, rather than directly by the researcher, to ensure that privacy was respected and that the study was not in any way associated with the CRNM or its mandate. This message is a standard one used by CRNM with this type of recruitment.

It was difficult to predict how many people would volunteer to be interviewed. In using this approach in two other studies involving a similar number of nurses on the register, my supervisor and/or students working with her had 10 to 15 volunteers for interviews. For this study, 12 nurses responded by email and all agreed to be interviewed. Once potential participants contacted me, I was able to respond to any questions they had about the study and, if they agreed, to arrange a meeting for the interview. At that meeting, the consent form (Appendix D) was reviewed, questions were answered, and, if the person agreed, the consent form was signed.

Data Collection

Demographic data were collected using eleven questions (Appendix E) and a semi-structured interview with each study participant took place. The semi-structured interview questions (Appendix F) were guided by the literature review, including previous studies involving acute care nurses caring for patients with dementia, and Donabedian's framework (see

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Table 1). In particular, the questions used by Parke et al. (2013), in a study carried out in western Canada examining facilitators and barriers to safe emergency department transitions for older people with dementia and their caregivers, informed the development of the interview guide. They had asked registered nurses and nurse practitioners questions about their experiences of “working with older people with cognitive impairment in the ED” (Parke et al., 2013, p. 1210) and about cases where things “went well” and “went wrong” (p. 1210), and outlined excellent probes in their article. These questions and some of their probes were used to inform the development of the interview guide used in my study.

Table 1***Examples of Structure, Process, and Outcome Interview Questions***

Structure Question	How would you describe the emergency department in which you work?
Both Structure and Process Question	Can you tell me about a situation of caring for a person with dementia in the ED and what you felt contributed to safe quality care?
Outcome Questions	In general, what good outcomes have you seen in relation to the care of persons with dementia in the ED?

Early in the interview, participants were asked to describe an experience they have had with caring for a person with dementia in the ED that stood out for them. Questions were then asked to gain an understanding of this experience, why it stood out for the participant, and how similar or different it was from other experiences they had caring for persons with dementia. Additional questions were posed regarding possible facilitators for quality care of these patients and their families and possible barriers to caring for these patients. Interviews were from 30 minutes to one hour in length, and were held at a mutually convenient time and place for participants and the interviewer (me), and recorded and transcribed verbatim. Participants were informed that a second interview, to be held at a later date either in person or by phone, could be

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required to discuss, clarify, and/or confirm comments made by participants in their first interview. As data were reviewed, it was decided that no second interviews were required to clarify comments made by participants. Field notes were recorded to describe and comment on observations made in the interviews, including, for example, emotional responses to questions or interruptions in the interviews, and my first impressions from the participants' responses (Appendix G). Field notes became a part of data analysis as they recorded what was seen, heard, and experienced during the interview (Streubert & Rinaldi Carpenter, 2011). The field notes were also used to inform the interview process. For example, after an interview in a coffee shop, notes were recorded about the many distractions that made the interview challenging, and a decision was made to ensure that all future interviews were carried out in more private spaces.

A reflective journal was kept and regularly updated. Thorne (2008) states core elements that inform the inductive analytic process are the ideas and thoughts that materialize while collecting data, or "what happens to the researcher subjectively and conceptually" (Thorne, 2008, p.209), and these ideas were documented. This process of sharing ideas and prior knowledge in a reflective journal was ongoing throughout the study. By including journaling, both rigor and attention to ethical considerations were demonstrated as this exposed unexpected responses from participants that confronted previous ideas held by me and my thoughts or emotions (Davies & Dodd, 2002). As I have had experience as an emergency room nurse, my emotions and experiences caring for patients with dementia needed to be in check and documented. This sort of documentation provides the researcher with an understanding of the "implications of your own role in data collection and construction" (Thorne, 2008, p.109). The notes kept in the journal informed the evolution of the interview guide and assisted with context when reviewing and discussing the transcripts with my advisor.

Data Analysis

The demographic data were analyzed using descriptive statistics (e.g., mean age, mean years of experience, age range). I transcribed all interviews verbatim using Dragon Dictation software for Mac, and the transcripts were checked and rechecked with audio recordings for accuracy. Data collection and analysis were carried out concurrently. All interview transcripts were read by me and my supervisor. Strategies outlined by Braun and Clarke (2006) were used to analyze the data. They described six phases in the analysis: familiarizing yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

Braun and Clarke (2006) described familiarizing oneself with the data as the continuous movement between data sources as the researcher reads and re-reads data sources, “jotting down ideas, and coding schemes, which continues through the analysis process” (p.15). To begin, my advisor and I reviewed the transcripts for the first two interviews independently, jotting down ideas and words or phrases in the margins. We then met to discuss our thoughts about the transcripts and began to generate initial codes. The first two transcripts were then coded. As each new transcript was reviewed, new codes were identified, discussed by me and my advisor, and added to the code list if agreed upon. There was a constant process of moving back and forth between transcripts. Throughout this process, discussions occurred with my advisor about collapsing groups of codes into categories, possible patterns evident in the data, and possible themes. In Word, NVivo software was used to assist in organizing and managing the data.

Braun and Clarke state a theme “captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set” (p.10). This process of looking for recurring patterns allows the researcher to engage

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with the data, continually going through transcripts and pulling out words and concepts which gave meaningful, rich descriptions of what was happening. Defining and naming themes occurred by organizing the categories into clusters, engaging in dialogue with my advisor about the meaning of those clusters and relationships evident between clusters, and ultimately naming the themes. My thesis advisor provided experiential knowledge with coding procedures and with sorting and organizing the data. By meeting regularly with my thesis advisor, codes, possible categories, and possible patterns in the data were discussed and agreed upon. After themes were identified, implications for education, practice, and research were explored.

Strategies to Ensure Rigor

Rigor in research has to do with its truth and validity. Davies and Dodd (2002) describe rigor as a “strict enforcement of rules” (p.280), and Streubert and Rinaldi Carpenter (2011) assert rigor is “demonstrated through the researcher’s attention to, and confirmation of, information discovery” (p.47). According to Sandelowski (1986), assessing rigor in qualitative research involves consideration of truth value in relation to the experience described through the research, the fittingness or transferability of the findings, the auditability of the research, and evidence of its neutrality. Thorne (2008) suggests procedures to ensure quality. The evaluation criteria to be used in interpretive description include: epistemological integrity, representative credibility, analytic logic, and interpretive authority.

The epistemological integrity Thorne refers to has to do with ensuring the research strategies reasonably match and address the research question. A qualitative approach was selected because our knowledge is limited regarding the experience under study. Interviews as the data collection strategy allowed participants to provide examples from their practice to illustrate their experiences and allowed the researcher to ask questions about those experiences.

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By keeping a journal to explain why decisions were made, epistemological integrity was promoted (Thorne, 2008). This documentation provided me with an understanding of the developing analysis.

Representative credibility has to do with the reality that “theoretical claims” (Thorne, 2008, p.224) need to be consistent with the way the study was sampled. Given that this was a convenience sample of ED nurses from the different hospitals within the WRHA, caution was exercised in terms of conclusions reached or inferences made. Sandelowski (1986) stated qualitative research is credible when others who share the same interpretations as the participants recognize descriptions and interpretations of human experiences as similar to their own. The researcher and thesis advisor were working throughout the study to compare transcripts, validate and expand or collapse codes, and search for and confirm patterns. Excerpts of data are provided in the thesis to allow for assessment by readers of the transferability of findings to other settings.

Analytic logic requires that the researcher explains the processes used throughout the study. The reflective journal provides information about decisions made throughout the study, including data analysis decisions. This formed a kind of audit trail. Auditability is a critical criterion of rigor that demonstrates consistency of the qualitative study (Sandelowski, 1986). By making decisions with my thesis advisor, providing specific coding procedures and instructions on organizing data and reflective journaling, information is available regarding the researcher’s logic.

Interpretive authority provides reassurance that patterns identified by the researcher and interpretations of the nurses’ experiences are trustworthy and come out of the data (Thorne, 2008). Working with my advisor ensured rigor was attended to and attention to outlining a

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decision trail, as described above, enables readers to better understand the interpretive account provided. Direct quotes from study participants are used to illustrate patterns and themes.

Ethical Considerations

Prior to data collection, approval from University of Manitoba's Education/Nursing Research Ethics Board (ENREB) was acquired. The ethical considerations of this study were guided by the three core principles outlined in the Tri-Council Policy Statement (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council, & Social Sciences and Humanities Research Council, 2014). They are: respect for autonomy, concern for welfare, and justice.

Autonomy involves respecting people's rights to make decisions for themselves. This was maintained through a process of informed consent. Study participants were provided with a careful explanation of the aim and purpose of study, the requirements of participation, and any risks and benefits associated with the interviews. It was stressed that participation is voluntary and that participants may refuse to answer questions or withdraw from the study at any time. Written consent was obtained from all participants after they have been provided information about the study and had an opportunity to ask questions. The participants were provided with contact information such as email and phone numbers for the researcher and thesis advisor, and were able to contact them at any time with questions or concerns.

With regards to concern for welfare, this study did not present any undue risk to participants. It was recognized that there was a possibility that the interview process could have proven to be upsetting. No participant became emotional in response to a question, therefore, none of the interviews were stopped. Study participants had an opportunity to debrief and discuss feelings or emotions with the researcher at the end of the interview if they so desired.

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Participants also had the researcher's contact information should they have wished to contact the researcher after the interview, and no participant did so. Participants were also given the opportunity to stop the interview at any time or withdraw from the study if they so desired. It was anticipated that there were benefits to participating in this study, such as providing participants with an opportunity to reflect on their practice, increasing our knowledge of nurses' experiences of caring for patients with dementia in the ED environment, and identifying what is needed to improve care for these patients.

Strategies were employed to ensure privacy was respected. No names appeared on transcripts or documents other than the consent forms. Instead code numbers were used. Consent forms were stored separately from the other data, and all data is kept in both a locked drawer/cabinet or on a password-protected computer. Only the thesis committee and I have access to the data. Any identifying information (e.g., names mentioned in interviews, place of work) was removed from the transcripts in the transcription process. Audio recordings were only accessed by the researcher and advisor, and will be destroyed after a period of two years. As well, all hard copies of the data will be destroyed as confidential waste after a period of seven years.

The principle of justice outlines the obligation of researchers to treat people fairly and with respect. As noted above, no foreseeable hardships were anticipated from participation in this study. Anticipated benefits included being a part of a research study to highlight nurses' experiences of caring for persons with dementia in the ED and any perceived gaps in ED nurses' education or the supports available to them in their workplaces.

The use of CRNM to assist with recruitment enhanced study feasibility. It was acknowledged, however, that some nurses may have viewed the person sending out the message

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at CRNM as an authority figure. CRNM is accustomed to research requests like this one, and have developed a standard disclaimer highlighting that the College of Registered Nurses of Manitoba is not carrying out the research but simply facilitating distribution of the message for the researcher, and encouraging nurses to read the message carefully to make an informed choice regarding volunteering for the study.

Summary

The purpose of the proposed study was to describe the experiences of nurses caring for patients with dementia in emergency departments in Winnipeg. The literature review confirmed that there is very little research done in this area. This gap in knowledge supported the need for this research to be completed and a qualitative research approach was identified as appropriate to address this gap. In particular, an interpretive description approach was selected for this study. The methods that were used for the study were outlined and presented, including a description of the design, sampling and recruitment strategies, and how data were collected and analyzed. Strategies to ensure rigor and ethical considerations were also outlined.

Chapter 4: Findings

In this chapter, the findings of the study are presented. The characteristics of the sample are described and the setting of the nurses' work is explored. The four themes identified through the process of data analysis to describe the ED nurses' experiences of caring for patients with dementia are outlined. Finally, the nurses' suggestions for strategies to improve the care of persons with dementia in the ED are provided.

Demographics

A convenience sample of twelve registered nurses working in emergency departments in Winnipeg volunteered to take part in this study. Demographic information is presented in Table 2. Six different hospitals are represented in this sample. Eight out of 12 nurses indicated they had experience working with geriatric populations in the past and the same number indicated they had received some form of education specifically related to dementia.

Table 2

Sample Demographics

Gender	11 Females 1 Male
Mean Age	40 years (range 22-63)
Mean Years of Nursing Experience	15.13 years (range 1.5-40)
Mean Years of ED Experience	10.38 years (range 1.5-30)
Type of Hospital	7 Community 5 Teaching
Nursing Education	5 Diploma 7 Degree

Categorizing the Findings

One of the early steps in the analysis process was to map out the preliminary codes and key terms identified through the review of the transcripts. The nurses' comments about the EDs they worked in and the persons with dementia and their family members provided context for understanding their experiences.

Understanding the ED Setting and Circumstances of the ED Visits

At the beginning of the interviews, nurses were asked questions about their emergency departments. Their departments were described by the nurses as chaotic, busy, and noisy, often with bright lights, few windows, and crowded waiting rooms. Some of the nurses provided details about the layout of their units, outlining the distinct areas contained within their emergency department (e.g., the triage area, treatment rooms, minor treatment area, resuscitation room, observation area, and cardiac monitoring areas). As the interviews progressed, this information was helpful in understanding where patients with dementia were sent to within the ED and where they waited.

Nurses were asked about the types of people they see in their EDs. Most of the nurses reported they see many elderly patients. Due to the location of one of the hospitals, the nurses that worked at that hospital reported that they see a high number of patients who could be classified as low-income and a significant number of new immigrants. Another nurse reported her ED sees the second highest number of paediatric patients (i.e., second to Children's Hospital), and two nurses reported a high number of PCHs and assisted living facilities in their catchment area, resulting in a high number of elderly persons coming to their EDs. With regards to the types of concerns that led people with dementia, their family members, or the people caring for them (e.g., staff in long-term care facilities) to go to or take the person with dementia

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to an ED, the nurses identified that this could occur for a number of reasons, including threats to life or health or a health issue that was viewed as serious.

The ED nurses were asked about their sense of what made a visit to the emergency department appropriate or inappropriate. It was noted in my reflective journal that this question of inappropriate visits led to smiles or laughter for some of the participants, with one chuckling as she responded “all of them.” The responses to the question were varied. Two of the nurses indicated that an appropriate visit involved a “true emergency”, that is to say, threats to a person’s “life or limb”, as indicated in the following excerpts:

“Well a true emergency is a threat to life and limb, excruciating pain. People who think that they are very, very ill and cannot get in to see a family doctor or a walk-in clinic, it's not appropriate.” (N11, 14-18)

“Anything that is life-threatening, anything that needs immediate medical attention after hours or even during the day, something that you can't wait to see, something you can't see at a walk-in clinic or a family doctor” (N6, 28-33).

Some nurses referred to specific types of threats to life or health in their responses to this question (e.g., chest pain, shortness of breath, abdominal pain). Other nurses identified that the idea of an “appropriate” or “inappropriate” visit to the ED was more nuanced than a focus on an “entrance complaint” or a life-threatening event or process. One nurse stated:

“My personal belief is that there is no such thing as an inappropriate emergency visit because we're here to meet the needs of that patient that is coming here. Um, if it's not a medical issue – or, it might be an emergency in the eyes of that caregiver, that family, that patient. And that's why we're here. This might not be the most ideal place for them to come, but that doesn't mean that it's inappropriate.” (N7, 328-336)

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As nurses described visits to the ED by patients with dementia, they often talked about the families and their role in the presentation to the hospital. When describing the different ways patients can arrive at the ED, only a few nurses talked about patients arriving by ambulance or arriving by themselves. Most of the nurses talked about patients who were brought to the ED by family members, as illustrated in this interview excerpt:

“It's more the family not the patient, because if they're that far gone it's not them making the decision. It's a family making the decision to utilize the emergency department.” (N3, 421-425)

In some instances, the nurses identified that what brought the person to the ED had more to do with the family of the person with dementia than the person himself or herself. One nurse described this as “caregiver burnout”, as illustrated in this interview excerpt:

“One thing we do see is like, you know, it's caregiver burnout. But, and I mean I can understand that if like, you know, it sort of depends on the circumstances. Like, if it's like an elderly woman taking care of my demented husband, and I also have health problems, I'm sure that is appropriate because they can't manage...” (N4, 494-506)

Two of the nurses used language related to not coping or failure to cope when describing the reason behind the ED visit. One nurse stated:

“We do have lots of patients with dementia, but frequently a lot of them come into us, um, they're not from long-term care, families taking care of them at home and then there's kind of a failure to cope at home. So, they come into our department and stay typically for quite a long time, in the observation area while, um, their panned for long-term care placement.” (N5, 67-74)

Another described how families reach a “breaking point”:

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“Families can't cope with them. They're at their breaking point; help hasn't been fast enough, or they have been on a wait list for so long, or in denial for so long, that they haven't bothered to get any of that in place. And then something happens and they snap. So they bring them in on Friday afternoon at this point.” (N3, 103-110)

Nine nurses acknowledged in their interviews that the reality is that the emergency department is seen as the “end of the line” for some members of the public, the place they go to when they have exhausted all other possibilities when seeking medical help, or, in some situations, other types of help, including support in the home. Of those nine, two nurses described this notion of reaching the “end of the line” in negative terms, using the language of “dumping”, as illustrated in this excerpt:

“Dumping. Family can't take care of them anymore. I've had enough – can't do it anymore, bring them to the emergency department.” (N11, 316-318)

When describing a situation involving a family that had not started the panelling process, and had reached a point where they felt they could not look after their loved one anymore because the person wandered at night, a nurse characterized the visit to the ED as a “dump and run” (N3, 113). The majority of nurses, however, discussed reaching the “end of the line” in ways that demonstrated their empathy for the circumstances that family members found themselves in. I also recorded in my reflective journal that the participants' body language and facial expressions seemed to demonstrate genuine concern and compassion for persons with dementia and their family members as they reflected on this reality. One nurse stated “the family is the ones that I'm very empathetic towards, because I know what it feels like” (N9, 439-442). Another nurse described a scenario of a family member bringing a loved one to the ED as follows:

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“I can't do it anymore I have to go to work I am out of sick leave. So she's your problem now.’ So, in my mind, I would think to myself, my initial thought is, oh my God, this is not what emergency department’s for, and why didn't you do something about this before? But, with my nursing hat on, this person might have not known what resources are out there.”(N6, 108-117).

One other type of concern that was identified as prompting a visit to the ED was behaviour on the part of the person with dementia that was viewed as aggressive and difficult to address. One nurse described a situation where the long-term care facility did not have enough staff and opted to send a “particularly aggressive patient” who had dementia to the ED for care.

“Nursing care homes, not having enough staff with a particularly aggressive patient, can’t deal with it, send them to emerg. That’s what we had last week. You know a violent patient, not taking him back... In a locked unit...he was becoming more and more aggressive. ‘Sorry, not doing it’. Send him to emergency and not taking him back.”
(N11, 316-321)

In summary, the nurses interviewed for this study described their EDs as busy and chaotic, with most nurses commenting on seeing many elderly patients in their EDs. Nurses also commented on the types of visits made by persons with dementia and the reasons patients with dementia present to their EDs, including serious or life-threatening illnesses, family members reaching a “breaking point” in caring for their loved one at home, and family members feeling that they had nowhere else to go to get assistance.

Themes

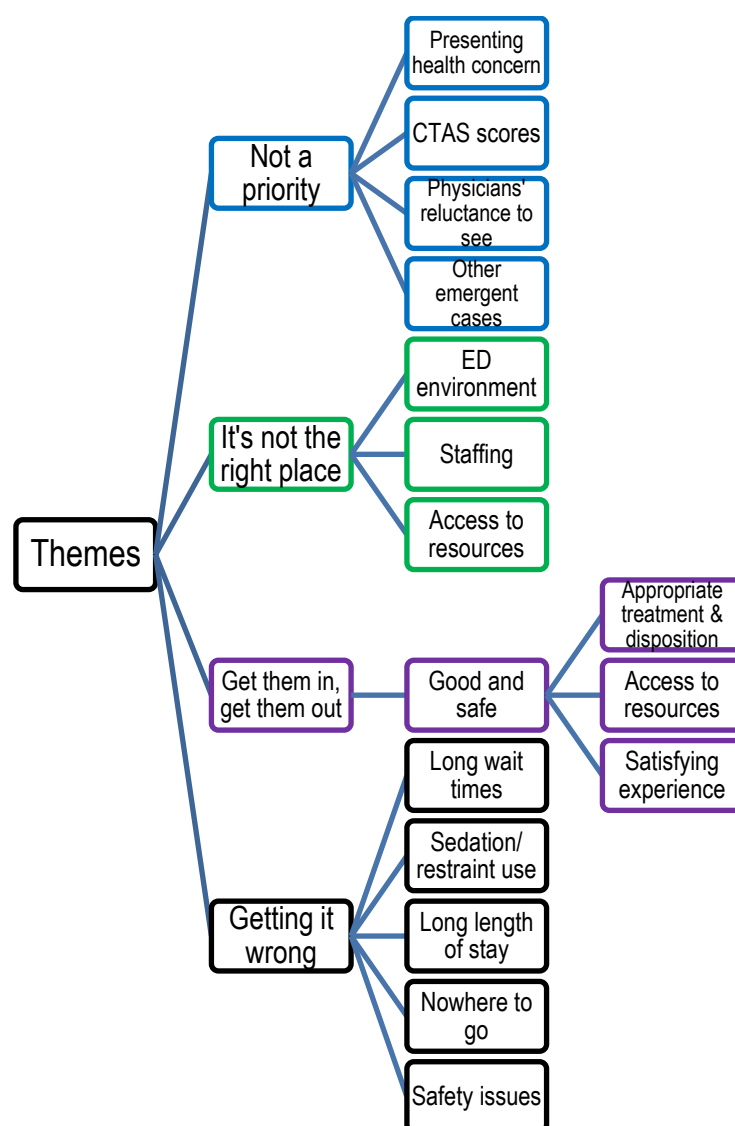
As noted above, through the data analysis process four themes were identified to describe the ED nurses’ experiences of caring for patients with dementia in the ED. These are: not a

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priority; it's not the right place; get them in, get them out; and getting it wrong. Figure 1 provides a pictorial representation of the themes illustrating the categories associated with the themes. Three of the themes speak to some of the barriers to providing good care to persons with dementia in the ED: not a priority; it's not the right place; and getting it wrong. The theme of get them in, get them out highlights factors that facilitate providing good care to persons with dementia in the ED. Each theme will be described in some detail.

Figure 1

The Four Themes



Theme 1: Not a priority. All of the ED nurses interviewed felt that, based on their experiences, patients with dementia are generally not viewed as a priority in the ED. Three factors were identified as contributing to this happening: patients with dementia generally score low on the Canadian Triage and Acuity Scale (CTAS); other patients are viewed as “sicker” than patients with dementia; and physicians appear reluctant to admit patients with dementia to hospital units. Each of these factors will be briefly discussed.

CTAS scores. ED nurses felt patients with dementia were neglected and often ignored because of the score they receive in relation to their acuity level when presenting to the ED. The Canadian Triage and Acuity Scale (CTAS) is a national guideline that describes patients’ health situation by level of acuity. Through entering into the computer the patient’s entrance complaint, vital signs, and other information, the program assigns a CTAS score ranging from one to five. This score determines the priority by which the patient needs to be seen. Level one is the most acute level, and these patients need to be seen right away. Level five is assigned to patients that need to be seen within two hours of presentation to the ED. The triage nurse is responsible to assess the patient and determine if the CTAS level is appropriate for the patient and helps determine what treatment area the patient will be sent to within the ED (WRHA, 2010).

From the perspective of the nurses interviewed for this study, the CTAS score generally works against the patient with dementia, leaving them classified as non-urgent and waiting for hours in the waiting room. If the person presenting to the ED was showing signs and symptoms of a serious illness, they would receive a low CTAS score and be seen right away. The patients with dementia the nurses had seen over the years they had practiced, however, were not always physically unwell. As a result, their vital signs might be normal and their assessment did not lead to an acuity score that required immediate attention. This meant that the patient with

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dementia would wait for hours to be attended to, as suggested by the comments of this participant:

"I think sometimes in emerg. they're shafted to the back of the rack [the patient's file is placed at the back of the rack, with the files at the front of the rack attended to first] because there is nothing life-threatening, or they're coming in for increased confusion. We get the blood work done and they wait and they wait." (N11, 361-365)

The nurses reported that patients with dementia were often on stretchers for hours waiting to be seen by an emergency physician.

Other patients are viewed as sicker. One of the challenges to providing good care to persons with dementia identified by the nurses was that in the context of a busy ED, other patients who were more acute or "sicker" needed to be seen right away. As one nurse explained:

"Unfortunately they [patients with dementia] just get, like they just get lower on the priority list than someone who has an unstable blood pressure, or chest pain, or short of breath, or whatever. So that makes it difficult, um, yeah, it's like, and just like if you're busy, it's just they are kind of last priority. I feel bad in saying that, but it is just how it is." (N4, 386-392)

Four of the nurses identified that patients with dementia were not a priority for the two reasons just discussed: the high CTAS scores and the acuity of other patients in the ED. This is illustrated well in the comments of one participant:

"It's just it's, I feel like sometimes we are guilty of putting them on back shelves, and he's fine. He's just confused. Because you've got the MI, and you've got people that are medically sick, life-threatening. And they're [patients with dementia] not life-threatening. And we just try to shelve them and maybe that's why they're not prioritized."

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Because they're not a priority. It's not their fault, they're just not a priority in our department. And I think that contributes to the whole problem.” (N10, 453-464)

The “whole problem” the nurse is referring to involves more than the long wait times for persons with dementia to be brought in to the treatment areas and assessed by the physician. For some of the nurses, the idea of not being a priority extended to not receiving appropriate nursing care. Given that the nurses were caring for a number of patients, the competing demands on their time sometimes led nurses to be “quicker to ask for medication to calm [the patient] down and sedate them” (N11, 203-208). It could also mean that patients did not receive the care they needed, as illustrated by this excerpt:

“I need to prioritize my tasks, and I need to look after the sickest people first. So, like taking your elderly, demented patient up for a walk, or spending some time with them and talking with them, is probably like last on your list. So, like you really get frustrated because you know that's what they need, but I don't have time to give that to them.” (N4, 111-117)

One nurse described how patients were sometimes “treated more as a nuisance than anything, especially if they are vocal, and acting out, and yelling, and then causing disturbances” (N3, 328-331). Another nurse described these types of scenarios as ones of neglect:

“I think like a lot of them, like I would say in general, that they do get neglected, like in my opinion... And, you know, it's difficult to, staffwise, like to recognize that. It's not that we don't know. It's kind of like we're in a position where we don't know what to do. Like I know this is bad, but I'm not really sure what we can do right now to make it better, so you just leave it as how it is recognizing, oh yeah, this person is really neglected.” (N4, 546-554)

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The nurses recognized that this was a real concern and some of them advocated for attention to the problem. As one nurse stated, even though the CTAS score for patients with dementia may be high (i.e., indicative of someone who is less acute than other patients), they need to receive attention in a more timely way:

“Well I think we need to see these people faster. And I know they’re level four or five on the CTAS score. Like I truly believe to get these people seen, diagnosed, and scripted [orders for medications written] if they are going to be, make a plan so they’re not sitting there as we all know they do, 8 to 10 hours, because they’re not acute.” (N2, 207-213)

Another nurse advocated for “bumping” patients with dementia forward, as sometimes happened with children who came to the ED:

“You know, there is a 97-year-old who keeps getting bumped and they are in the waiting room. You know, when you realize there has been a 97-year-old that has been out there for eight hours it is completely unacceptable. We bump the pediatric patient. Why are you not bumping forward a 97-year-old?” (N1, 489-497)

Reluctance of physicians to admit patients with dementia. Two of the nurses interviewed described situations where physicians did not view the patient with dementia as a priority. One of the nurses indicated that sometimes physicians do not even see the patients if they are waiting for assessments by services like social work and OT:

“...the other thing, too, is that the physicians tend to, if there's nothing medical going on, like there waiting for services, they won't really even see the patients” (N4, 264-273).

From the perspective of the nurses interviewed, one of the issues related to care for people with dementia was the availability of beds. One nurse stated:

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“...like part of our wait time problem is that there ain't enough beds.... [W]e can't count how many times we see people that have been in our department for 100, you know, 180 hours and, you know. So they failed OT/ PT, and then they get referrals to medicine, and then medicine doesn't want them.” (N4, 578- 588)

These nurses identified that the admission process was problematic because physicians are sometimes not keen on admitting patients for what are viewed or described as social reasons when there are other patients identified as quite ill needing beds. The notion of a “social admission” relates back to the perception that the ED visit was prompted by the family’s or caregiver’s inability to continue to care for the person with dementia at home for any number of reasons. Patients that are classified informally by staff as “social admissions” were viewed as often staying in acute hospital beds for weeks or months, waiting to be paneled for a personal care home or awaiting a bed in a specialty unit. The reason for their stay, from their perspective, was not a “medical” one. As a result, as one nurse explained, these patients are “unwanted” by different physician services (e.g., medicine):

“Because, sadly, they get a medical consult and medicine doesn't want them, because they bung up a bed. Nobody else wants them. A lot of the time they're not sick enough, so you get too many, too many people saying no. There's a lot of rejection, and home care can't, unfortunately, move fast enough. Most of the time they also need OT, PT, and GPAT [Geriatric Psychiatric Assessment Team] – that kind of stuff, and that's the excuse every service seems to have.” (N3, 155-162)

To summarize the theme of “not a priority”, nurses felt patients were not a priority in the ED and commented on the factors that contributed to this. These factors included the patient having a low score on the CTAS scale, sicker patients being seen and treated by various health

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care providers first, and the perception that physicians can demonstrate an unwillingness to admit patients with dementia to hospital beds to avoid “bunting up a bed” for a long period of time.

Theme 2: It’s not the right place. When describing their experiences caring for persons with dementia, all of the nurses identified that a key aspect of what makes it difficult to care for these patients is the feeling that the ED was not the right place for them. As one nurse explained:

“I don't believe that emergency is the best place for them. So, with all of the push to improve patient flow, wanting to meet the regional targets we have, um, this is truly a patient population that, if we've completely ruled out everything that needs to be ruled out in emerg., and they're not safe to go home, then the best place for them would be potentially to be admitted [to a hospital bed outside of the ED].” (N7, 265-273)

Nurses described two elements which had an impact on their care for a patient with dementia and contributed to the ED not being the right place for patients with dementia: a) the physical environment; and b) threats to patient safety.

Physical environment of the ED. The environment of the ED was viewed by the nurses as inappropriate for the patient with dementia. And yet, these patients sometimes stayed in the ED for extended periods of time. One nurse stated:

“We've had patients that would stay in our observation department, which is a very quiet, a very closed off area, for up to two months, waiting for placement – in an emergency department, which is unreal. It's sad, it's terrible, it's not a place for somebody to be.” (N5, 58-61)

Three nurses described the ED environment as chaotic, five nurses mentioned the high noise level in the ED, and eight nurses talked about the lack of natural light and windows in ED and the reality that the lights are always on making it difficult for patients to sleep. The two

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interview excerpts that follow illustrate these aspects of the ED environment and their impact on patients with dementia:

“We move people out 24-seven, so like we move people day and night. So, like day and night routines get disrupted. It's difficult to orientate them, because the way the unit is, we do have to leave the lights on at night, because we need to get into so-and-so's room. The noise makes it difficult.” (N4, 375-382)

“It's the noise, it's the constant people, it's the lights never get turned off, you know, trying to convince them it's nighttime and all the lights are on. And people are yelling like it's, it feels like daytime.” (N10, 142-147)

The constant activity and noise were recognized as contributing to increased confusion in some patients in the ED.

Nurses described other aspects of the environment that were problematic for patients with dementia, including the food in the ED (e.g., “It’s sandwiches for supper and sandwiches for lunch” (N6, 874-875)), the uncomfortable stretchers, the lack of activities for patients, and the lack of natural light. One nurse described the ED environment as follows:

“The stretchers are poor quality, there is [sic] no windows. That makes a huge difference. There's nothing for them to do back there. I mean, that would drive me stir crazy with nothing to do, and the long waits back there.” (N9, 311-316)

Another nurse acknowledged how the environment of the ED contributed to exacerbating the patient’s symptoms:

“Many things are documented, natural light, the lack of natural light, the noise, the constant noise, the lights that are always on, so all that contributes to, um, negatively to

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the situation, um, and may exacerbate symptoms that, or behaviour, that – a patient is definitely made worse by the environment.” (N8, 192-199)

The results for patients could be increased confusion, as illustrated in this excerpt:

“It's confusing; it's confusing for people that don't have dementia. And then to be in our environment it agitates them, it brings out the worst in who they are, and they can't really control that. It's a lot of work for us, and then quite often we wind up getting exasperated and impatient, and [they're] thrown in a Broda chair, you know, given Haldol, so we can get the rest of our work done, which sometimes is the only alternative.” (N10, 147-158)

Threats to patient safety. A second reason nurses identified for why the ED was not the right place for patients with dementia was related to safety. Nurses believed patients with dementia exhibiting responsive behaviours, such as wandering and aggression, created concerns for staff in terms of safety for patients in the ED. Patients who wander were described as being at the greatest risk, as illustrated by these two excerpts:

“Wandering, agitated patients, they are not safe in an emergency department. We had people go outside and we are on the corner of busy, busy streets. And, and we had a lady go out with no coat onto the median on [street name]. And we couldn't get one-to-one for her because she was for urgent respite; very frustrating.” (N1, 149-155)

“I had a case of a patient with dementia that was on close observation, and we had to call a code yellow [for missing patients] because she had actually left the department and walked home. And she actually came back with police.” (N4, 332-337)

Because emergency departments are built on the perimeter of hospitals, are high traffic areas, and are accessible to the outside, it is easier for patients to come and go as they please.

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This can lead to at-risk patients walking out the door if they are not being carefully observed.

One nurse stated:

“Safety issues, wandering, um, you know, emerg. departments are not secure facilities. We don't like to have constant care if we can avoid it because it can sometimes exacerbate the situation if you have somebody sitting and staring at you... But at the same time we can't risk losing [someone].” (N7, 193-199)

Another nurse described the following situation:

“We found another man upstairs on the fourth floor, and our doors to get out into the main hospital, you have to know to push a button on the wall to open it. You have to use your pass to get back in. So, whether he slipped out when the door was open and something was going through...” (N1, 184-193)

A common thread in these stories is that staff members were generally busy elsewhere with other patients, preventing them from monitoring the activities of the patient with dementia.

The other safety concern raised by the ED nurses interviewed for this study related to aggression exhibited by patients with dementia. This type of situation could create a safety risk for the patient himself/herself, the staff, or other patients. For example, one nurse described a situation where a patient with dementia hit her:

“She had her purse, and she actually started hitting me. She hit me several times, and at her worst, I was beside her bed, like we had the bed and then another bed and she pinned me against the wall.” (N6, 786-791)

This nurse was also concerned for the safety of others in the ED:

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“Just prior to that, yeah, I had to draw her away from the man who was sitting beside her because she started going towards him and his daughter, who was there. He was waiting to be discharged home. She started, she was going to hit them too.” (N6, 805-811)

Threats to the safety of the person with dementia or those around them could lead nurses to restrain the patient. As the excerpt that follows illustrates, this would occur to protect the patient, but restraint use could leave the nurses involved feeling quite conflicted:

“I hate to see an elderly patient in restraints, but it happens for our protection, for their protection. But I don't think it's necessarily inappropriate because at times it's necessary, but I just hate to see it. I think people need to understand that is an illness, it's not them, and they can't help it, but it is – it's frustrating when you have a patient that comes in, and you're getting information, and they won't let you do anything, other than constantly trying to get out of bed. That is tough.” (N9, 462-474)

In summary, the nurse participants in this study felt the ED was not always the right place to care for patients with dementia. This was true, in part, because of the environment of the ED, but also due to concerns for the safety of the patient, other patients, and staff members when person with dementia exhibited behaviours such as wandering or aggression.

Theme 3: Get them in, get them out. When the nurses interviewed for this study spoke about positive outcomes for patients with dementia in the ED, they all agreed that getting patients in to be seen as quickly as possible and then getting them discharged from the ED in an expedient manner led to better outcomes. One nurse stated that “it's all in the duration of stay” (N2, 104). Another summed this idea up as follows:

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“And that's when everything works fast enough. I think the trick with dementia patients is to get them out, don't leave them in our environment very long, because it just doesn't, it never does any good.” (N10, 134-139)

Part of “getting them in” seemed to relate to acknowledging that: a) in some situations, the patient’s health issue could be addressed quickly, with a potential for timely movement through the ED; and b) requiring the patient to wait an extended period of time in the ED was likely to have a detrimental effect on the patient.

For the nurses interviewed, the nature of the patient’s health issues clearly influenced the outcome in terms of moving through the department. As one nurse noted:

“When it is a medical problem, I think it is a positive experience because we can actually, there's [sic] things we can do to help.” (N4, 105-108)

If the medical issue was identified as relatively simple to resolve, this facilitated getting the patient with dementia in and treated, as illustrated in this excerpt:

“Instead of him having to wait around, that was the only issue there was. We just change the catheter and send the patient home. He didn't get all upset having to wait 10 hours for something so simple.” (N2, 56-60)

The “getting them out” part of this statement referred to moving the patient through the ED as quickly as possible, but, as noted in theme one, this was not always possible given some of the barriers that arose in the process. The nurses identified that when patients with dementia did not move through the ED in a timely fashion, the outcomes for the patients were not always positive. It was identified that the sooner patients with dementia are seen by physicians, diagnostic tests are completed, and disposition decided, the better the outcome. The nurses felt if

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patients are discharged back to their home setting or admitted to a hospital ward, that this was a good outcome, as illustrated in this excerpt:

“Either get them up to the ward, or get them home, because our department is not an ideal place. And a lot of times our patients get more confused or agitated the longer they're there [in the ED].” (N4, 414-418)

For others, the ideal disposition was being sent home, wherever that was (e.g., family dwelling, assisted living facility, PCH). Hospitals were recognized as potentially dangerous settings for a number of reasons, as described by this participant:

“Like getting them out of hospitals. Because I think they, hospitals don't do elderly people very well. They tend to get sicker quicker, and then they don't live as long. And I think you don't need to introduce other things, like you don't need to get MRSA, or VRE, or any of that stuff, just because they decided to show up to a hospital.” (N3, 481-489)

To summarize the theme of “get them in, get them out”, participants described how, from their perspective, getting patients with dementia into and out of the ED quickly resulted in better outcomes for these patients. The preferred disposition was the patient’s home, but this was not always possible. Admission to a hospital unit in a timely manner was also viewed as a good outcome.

Theme 4: Getting it wrong. The nurses interviewed for this study described their experiences with “bad outcomes” related to the care of patients with dementia in ED. In fact, the nurses told more stories of getting it wrong than stories that involved what they viewed as good outcomes. One nurse described care of patients with dementia in the ED as being a generally “a dark corner” in healthcare:

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“It just seems to be this quiet, dark corner that people in healthcare are aware of, but it – because it's not, nothing has seriously, has happened to somebody that has been brought to light, there is no push to change anything.” (N6, 1359-1365)

Outcomes that were consistently identified as problematic were calling a “code white” for a patient (i.e., an emergency code called to get help for a patient that is putting himself/herself or others at risk for harm) and restraining or sedating the patient when the patient exhibited responsive behaviours. Two of these outcomes are illustrated in the following excerpt:

“I don't know if it's just because I'm remembering the bad stuff, but a lot of, like the times I can think of these things, when they're in like a reassessment unit for like weeks, and more confused and have a constant care, we've called a code white on them. And then they've had sedation, like, you know, Haldol or something. So, then that makes them even more confused and they end up either, like usually, like they finally get admitted until they can be paneled.” (N4, 185-194)

A few nurses expressed concerns that sometimes it was a “knee jerk” reaction on the part of the ED staff to restrain or sedate patients in response to the behaviours the patients with dementia exhibited. One nurse stated:

“So I think a lot of the time, when there's behavioural concerns, um, we are very quick to jump to, they need restraints, they need chemical restraints, whatever it is um, so obviously that's never ideal for patient safety.” (N5, 151-154)

The sedation could also occur because of the response of the ED physician involved, as illustrated in this excerpt:

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“They [patients] are pinching or scratching or hitting. What I find different between the emergency department and the medical ward is that emergency physicians tend to sedate. We don’t sedate these patients on the medical floors...” (N1, 64-68)

One nurse described how she tried other interventions before sedating and restraining the patient:

“There’s different ways I contribute – it stands to my mind, like slow down rushing on things like restraints, and use of chemical restraints, and use of physical restraints, um, trying to talk to the person.” (N8, 115-119)

As described already, keeping patients with dementia in the ED for a period of time could contribute to getting it wrong. A patient story told by one of the nurses highlights how delays in accessing resources, home care in this case, led to a poor outcome for the patient:

“We had a lady, she was here, this was not too long ago. She was in our treats [treatment] area, and she was mild dementia, and she was a home care hold for something. Just increase home care. And she spent like, I think I had her for three nights in the stretcher. Now the third night she didn’t know where she was, certainly she is not the same woman anymore, and I swear it was from being in, she was in a room and isolation for something, so we made her cuckoo.... We wound up, she was supposed to be going home the next day from the report I got. But evenings was so concerned that she slipped so far from baseline, so now the home care that was waiting for her, she wasn’t ready for them anymore. She was too confused.... When they realized she really was getting confused, they found her walking around in the waiting room with the gown wide open in the back dragging her foley behind her. And somebody went, ‘Oh, I think she’s confused’.... So, I just thought that is just such a messed up situation. We didn’t move fast enough. And I don’t know the outcome, hopefully she went home. I just think

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we make their situations worse when we keep them for too long. (N10, 164-185; 185-193; 250-255)

There was an interesting tension in the comments of nurses, as sometimes actions taken by members of the health care team to protect the patient resulted in “getting it wrong”. When referring to a situation where the patient was confused and exhibiting challenging behaviours, one nurse stated:

“It's hard to deal with especially for 12 hours or 16 hours, even eight hours. You just want to keep them in bed, because they fall and that brings on a slew of problems like you don't want to happen to anybody. Yeah, I think a lot of people just get very frustrated.”
(N9, 474-481)

As this nurse described, these feelings of frustration might not always lead to the best outcome.

The nurse went on to say:

“Like people get frustrated and angry and it's not intentional. It's human nature to get frustrated. People are pretty good about stepping away and recognizing, you know, it's not them. Or, you know, it's unfortunate when you have, you know, a very confused patient and you end up having to call a code white. And you have 20 health care aides, doctors, nurses all show up because, you know, an old man is sitting in the hallway and he's yelling because he doesn't want to go with you, you know. That doesn't help either, you know, to get that person into a spot.” (N9, 555-569)

The nurses' feelings of inadequacy in relation to being able to do their job were evident, and they would describe how “hard” it can be to care for these patients in the ED. One nurse stated:

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“But it was awful, just to see like this poor woman, she was, she was so, like not, not coping well. We weren’t, we weren’t able to provide that care for her, so it was horrible.” (N5, 118-120)

One nurse explained why she thought ED nurses and personality may play a role in their negative emotions.

“I think maybe the type of staff that are attracted to the emergency type of nursing are not the same that would be attracted to looking after, to working on that (dementia) unit” (N10, 297-301).

In one interview, a nurse talked about a patient with dementia that was transferred from a rural facility with a fractured femur. The patient was transported with the leg not stabilized, and was screaming when he arrived. She stated:

“I wondered with that case, and at the time and still do, if it was um, maybe assumed that, or believed that because he had dementia, we don’t have to do the things that we would normally have to do for someone who doesn’t have dementia. Because I couldn’t imagine someone who was able to verbalize to you, ‘I’m in this much pain and you need to do something about it’, that somebody wouldn’t do something like stabilize the leg and give pain control for transport.” (N7, 166-176)

In summary, nurses spoke about poor outcomes related to patients with dementia in the ED and described how these outcomes were related to delays in getting care, sedating and restraining patients, or calling a code white. These “bad outcomes” could cause the nurses to experience frustration, feelings of inadequacy, or regret in relation to the quality of care provided.

Strategies for improvement. The nurses identified a number of strategies for improving the care of persons with dementia in relation to the ED. These suggestions can be categorized into proposed changes to structure and proposed changes to processes. As described in chapter one, structure is defined by Donabedian (1988) as the characteristics of the environment where a person receives care and includes things like staffing and the facility environment. Process is defined as how and when things are done or care is received (Donabedian, 1988).

Structure. Some of the nurses identified that strategies to improve patient flow would prove beneficial for persons with dementia. One nurse described how the hospital where she worked was exploring ways to eliminate “silos” in hospitals to promote better care delivery:

“It’s senior management and all of the directors here are working on a change model, to get rid of the idea of every program works in silos, and that we have to work as a team. Within – like this patient is a patient in the hospital not of emerg., not of medicine. And um, move the patient through the system in the quickest way possible and the safest care. And are they in the right place to receive the right care that they need?” (N7, 283-292)

Another nurse suggested that more beds in the region are required to improve patient flow and ensure bed access for persons with dementia when the need arises. She stated:

“Respite beds, better access, easier access to respite beds. Is there any like short-term stay, respite beds for patients with dementia? Or more community support for family, or the day program, stuff like that – just more resources in the community.” (N10, 420-426)

It was also identified that more PCH beds are needed:

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“I think we need more medicine beds. I think we need, we need more PCH beds. It’s the bottom line, right? Get them in an environment where they will do that, right? So it’s all about the PCH.” (N12, 221-224)

Some of the nurses described the model used in the region for patients experiencing a psychiatric crisis and wondered if something similar could be used for persons with dementia. The Crisis Response Centre (CRC) at Health Sciences Centre is an assessment and treatment centre for people experiencing a mental health crisis. People can walk in without an appointment and are able to receive referrals to other services (WRHA, n.d.). The centre is staffed by crisis workers, mental health clinicians, including social workers, nurses, and psychiatrists, and is home to the Mobile Crisis Team (Strachan, 2013). The two interview excerpts that follow point to the possibility of a crisis response centre for persons with dementia:

“Turn CRC into a dementia kind of thing, because it’s full of social workers. I don’t know if nursing and medicine is necessarily the right avenue.” (N3, 358-361)

“You know, like a mental health program that is external to the emergency department that crisis unit patients can go there on their own. Why couldn’t we create something like that for patients with dementia, for families who feel that, you know, there is nothing really medically wrong with their family member?” (N12, 265-270)

Other nurses felt having a special area in an ED for persons with dementia would be helpful. The environment of this area could be designed in ways to minimize harmful stimuli and keep people safe. As one nurse stated:

“I think in a perfect world we would have a special area, where you could put them that would be quieter. You would have higher ratio of staff that can keep an eye on them.

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You wouldn't be rushing at them all the time, you know lights out at midnight, you know."

(N11, 185-190)

Still other suggested that perhaps the city would benefit from a specialized ED for persons with dementia, as illustrated by this interview excerpt:

"Having a specialized emergency department like they do at Children's, where you could bring somebody in, you have access to extra help, we have the [Crisis Response Centre] mentioned already in place. If we had rooms we could have dimmer switches, for lights, proper beds, not just stretchers." (N6, 975-982)

One nurse identified that it might be possible to use the existing urgent care centre in the city in this way. She stated:

"You know we can use the Misericordia Health Centre in a different manner. I mean essentially it is a waiting ground now as a PCH. Why can't we make an intake center there? For folks who are, you know, we have urgent care there. Make it an urgent geriatric care." (N12, 275-280)

One other structure-related suggestion offered for improving care for persons with dementia was enhanced care in the community. For example, existing structures for mental health crises might inform the development of a mobile response team for persons with dementia, as illustrated in this excerpt:

"Even if it was providing like a public health phone number or like, like if... You know, if you have a mental health crisis, you can call and then crisis response, mobile crisis response, will come to your home. Like is there a mobile crisis thing for dementia?" (N3, 447-452)

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Process. When asked about possible strategies to improve the care of persons with dementia, three nurses offered suggestions to improve processes in the health care system. Two nurses identified that care maps for dementia care would prove helpful:

“Like whether we have like, you know, um, an ACS [acute coronary syndrome] care map, or like a sepsis care map. It's like, I don't know if we can necessarily, like maybe you can put some key things in like a dementia care map. Like okay, so you're – I don't really know, but they should have daily blood work, or they should um, be up and moving this often, something along... Like the time – to give you a guideline. It may make it easier. (N4, 400-408)

“I would say put a care map in place, um, that a – like we have care maps for so many things that are medically focused. Um, like we have flow sheets for asthma, and we've got a flow sheet for DKA [diabetic ketoacidosis]. It's all those very medical things, but um, if there was a care map with interventions, or like reminders, things like that, that we can help, like reorient people regularly.” (N5, 224-228)

Another nurse suggested that it would be helpful if persons with dementia could be “fast-tracked” through the ED and discharged in such a way that they are able to access the services they need. She stated:

“I think I'd have them fast-tracked out of emerg, kind of like what they're trying to do with psych patients to crisis response. If you could triage them, and get them looked at by a doc, and say this is not something that is appropriate for an emergency. But, yes, they are emergency respite, yes, they need care, yes they need to be pushed through the system faster if they are on a wait list already...” (N3, 342-351)

Summary

In this chapter, the experiences of the ED nurses interviewed for this study in relation to caring for patients with dementia are examined. Nurses described the EDs in which they work and the types of ED visits they have seen from persons with dementia. The four themes identified in the analysis process were described. Nurses talked about the fact that persons with dementia were not always a priority in the ED, with CTAS scores working against them, sicker patients in the department being seen and treated first, and barriers in place for admissions to hospital beds. The participants shared concerns about the ED environment not being the right place for patients with dementia and how some patient behaviours, including wandering and aggression, put patients and others at risk for harm. Nurses perceived calling a code white and restraining and sedating patients with dementia as poor outcomes, while moving patients in and out of the ED in a timely manner was viewed as a positive outcome. The nurses also identified strategies for improving care for persons with dementia, including changes to both structures and processes in the health care system.

Chapter 5: Discussion

In this chapter, the findings of this study are examined in the context of the current literature on ED use by persons with dementia and nurses' experiences of caring for patients with dementia in the ED. Limitations of the study are also identified and the implications for practice, education, and future research are explored.

Persons with Dementia and ED Use

It is clear from the literature that effective care for persons with dementia requires attention to knowing the person, relationship building, collaboration, and manipulation of the environment (Alzheimer's Society of Canada, 2011; Bray, Evans, Thompson et al., 2015; RNAO, 2004; Thompson & Heath, 2013). Overcrowding, lack of privacy, and periods of decreased attention from hospital staff are identified as risks to increase the challenging behaviours of individuals with dementia (National Collaborating Centre for Mental Health, 2007), and all of these factors may contribute to the development of adverse events in hospitals (Salen et al., 2009; Watkin et al., 2011). The nurses who took part in this study to a person described the environments they work in as busy, often chaotic, and noisy. Many of the nurses described cramped working spaces, the use of bright lights around the clock, and constant activity in their EDs. It is not surprising, then, that many of the stories told by the nurses interviewed for this study highlighted concerns regarding the care persons with dementia received in the ED. It is also not surprising that the nurses questioned the appropriateness of their environments for extended stays for persons with dementia.

In chapter two it was noted that older adults visit the emergency department (ED) more than any other age group, and typically with serious illnesses (Parke et al., 2011). Studies have also identified that persons with dementia visit the ED more frequently than older adults without

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dementia (LaMantia et al., 2015). While questions were not asked regarding the numbers of patients with dementia participants had cared for, the nurses had no difficulty in recalling situations in their practice involving the care of a person with dementia.

The participants in this study did not provide many examples of, or spend much time discussing, situations involving threats to “life or limb” with persons with dementia presenting to the ED, although these occurred in their practice. Instead, they tended to focus on what the nurses described as situations of caregiver “burnout” or the “failure” of family members or caregivers to “cope” with the increasing challenges of caring for a person with dementia at home or in a PCH. As with Bache’s (2005) work, nurses in this study identified that when families are struggling to cope with a particular situation or a series of events related to a person with dementia, the ED can become the “default” resource for patients and families (p. 257). Similarly, Buswell et al. (2016), in a review of the literature, located seven papers that discuss the perception of EMS as the “last resort” or “safety net” for the care providers of persons with dementia, even in the absence of an “urgent or emergency care need” (p. 64), and especially outside of the normal business hours for other types of available services. From the comments of the nurses interviewed for my study, they appeared to focus on situations of caregiver “burnout” or families reaching the “end of the line” because they were memorable in terms of outcome and/or because of the time the patient spent in the ED. Some of the nurses referred to this type of situation as a “social admission.” George et al. (2013) conducted a literature review on how to keep patients safe in acute care when they have dementia. They found literature that suggested that patients with cognitive impairment were discriminated against and felt they were “unwelcome” (p.357) in EDs. The literature also indicated that physicians and nurses did not

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spend much time with these patients and, once the patient with dementia is labeled “social admission,” proper assessments and treatments do not happen (George et al., p. 357).

All of the nurses in this study provided a story about an encounter with a person with dementia who may not have required the services of an ED in that the concern that brought them there was not an emergency in relation to physical health. In the telling of these stories, the nurses expressed feelings of empathy for the family caregivers of these patients, and understood why families sometimes had reached “the end of the line.” Previous research examining ED nurses caring for older patients found good nursing includes understanding and empathizing with the stories and situations of the older patient (Gallagher et al., 2014; Kihlgren et al., 2005).

There is certainly evidence in the literature that caring for a family member with dementia can prove both rewarding and challenging. The idea of reaching a point at which help is required urgently has been described in the literature using the language of burden or crisis. Research has shown that as persons with dementia start to decline functionally and cognitively, families are less able to adapt, increasing their burden, defined in a review article as a “multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving experience” (Kasuya, Polgar-Bailey, & Takeuchi cited in Etters et al., 2008, p. 423). As caregivers age, the stressors they experience can increase (Moons, Arnauts, & Delooz, 2003). There is also evidence in the literature that caregiver burnout results in increased visits to health care settings by families and patients (Etters et al., 2008). Ledgerd et al. (2016), using an online questionnaire sent out to key stakeholders in dementia care (n = 719) in the United Kingdom, categorized the top causes of crisis in dementia into five domains: behavioural/psychological issues (e.g., wandering, aggression); physical health issues (e.g., falls, incontinence); vulnerability issues (e.g., non-adherence to medication regime, inability to

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manage finances); family carer issues (e.g., burden, caregiver health); and environmental factors (e.g., hazards in the home). In that same study, accident and emergency services were identified as one of the top five interventions to manage a crisis in dementia (Ledgerd et al., 2016).

Issues that Arise in Care for Persons with Dementia in the ED

Three of the four themes identified in this study, “not a priority”, “it’s not the right place”, and “getting it wrong”, speak to the nurses’ perspectives on issues that can arise in the care of persons with dementia in the ED or factors that act as barriers to providing good care to this population. Table 3 provides a comparison of the findings in the theme of “not a priority” in relation to findings from similar studies done in other jurisdictions (e.g., Sweden, Canada, and the U.S.). Just as in my study, clearly evident in the findings of other studies from EDs are issues related to lengthy wait periods for persons with dementia to be assessed, care that was viewed by the nurses as being less than ideal, challenges related to getting persons with dementia admitted to hospital units, and inappropriate or worrying discharge plans. It is important to acknowledge that sample sizes are small in all but the Boltz et al. (2013) study. None of the other studies comment on issues with a triage tool (e.g., the CTAS in Canada), but the Parke et al. (2013) study, also from Canada, found that nurses felt persons with dementia were under-triaged, often leading to hours of waiting and the patients’ basic needs not being met.

Much like my study, the nurses in the Gallagher et al. (2015) study identified that it was difficult to find a physician who was willing to admit complex patients in the ED. Nurses in the Gallagher et al. (2015) study felt they had to convince a physician to accept patients; one nurse in that study referred to this as “selling the patient” to the physician (p. 315). It has been identified that the volume of patients in EDs, the lack of resources, and the push to move patients out of EDs makes it challenging to address issues related to living conditions and progressive dementia

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(Aldeen, Courtney, Lindquist, Dresden, & Gravenor, 2014). One solution to this might be improved “cooperation and admission systems ... between the ED and the hospital” (Gallagher et al., 2015, p. 315). Another solution suggested by the nurses in this study was increasing the resources available in the community for persons with dementia and their families.

Table 3***Comparison of Study Findings with the Literature: Not a Priority***

Persons with dementia are not a priority in the ED	Comparable Findings in Previous Studies
<ul style="list-style-type: none"> • Patients with dementia are often ignored because of CTAS scores • Other patients are viewed as sicker 	<ul style="list-style-type: none"> • Kihlgren et al. (2005) – interviews with 10 ED nurses in Sweden: patients with dementia waited hours for ED physicians to do an assessment and develop a plan • Parke et al. (2013) – interpretive descriptive study with 10 ED RNs, 4 NPs, and 10 patient-family dyads in Canada: patients were under-triaged; patients and families felt overlooked
<ul style="list-style-type: none"> • Lack of time and staff to provide appropriate care 	<ul style="list-style-type: none"> • Kihlgren et al. (2005) – interviews with 10 ED nurses in Sweden: lack of time and heavy workload prevented good nursing care • Boltz et al. (2013) – survey of 527 U.S. ED nurses: issues with time and enough staff to provide quality care • Parke et al. (2013) – interpretive descriptive study with 10 ED RNs, 4 NPs, and 10 patient-family dyads in Canada: nurses identified that patients’ basic needs were often not met • Gallagher et al. (2014) and Fry et al. (2014) – focus groups with 27 ED nurses in Australia: nurses frustrated by their inability to provide quality care to older persons in ED due to time constraints; family members viewed as demanding or obstructive if they “cost” nurses time
<ul style="list-style-type: none"> • Reluctance of physicians to admit patients with dementia • Challenges related to appropriate disposition of patients with dementia 	<ul style="list-style-type: none"> • Gallagher et al. (2014) – focus groups with 27 ED nurses in Australia: difficult to find physician willing to admit socially at risk patients • Boltz et al. (2013) – survey of 527 U.S. ED nurses: concerns with unsafe discharges

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Table 4 provides a comparison of the findings in the theme “it’s not the right place” in relation to the findings of similar studies. As with my study, challenges with the environment and the safety of persons with dementia in EDs have been acknowledged and discussed in the literature. Interestingly, Kihlgren et al. (2005) also used the phrase “not the right place” in the discussion of their study findings as follows: “The emergency nurses said that the older patients are uncomfortable and that the ED is not the right place for these patients, because the ED is not organized to meet their needs” (p. 606). Two areas the nurses in the Boltz et al. (2013) study identified as influencing safety in the ED were “nonelder friendly physical plant design and lack of equipment” (p. 449). The specific aspects of the environment identified by the nurses in that study included the hectic environment of the ED, the lack of appropriate stretchers, the lack of appropriate toileting facilities, and the inability to see patients to ensure they are not climbing out of stretchers (Boltz et al., 2013). The nurses in my study also spoke to issues with the environment, the stretchers, and the physical set up of the EDs.

Table 4***Comparison of Study Findings with the Literature: It’s Not the Right Place***

EDs are not the right place for care of persons with dementia	Comparable Findings in Previous Studies
<ul style="list-style-type: none"> Challenges with the environment of the ED 	<ul style="list-style-type: none"> Kihlgren et al. (2005) – ED not structured in a way to meet the needs of older patients (“not the right place”, p. 606) Boltz et al. (2013) – survey of 527 U.S. ED nurses: concerns regarding the environment, including toileting facilities, noise, hectic pace
<ul style="list-style-type: none"> Safety issues 	<ul style="list-style-type: none"> Boltz et al. (2013) – survey of 527 U.S. ED nurses: concerns for safety of patients

Table 5 provides a comparison of the findings outlined in the theme “getting it wrong” with findings from similar studies. Two issues identified by the nurses in my study in relation to “getting it wrong” are prolonged lengths of stays in the ED for persons with dementia and the inappropriate use of chemical or physical restraints with these patients. Previous studies have found that inefficiencies in ED processes (Boltz et al., 2013) and restraint use (Rhodes et al., 2016) contributed to prolonged lengths of stays for older adults in the ED.

In their retrospective electronic health record review, Rhodes et al. (2016) found patients with behavioural issues had longer lengths of stay if they were being restrained and/or were not able to return to their previous living arrangements. Increased lengths of stay correlate with increased risk for adverse events and decreased quality of care. One issue described by Rhodes et al. relates to what is known as alternate level of care (ALC), referring to patients that do not meet the guidelines for hospital admissions but also cannot return home due to safety issues. ALC patients that stay in hospital but could be cared for in a different type of setting lead to acute care beds being filled and EDs that are overcrowded with boarded patients (McCloskey, Jarrett, Stewart, & Nicholson, 2014). In the literature the notion of boarding has been defined as “the practice of holding patients in the emergency department after they have been admitted to hospital, because no inpatient beds are available” (American College of Emergency Physicians, 2011, p.1).

Rhodes et al. (2016) suggested that processes like admitting patients classified as “social admissions” should be put in place to decrease patients’ length of stay in the ED, and avoid any risk of adverse events (p. 8). Birrer et al. (1999) identified that a “social admission” is sometimes the only alternative as a possibility for disposition of some patients (p. 515). Similarly, Eriksson and Saveman (2002) described patients with dementia being admitted for

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social reasons, not medical ones, when families could not care for them at home anymore. Given that the nurses in my study tended to focus on ED visits based on families reaching a point at which caring for their loved one at home proved challenging, it is reasonable to assume that policies and processes to facilitate admission to the hospital or other appropriate settings would prove beneficial.

Table 5*Comparison of Study Findings with the Literature: Getting it Wrong*

Getting it wrong	Comparable Findings in Previous Studies
<ul style="list-style-type: none"> • Long stays in the ED 	<ul style="list-style-type: none"> • Boltz et al. (2013) – survey of 527 ED nurses: “prolonged triage and throughput” (p. 448) • Rhodes et al. (2016) – retrospective electronic health record review for people 65 years of age and older who visited ED with behavioural health issues (US): longer length of stay with restraint use; recommended selective use of ‘social admit’ for patients with a failed discharge
<ul style="list-style-type: none"> • Inappropriate use of chemical or physical restraints 	<ul style="list-style-type: none"> • Parke et al. (2013) – interpretive descriptive study with 10 ED RNs, 4 NPs, and 10 patient-family dyads in Canada: restraint use due to limited physical space and health care providers’ lack of knowledge about dementia

Parke et al. (2013), in their study of nurses and patient-family dyads in the ED, found that health care providers’ lack of knowledge about dementia contributed to the use of restraints for persons with dementia. Schnitker et al. (2015) identified that one structural quality indicator in the ED is a policy “outlining the assessment and management of behavioral symptoms, with specific reference to older people with cognitive impairment” (p. 277). Interestingly, the nurses in my study did not identify their own lack of knowledge as a particular issue in the care of

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persons with dementia. They also did not immediately suggest that additional education is required for ED nurses to improve the care of persons with dementia in ED, although they agreed with this idea when asked if additional education for nurses related to the care of persons with dementia in the ED would be beneficial. One exception to this related to recognition of a need to learn more about preventing the use of restraints. It is not clear why the nurses did not view broader education about the care of persons with dementia as an area for improvement. As will be discussed in the next section of this chapter, the nurses in this study looked outward for strategies to improve the care for persons with dementia.

Suggestions for Improvement

One of the strengths of this study is the contribution the findings make in relation to suggestions for improvement of the care of persons with dementia in the ED. The theme of “get them in, get them out” provided insight into strategies for achieving positive outcomes when caring for persons with dementia, most of which pertained to trying to limit the amount of time patients with dementia spend in the ED from entry to discharge. From the perspective of the nurses interviewed, patients with dementia who present to the ED need to be seen and assessed quickly to expedite disposition and prevent adverse events or poor outcomes. The use of nursing judgment to “bump up” persons with dementia was one strategy that was promoted.

At the end of their interviews, the nurses in this study were asked to provide additional suggestions for improving the care of persons with dementia in the ED (see Table 6). Some of their ideas were focused on structural changes, including increasing resources in the community or beds in the system, creating specialized areas within EDs or specialized EDs for care of persons with dementia, or creating a centre modeled on the Crisis Resource Centre for persons with dementia and their families. Other ideas put forward by the nurses related to process

changes, including the development of care maps or processes to fast-track persons with dementia through the ED.

Table 6

Suggestions for Improvement of Care of Persons with Dementia in EDs

Participants' Suggestions for Improvement	Suggestions Outlined in Previous Studies
<p>Structure</p> <p>Focus on Beds, Environment, Specialization</p> <ul style="list-style-type: none"> • Facilitate movement through the emergency department by eliminating “silos” in hospitals • Increased number of beds available, including respite beds • A special area in the ED for persons with dementia (with a redesigned environment) • A type of crisis response centre (similar to what exists for mental health) • A specialized ED for persons with dementia • Enhanced resources and care in the community 	<p>Structure</p> <p>Focus on Education and Training</p> <ul style="list-style-type: none"> • Boltz et al. (2013): training: need for nurses to learn ways to care for patients without the use of restraints • Parke et al. (2013): importance of education/training of nurses, addition of clinical resource nurses, staffing changes • Gallagher et al. (2014): nurses need to increase their specialist geriatric knowledge; need for support from specialist geriatric services in ED
<p>Process</p> <ul style="list-style-type: none"> • Care map for persons with dementia in the ED • “Fast-track” persons with dementia through the ED 	<p>Process</p> <ul style="list-style-type: none"> • Boltz et al. (2013): need for evidence-based protocols to guide assessments of patients with cognitive impairment • Parke et al. (2013): importance of relationship-centred care • Fry et al. (2014): ED nurses need to accept that “care of the older person is core business” (p. 35) • Rhodes et al. (2016): recommended selective use of ‘social admit’ to a hospital unit for patients with a failed discharge

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There is a growing literature around improving the care of older patients in the ED. Included in this literature are suggestions for: the use of tools to screen for seniors at risk (Asomaning & Loftus, 2014; Melady & Banerjee, 2015); specialized nurses in geriatric care working within the ED to assess patients and coordinate care (Aldeen et al., 2014; Baumbusch & Shaw, 2011; Donnelly, McElhaney, & Carr, 2011; Flynn et al., 2010; Wolfe, 2006); and specialized teams that can be consulted and that arrange for fast-track assessments and management or referrals of older persons in the ED (George et al., 2013; Shanley et al., 2009). In addition, changes to the environments of ED to enhance care of older persons have been suggested by various authors, including the development of areas within the ED specifically for persons with dementia that attend to issues with noise and provide appropriate beds and facilities for these individuals and their family members (Bray, Evans, Bruce et al., 2015; Joanna Briggs Institute, 2012).

The nurses in this study did not discuss the need for specialised nurses to care for persons with dementia in the ED. They did recognize the need for expertise through, for example, mobile crisis response teams or the creation of a separate emergency department or crisis response centre, staffed with appropriate health care providers from multiple disciplines (e.g., nurses, physicians, social workers, and mental health workers), to ensure people with dementia receive the assessments and supports they need.

Limitations of Study

There are a number of limitations to this study. The first limitation was the sample size ($n = 12$) and the fact that only nurses from one regional health authority were interviewed for this study. A larger sample size, including nurses working in different types of ED settings (e.g., urban, rural, northern), may have uncovered different experiences related to the care of persons

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with dementia in the ED or illustrated similarities across settings. Another limitation was that eleven out of the twelve nurse participants were female. It is not known if any differences exist between the experiences of male and female nurses when caring for patients with dementia and their families in ED and further study is needed to explore this. The nurses involved in this study were interviewed once at one point in time. Additional interviews may have allowed for richer data. For example, interviewing nurses over time could create opportunities to discuss interactions with persons with dementia and their families in the ED as they occurred in practice. Adding additional data collection strategies, for example, observation of interactions, would be logistically challenging, but could provide real-time opportunities to discuss situations as they unfold.

In addition to the limitations discussed above, it is possible that my background as an ED nurse may have had an impact on the data collection and analysis processes due to my experience and knowledge as an ED nurse. Given my familiarity with this role, it is possible that I may have taken some participant statements or comments for granted rather than asking follow-up questions or seeking clarification. A different interviewer, one with no familiarity with the ED setting, may have taken the interviews in different directions.

Implications for Education, Practice and Research

The findings of this study have implications for education, practice, and research. Each of these areas will be briefly discussed.

Education. A few of the concerns identified by the nurses interviewed for this study have implications for education at both the undergraduate level within academic nursing programs and within the context of emergency nursing. In a very general sense, nurses working in EDs would benefit from additional education about dementia, the care of persons with

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dementia in the ED, and the issues that can arise for this population. The participants in this study acknowledged that it was important for nurses to understand their role as advocates in the care of persons with dementia, particularly in terms of assisting to move people with dementia through the ED by “bumping” them up so they are seen by the appropriate people in a timely fashion or mobilizing resources to respond to the crises patients and families members face in the trajectory of their illnesses. The nurses recognized that education is needed regarding appropriate strategies to address or deal with responsive behaviours, particularly agitation, aggression, and wandering in persons with dementia in the ED. As noted in the findings chapter, nurses identified that restraint or sedative use was perhaps over-utilized and viewed as a poor outcome by the nurses. Andrews and Christie (2009) also found a need for education related to additional strategies to deal with challenging behaviours of patients with dementia.

Practice. The findings of this study point to a general need for re-examination of dementia care in the community and within health care systems and the resources needed to provide care to families in crisis. Some of the nurses in this study suggested it would be helpful to have similar emergency resources available for families of persons with dementia as are available for persons with mental health issues, such as the Crisis Response Centre (CRC) created for persons with mental health concerns in the region. Having a multi-disciplinary team available around the clock and staffed with social workers and crisis workers would be helpful for families and caregivers of persons with dementia and this could potentially eliminate some visits to the ED. Nurses also suggested it would be helpful to have a mobile unit to respond to concerns and issues in the community similar to the mobile crisis unit that is used for mental health emergencies. A few nurses thought having a specialized ED for persons with dementia was a good idea and it was suggested that the Misericordia Urgent Care Centre could be used in

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this way to provide a quiet, relaxed area to care for this population. This urgent care centre is also attached to a personal care home, which could prove advantageous.

A few participants suggested families would benefit from receiving education on what resources in the community are available to them and how to mobilize them such as when and how to increase home care services and having the family doctor start the paneling process for long term care (LTC). Perhaps changes to structure, such as hiring Geriatric Emergency Management (GEM) nurses (Wolfe, 2006) into positions in our EDs as they have in Ontario, would help with problem solving related to the care of persons with dementia and providing evidenced-based care in our EDs. Hiring more nurse practitioners (NPs) for LTC facilities could not only help provide appropriate treatments and medications for residents, but they could also order necessary diagnostics (i.e., lab work and imaging) to prevent visits to the ED. Structure changes in regards to staffing could include: increasing staffing levels and supports for patients and family members; and working with management to assist them to recognize the frustration among staff members when they are unable to get another nurse or health care aid to help provide quality care to patients who display reactive behaviours. The changes to structure mentioned here may improve outcomes.

Changes to processes such as creating a care plan when a patient with dementia presents to the ED may improve care and promote better outcomes for these individuals and their families. Changes are also needed in the way physicians screen and admit patients from the ED to the ward when patients are unsafe and unable to return home. Understanding the need for “social admissions” and streamlining the patient with dementia for urgent respite are necessary approaches to promote safety and improve outcomes (Rhodes, 2016). A process change to throughput that may also improve outcomes is looking at the triage process. For example, it

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would be helpful to encourage nursing judgment to bump up patients with dementia to a higher acuity CTAS score to get them seen by physicians sooner and plan for disposition sooner.

Getting these patients in and out of the ED sooner with appropriate dispositions is key, as described by the ED nurses in this study.

Research. The findings of this study have implications for future research. As noted above, the sample size for this study was small and additional research exploring the questions guiding this study is needed with a larger and more diverse sample. There is also a need for a larger study with interdisciplinary staff in the ED (e.g., nurses, physicians, social workers, health care aids) to explore their experiences and perspectives of caring for patients with dementia. Research that examines other staff members in the ED could uncover gaps in our knowledge, add to the body of research in this area, and potentially offer additional insights into strategies to improve the care of persons with dementia in the ED. It would also be valuable to explore and identify poor outcomes related to patients with dementia who cannot return home and need respite or become social admissions, as there is a compelling association between patients with dementia and reported adverse events (Watkin et al., 2011).

One of the interesting aspects of this study was the empathy the nurses had for patients with dementia and their families, particularly in the context of the notion of reaching the “end of the line” in relation to caregiver stress. This is an area that has not received much research attention to date. It would be interesting to explore ED nurses and empathy in regards to families of patients with dementia and how families perceive that empathy.

It is clear that research is also needed to explore how changes to systems and/or processes might lead to improved outcomes in the care of persons with dementia presenting to the ED. One example of a study would be an education intervention related to nursing care for persons

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with dementia exhibiting responsive behaviours in the ED. The nurses in this study identified that a “bad” outcome in the care of persons with dementia was the use of restraints or sedatives. An educational workshop on the topic of responsive barriers and best practice in relation to nursing interventions in the care of persons exhibiting these behaviours in the ED could be developed, and variables such as the use of restraints, the use of sedatives, and length of stay in the ED could be measured pre- and post-workshop.

Summary

In this interpretive descriptive study, 12 ED nurses volunteered to be interviewed about their experiences of caring for patients with dementia. The EDs in which they worked were described as being busy, chaotic, and noisy, with bright lights kept on around the clock, creating issues for these patients. One key finding was that the nurses tended to focus on stories of caregiver burnout leading to the ED visits, with EDs seen as the default when families have no place else to go. Of note was the empathy the ED nurses exhibited for these patients and their families, a finding that requires further investigation in future studies.

Using the thematic analysis process described by Braun and Clarke (2006), four themes were identified: not a priority; it’s not the right place; get them in, get them out; and getting it wrong. The nurses described patients with dementia waiting for long periods of time in their departments, while patients who were viewed as sicker were seen first. Barriers to moving patients with dementia through the ED were identified, including their CTAS scores, physicians not prioritizing these patients to assess and treat them or admit them, and the lack of available beds. Nurses spoke about the benefits of moving persons with dementia through the department more quickly, and discussed strategies, including the use of nursing judgment to “bump” forward these patients, to ensure timely treatment and disposition. An important finding, one that has

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clear implications for education and practice, was that sedating and restraining patients with dementia in the ED were viewed as occurring too frequently by the nurses interviewed for this study, increasing the possibility of negative outcomes for these patients. This has been discussed in previous studies, and requires additional research attention.

One of the ways this study contributes to knowledge development in this area is through the suggestions provided by the nurses interviewed for improving the care of persons with dementia in the ED. These included structure improvements (e.g., enhanced access to resources in the community, more beds, specialized EDs, or a crisis resource centre for people with dementia) and process improvements (e.g., care maps and processes to fast-track persons with dementia through EDs). While some of these suggestions have been discussed in the literature, ideas like a crisis resource centre or specialized EDs for people with dementia and their families warrant further exploration. One area of improvement that has received considerable attention in the literature to date is educational opportunities for ED nurses related to the care of persons with dementia. While the need for additional education was briefly mentioned by the nurses in the study, it was not mentioned by all of the nurses interviewed and seemed to be focused on the need for education related to restraint and sedation use.

The limitations of the study included the small sample size from one western Canadian city, the reliance on the nurses' reflections from one moment in time, and the fact that only one male participated in the study. A larger study, including multiple ED settings and a more diverse sample, may provide valuable information on caring for patients with dementia. The findings of this study have implications for nursing education at the undergraduate and post-graduate level, practice, and research. As was noted in chapter one, "nurses are well placed to facilitate best practice 'at the coalface' in the clinical processes" related to care of persons with dementia

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(Department of Health, State of Western Australia, 2011, p. 20), and this would certainly be true in EDs. The findings of this study broaden our knowledge related to ED nurses' experiences of caring for persons with dementia and add to the growing body of literature focused on improving that care.

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Appendix A: Ethics Approval



APPROVAL CERTIFICATE

January 22, 2015

TO: Jennifer Charlene Fulcher
Principal Investigator (Advisor: M. Edwards)

FROM: Lorna Guse, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2014:155
"Emergency nurses' experiences of caring for patients with dementia"

Please be advised that your above-referenced protocol has received human ethics approval by the Education/Nursing Research Ethics Board, which is organized and operates according to the Tri-Council Policy Statement (2). This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, please mail/e-mail/fax a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- If you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix B: Letter to CRNM

Date: February 1, 2015

Research Project: *Emergency Nurses' Experiences of Caring for Patients with Dementia*

Dear: Kristin Mitchell,

My name is Jennifer Fulcher, a registered nurse completing my Master of Nursing program at the University of Manitoba. My thesis advisor is Dr. Marie Edwards. I am carrying out this research study as part of my program requirements. The purpose of my study is to explore and describe emergency nurses' experience of caring for patients with dementia in the emergency department, including what facilitates or detracts from this care. The findings from this study may inform education and future research. The Education and Nursing Research Ethics Board, at the University of Manitoba, have approved this research.

I would like permission to have the College of Registered Nurses of Manitoba send out one recruitment email message on my behalf and I recognize that there is a fee associated with this service. The population of interest for this study is those registered nurses who self-identify the emergency department (ED) as their place of work within the Winnipeg Regional Health Authority. I would like to exclude nurses working at the Misericordia Urgent Care Centre.

I have attached a copy of the research ethics board approval letter. If you have any questions about this study and would like to speak to me, please feel free to contact me at:

xxxx.xxx@cc.umanitoba.ca or 204-xxx-xxxx. **You may also contact my advisor, Dr. Marie Edwards, at 204-xxx-xxxx or xxx.xxxxxx@umanitoba.ca or the Human Ethics Coordinator at University of Manitoba, Margaret Bowman, at 204-xxx-xxxx or xxx.xxxxxx@umanitoba.ca.**

Sincerely,

Jennifer Fulcher, Student in the Master of Nursing Program, University of Manitoba

Appendix C: Recruitment Letter

Date: February 1, 2015

Message from CRNM: Below you will find an invitation to participate in a survey about emergency department nurses' experiences of caring for patients with dementia. We are emailing you this information because we protect your personal information and do not permit outside parties to access our member database. If you have any questions, please do not hesitate to contact me.

Kristin Mitchell BA
Manager, Communications
Phone: 204-xxx-xxxx
Email:xxxxxxx@crnm.mb.ca
Website: www.crnmb.ca

Research Project: *Emergency Nurses' Experiences of Caring for Patients with Dementia*

Dear CRNM member:

My name is Jennifer Fulcher, a registered nurse completing my Master of Nursing program at the University of Manitoba. My thesis advisor is Dr. Marie Edwards. I would like to invite you to participate in my research study.

The purpose of my thesis research study is to explore and describe the experiences of emergency nurses caring for patients with dementia. The findings of this study will enhance our understanding of this experience and may be used to inform education for emergency department nurses and future research. The Education and Nursing Research Ethics Board at the University of Manitoba has approved this research.

If you are working in an adult emergency department, are registered with the CRNM, and have been working part-time or full-time in an ED longer than six months, you are eligible to participate in this study. Nurses working in the Urgent Care Centre at the Misericordia Health Centre are not eligible to participate. If you volunteer to take part, you will be asked to complete a brief demographic questionnaire about age, gender, years of experience, work setting, and education and training background, and participate in a one-hour individual interview. This interview will be audio-recorded and will last approximately 45 to 60 minutes and will be carried out at a mutually convenient time and place. If after reviewing the transcript of the interview I would like to ask you some additional questions to clarify comments or to discuss themes

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evident in all of the interviews, I may ask you to participate in a second, shorter (30 to 45 minutes) interview. This interview will also be scheduled at a mutually agreed upon time and place.

Participation in this study is voluntary. You may refuse to answer any questions you do not wish to answer and withdraw from the study at any time without any negative consequences.

The information gathered will remain confidential. The only people who will listen to the audio-recordings are me and my advisor. The transcribed interviews will be read by me and my advisor and may be reviewed by the two other members of my thesis committee, Dr. Malcolm Doupe and Dr. Genevieve Thompson. All identifying information will be removed from the transcripts. At no time will your name be shared in any report or presentation of the study. My advisor, Marie Edwards, is currently on the board of the CRNM, but in her role as a researcher does not have access to membership data. She will also not know the names of the participants in this study. Data will be stored in a secure, locked filing cabinet or on personal password-protected computers in my home (i.e., all data collection forms, audio-recordings, transcripts), Dr. Marie Edwards' office, 381 Helen Glass Centre at the University of Manitoba (i.e., audio-recordings, transcripts), or the offices of my other committee members, Dr. Malcolm Doupe and Dr. Genevieve Thompson (i.e., transcripts). The audio-tapes will be destroyed after one year and all other data will be destroyed as confidential waste after a period of 7 years.

If you have any questions about this study or would like to participate, please feel free to contact me at xxx.xxxx@umanitoba.ca or xxx-xxx-xxxx. If you have any concerns, you may also contact my thesis advisor, Dr. Marie Edwards, at xxx.xxxxx@umanitoba.ca or 204-xxx-xxxx or Margaret Bowman, the coordinator of Human Ethics, at xxx.xxxxxxxxxx@umanitoba.ca or 204-xxx-xxxx.

Sincerely,

Jennifer Fulcher RN, BN
Student in the Master of Nursing Program, University of Manitoba

Appendix D: Consent

**UNIVERSITY
OF MANITOBA**

Faculty of Health Sciences

College of Nursing
Helen Glass Centre for Nursing
89 Curry Place
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-7452
Fax: (204) 474-7682

Title of Study: Emergency nurses' experiences caring for patients with dementia

Principal Researcher: Jennifer Fulcher

xxx.xxxx@umanitoba.ca

204-xxx-xxxx

Thesis Committee Members:

Advisor: Dr. Marie Edwards, Associate Professor, **Faculty of Health Sciences, College of Nursing**, University of Manitoba (xxxx.xxx@umanitoba.ca; 204-xxx-xxxx)

Dr. Genevieve Thompson, Assistant Professor, **Faculty of Health Sciences, College of Nursing**, University of Manitoba

Dr. Malcolm Doupe, Assistant Professor, **Faculty of Health Sciences, College of Medicine**, Department of Community Health Sciences, University of Manitoba, and Senior Research Scientist with the Manitoba Health Policy

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something

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mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I am a student in the Master of Nursing Program at the University of Manitoba, supervised by Dr. Marie Edwards, and am carrying out this study as part of my program. The purpose of this study is to explore and describe emergency nurses' experiences of caring for patients with dementia in the emergency department (ED). The findings of this study will provide an opportunity to develop recommendations for education, practice, and future studies aimed at supporting ED nurses in offering quality care for patients with dementia.

You have been invited to participate in this study as you have indicated on your CRNM yearly renewal that you work in the ED. Inclusion criteria for this study are that you have worked more than 6 months, either part- or full-time, in an ED. Nurses working at the Misericordia Urgent Care Centre are not eligible to participate.

If you participate in this study, you will be asked to share your experiences when caring for patients with dementia in an interview with me lasting approximately 60 minutes. If you agree, this interview will be audio-recorded. This interview will occur at a mutually agreed upon time and private place. You will be asked to answer a few demographic questions about, for example, gender, age, and years of experience. You will also be asked about your experiences when caring for patients with dementia in the emergency department in which you work. A \$10.00 gift card for coffee (e.g., Tim Hortons) will be provided to all participants, even those who provide consent and then decide to withdraw from the study.

Your participation in this research project is voluntary. Every effort will be made to ensure that the information you provide to me remains confidential. A numbered code will be assigned to you, and your name will not appear on any documents or on interview tape. Any identifying information provided in the interview will be removed from the transcripts. This will ensure the protection of your identity.

There are no known risks to participating but if anything we talk about evokes difficult memories or makes you uncomfortable, you can opt out of answering the question, stop the interview, or reschedule for another time without consequence. You will have an opportunity to discuss your feelings with me if that is desired. You are free to withdraw at any point of the study without consequence **in-person, by email (xxxx@umanitoba.ca or by phone (204-xxx-xxxx).**

All data will be secured in password-protected computers or locked cabinets in my home or the offices of my committee members. Audio-recordings and data collection forms will be kept in a locked filing cabinet in my home. The consent forms will be stored separately from the other data in a locked filing cabinet in my home. The only people who will hear the audio-recordings are me and my thesis advisor and the electronic recordings will be stored on password-protected computers either in my home or in my advisor's office in Room xxx Helen Glass Centre. Only my committee members and I will have access to the

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transcripts of the interviews. Electronic copies of the transcripts will be stored on password-protected computers in their offices at the University of Manitoba and hard copies of the transcripts will be stored in locked cabinets in their offices. Confidentiality of participants will be maintained by using a coding system; no names will be used on any documents and all identifying information will be removed. My advisor is currently on the board of the College of Registered Nurses of Manitoba, but in her role as a researcher she does not have access to membership data. She will also not know the names of the participants in this study. Audio-recordings will be destroyed after one year and all other data will be destroyed as confidential waste after 7 years.

Your participation should be informed, and you may ask for clarification about any aspect of the study at any time throughout your participation in the project.

If in the unusual circumstance that in the course of the interview you disclose something I have to report by law (e.g., abuse of an adult in care), as per the Protection for Persons in Care Act, that information will be reported to the appropriate authorities. If any such information is disclosed, the interview will be stopped and you will be informed of my legal duty to report.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/Nursing Research Ethics Board (ENREB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at 204-xxx-xxxx or xxx.xxxxx@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Your signature indicates that you have understood the information regarding participation in the research project and agree to participate in the study.

I agree to participate in the project

Participant's signature _____
date _____

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Researcher's signature _____
date _____

I agree to be contacted by the researcher to determine my interest in participating in a follow-up interview

yes _____ no _____

I would like a summary of the findings:

yes _____ no _____

Please mail a summary of the findings to:

Name: _____

Address (email or mailing): _____

Postal code: _____

Appendix E: Demographic Data Collection Tool

Date:

Facility _____ I.D. _____

1. Gender: Female Male

2. Age _____

3. Nursing experience in years _____

4. Nursing experience in ED in years _____

5. Nursing education completed: LPN RN BN MN

6. CNA Certification? Yes No

7. What type of facility do you work in? Teaching Community

8. **a) Do you have experience working in gerontology?** Yes No

b) Do you have experience caring for patients with dementia? Yes No

9. Have you received any education or training in the care of people with dementia or in gerontology? Yes No

10. If yes, how long was the training? _____

11. What did the training include?

Appendix F: Interview Guide

Draft of Interview Questions – November 4, 2014

[From Donabedian Model: S – Structure; P – Process; O – Outcome]

1. How would you describe the emergency department in which you work? [S]
2. In your view, what makes an ED visit appropriate? [S]
3. Tell me where you see your strengths in terms of knowledge and skills in relation to working in an ED. [S]
4. Please describe your experiences as a nurse working with older adults. [S & P]
5. Have you had many experiences working with patients with dementia? [S & P]

How is dementia diagnosed or recognized in the ED?

Can you recall and describe a case where things went well?

- Can you tell me about the situation and what you felt contributed to safe quality care for the patient with dementia? [P & O]
- What was the outcome?
- In general, what good outcomes have you seen in relation to the care of persons with dementia in the ED?

Can you recall and describe a case where things went wrong?

- Why do you feel things went wrong?
- How was this event different from the case that went well?
- What was the outcome? [P & O]

Can you think of safety issues or any adverse events that occurred in relation to the care of a person with dementia? What contributed to that event? [S, P, & O]

6. Can you identify factors that help facilitate caring for patients with dementia in the ED? [S & P]
7. Can you identify factors that make it difficult to provide care for patients with dementia in the ED? [S & P]
8. What changes would you propose to improve your ability to care for patients with dementia in the ED? [S, P, & O]
 - What support can be provided by the facility or management to help provide quality care for patients with dementia in the ED?
 - What resources are needed to help provide quality care for patients with dementia in the ED?

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- Would more information/education be beneficial? How would it influence the care you provide?

9. From your perspective, what would make an ED visit by a person with dementia an inappropriate visit? [S, P, & O]

Can you think of solutions for these visits you consider inappropriate? [S, P, O]

- Any suggestions for action?

10. Is there anything else that you think is important for me to know about older people with dementia and the treatment process, use of diagnostic tests and procedures, or wait times? Or is there anything else you would like to say?

Thank you!

Appendix G: Process Notes/Field Notes Form

Code #

Date _____

1. Place of interview _____ and length of interview _____
2. Thoughts regarding how the interview went (e.g., flow, any interruptions or distractions, etc.)
3. Were there any issues with any of the questions on the interview guide? Please describe.
4. Based on this interview, any thoughts on additional questions we ought to consider adding to the guide?
5. Anything that particularly stood out for you in this interview (e.g., any interesting insights, concerns, etc.)