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EXPERIENCES OF
HOSPITALIZED PATIENTS WITH DEMENTIA

by

SAMANTHA BAINBRIDGE

A thesis submitted in partial fulfillment of the requirements
for the Honors in the Major Program in Nursing
in the College of Nursing
and in The Burnett Honors College
at the University of Central Florida
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Thesis Chair: Mrs. Jacqueline LaManna

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ABSTRACT

People with dementia are hospitalized for a variety of reasons. The combination of dementia with additional health conditions creates a unique challenge to caregivers in acute care settings. There is a dearth of information available to provide guidance to the nursing staff caring for these patients. This integrated review of the literature examined the experiences of hospitalization from the perspective of the older adult with dementia, the family caregiver, and the patient care staff. Results showed a limited body of literature that addressed hospital experiences of people with dementia and those of family and professional caregivers. Additionally, few studies addressing this topic have been conducted in the United States. The primary finding from this study is that better communication is needed between nursing staff, patients, and their family caregivers. Nurses should carry out detailed assessments of cognition and pain in all elderly patients, and strive to provide appropriate palliative and end-of-life care. Dementia- specific training for all staff members may help to promote a better understanding of patients with dementia. Lastly, further research into the experiences of hospitalized dementia patients is needed, with a focus on acute care settings within the United States.

Dedication

To my family and friends near and far: Thank you for your words of encouragement during the tough times, and for celebrating with me during the good times.

To Mike, whose unwavering support has kept me going: My achievements in Nursing School and beyond are possible thanks to you.

To Grannie: You are my inspiration for this paper, and my inspiration in life – thank you.

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INTRODUCTION

The term “dementia” is used to describe a variety of clinical changes that affect the human brain. The National Institute of Neurological Disorders and Stroke (2011) explains that “people with dementia have significantly impaired intellectual functioning that interferes with normal activities and relationships” (What is Dementia section, para. 1). Over time, people with dementia may begin to exhibit personality changes and behavioral issues, along with memory loss and poor problem solving abilities (National Institute of Neurological Disorders and Stroke). There are a variety of disease that can cause these dementia symptoms, including Alzheimer’s disease, vascular dementia, Lewy body dementia, frontotemporal dementia, and Creutzfeldt-Jakob disease (National Institute of Neurological Disorder and Stroke).

There are currently 5.4 million people in the United States with Alzheimer’s disease, and that figure rises every year (Alzheimer’s Association, 2011, p. 12). In Florida alone, it is estimated that 590,000 individuals will suffer from Alzheimer’s disease by 2025, a 64% increase over the year 2000 (Alzheimer’s Association, 2011, p. 18). Because the risk of developing dementia increases with age, the prevalence of Alzheimer’s disease will significantly increase as the population of aging elders in the United States grows. The toll of this debilitating illness that inevitably leads to death is significant on affected individuals, families and the health care system (Alzheimer’s Association, 2011, p. 21).

The challenges brought about by dementia are often exacerbated by other physical ailments that commonly affect the elderly such as hypertension, coronary heart disease, diabetes, and stroke (Alzheimer’s Association, 2011, p. 38). These comorbid conditions can lead to the need for acute medical care. People with dementia are hospitalized three times more often than

those without dementia (Alzheimer's Association, p. 36). Hospital stays are often longer than those for people without dementia, leading to greatly increased costs for patients and to services like Medicare (Alzheimer's Association, p. 38).

Problem

Over 40% of hospital in-patient services in 2009 were provided to people over the age of 65 (Centers for Disease Control and Prevention [CDC], 2009, p. 1). It is estimated that approximately one quarter of all hospitalized older adults suffer from some form of dementia. People with dementia often require treatment for fall-related injuries, heart disease and a variety of other conditions (Alzheimer's Association, 2011, p. 36). Though people with dementia are hospitalized frequently, there is very little research that describes the experiences of these patients in the acute care environment. Few evidence-based guidelines to support best nursing practices in the general care unit are available (Nolan, 2006, p. 208).

The combination of dementia with additional health conditions creates a unique challenge to those providing care within the acute care setting (Moyle, Olorenshaw, Wallis, & Borbasi, 2008, p. 122). Environmental changes, unfamiliar caregivers, communication difficulties and pain or discomfort can be disturbing to any patient, but are intensified in those suffering with dementia. These factors often precipitate agitative behaviors in patients affected by dementia (Wierman, Wadland, Walters, Kuhn, & Farrington, 2011, p. 44). Behavior changes in hospitalized dementia patients can be unsettling for patients, family members, and hospital staff. However, there is a dearth of information available to provide guidance in handling such situations. The few research findings that have been published on this topic have often been

carried out in European countries where healthcare systems differ greatly from those of the United States.

Cowdell explains “care of older people with dementia in hospitals remains sub-optimal” (2010, p. 42). Further research into the experiences of these patients, their families, and their nursing staff, could help to identify common problems, and ultimately act as a guide for nursing practice to provide optimal care for everyone involved.

Purpose

The purpose of this thesis was to complete an integrated review of the literature related to the experiences of hospitalized older adults with dementia, their family caregivers, and the hospital care providers. It is hoped that the information gathered during the course of this review will provide suggestions for nursing practice, and drive further research into the important topic of caring for dementia patients in the acute care setting.

Method

An integrated review of relevant literature related to hospitalized dementia patients was conducted. Information was gathered from four databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with Full Text, MEDLINE, PsycINFO, and Academic Search Premier. The search included peer reviewed articles from all countries with a focus on elderly dementia patients in acute care settings. Articles were excluded if they were not written in English, were published prior to 1990, or focused on patients with early-onset dementia or delirium. Key search terms included variations of the following words and phrases: life

experience, perception, inpatient, experience, aged, hospitalized, dementia, senile, acute, caregiver, family (Appendix A). A summary of findings from each search strategy is provided in Table 1.

The initial aim, which was to just study the experiences of elderly dementia patients, produced few articles. Therefore the study goals were expanded and the search criteria broadened to include experiences of family caregivers and hospital staff. Citation lists from each article were also reviewed to identify additional sources of research information. A preliminary review was conducted of all the articles that met the inclusion criteria and duplicates were eliminated. After the removal of all non-relevant articles, a total of 128 remained and were further delimited. Citations from each article were reviewed further, and applicable articles were pulled for analysis, until data saturation was met. A total of 27 studies were included in this literature review. A table of evidence was constructed to help organize overall findings and identify gaps in the literature (Appendix B). The evidence table includes the following categories: article title, country of origin, purpose, sample size, study design, intervention, key findings, and nursing implications. The articles were then divided into three separate groups: experiences from the patient's perspective, experiences from the family caregiver's perspective, and experiences from the perspective of the nursing staff.

Table 1: Literature Search Strategy

Database Searched	Date of Search	Search Strategy	No. of Articles Found	No. of Relevant Articles
CINAHL Plus with Full Text	12/15/11	((MH "Life Experiences") OR (MH "Perception") or perception* or experience*) AND ((MH "Inpatients") OR (MH "Aged, Hospitalized") or hospital*) AND ((MH "Dementia") OR (MH "Dementia, Senile"))	227	21
	12/22/11	("Life Experiences" OR "Perception" or perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute	45	13
	1/21/12	(perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute AND (caregiver or family)	9	5
MEDLINE	12/15/11	((MH "Life Experiences") OR (MH "Perception") or perception* or experience*) AND ((MH "Inpatients") OR (MH "Aged, Hospitalized") or hospital*) AND ((MH "Dementia") OR (MH "Dementia, Senile"))	475	27
	12/22/11	("Life Experiences" OR "Perception" or perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute	118	15
	1/21/12	(perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute AND (caregiver or family)	16	4
PsycINFO	1/7/12	((MH "Life Experiences") OR (MH "Perception") or perception* or experience*) AND ((MH "Inpatients") OR (MH "Aged, Hospitalized") or hospital*) AND ((MH "Dementia") OR (MH "Dementia, Senile"))	0	0

Database Searched	Date of Search	Search Strategy	No. of Articles Found	No. of Relevant Articles
	1/7/12	("Life Experiences" OR "Perception" or perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute	43	7
	1/21/12	(perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute AND (caregiver or family)	9	2
Academic Search Premier	1/7/12	((MH "Life Experiences") OR (MH "Perception" or perception* or experience*) AND ((MH "Inpatients") OR (MH "Aged, Hospitalized") or hospital*) AND ((MH "Dementia") OR (MH "Dementia, Senile"))	345	24
	1/7/12	("Life Experiences" OR "Perception" or perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute	35	8
	1/21/12	(perception* or experience*) AND ("Inpatients" OR "Aged, Hospitalized" or hospital*) AND ("Dementia" OR "Dementia, Senile") AND acute AND (caregiver or family)	4	2
Total			1326	128

BACKGROUND

The population of the United States is aging. In the next forty years, the number of people age 65 and older is expected to reach 85 million, over two times the current figure (Lange, 2012, p. 42). Florida is the state with the highest percentage of individuals over 65 years of age (U.S. Census Bureau, 2010, Florida section). With the Baby Boomers beginning to reach retirement age, those figures are set to climb further.

As the aging population increases, so does the number of dementia sufferers. It is believed that 1 in 8 of all individuals over the age of 65 has Alzheimer's disease, the most common form of dementia (Alzheimer's Association, 2011, p. 12). The prevalence of dementia in the old is particularly high. Almost half of all people over the age of 85 have the disease (Alzheimer's Association, 2011, p. 12). Due to changes in reporting guidelines, it is becoming apparent that Alzheimer's disease is the underlying cause of numerous deaths annually and is the fifth leading cause of death in the elderly population (Alzheimer's Association, 2011, p. 20-21).

Escalating health care costs and the increased prevalence of chronic illness means that older adults typically spend more out-of-pocket for health care than their younger counterparts (Administration on Aging, 2012, Health and Health Care section, para. 4). The financial burden of caring for a person with dementia often falls to the government as approximately 70 percent of charges are covered by Medicare and Medicaid (Alzheimer's Association, 2011, p. 35). The average payments made from Medicare for a single hospital stay totaled almost \$10,000 for a person with dementia, versus \$3,500 for a person without dementia (Alzheimer's Association, 2011, p. 38). These figures are expected to increase.

As the body ages, physiologic changes take place, resulting in the numerous physical ailments commonly found in the elderly. Older adults are hospitalized for a variety of reasons, including heart failure, cerebrovascular disorders, musculoskeletal issues, and chronic pulmonary diseases (Meiner & Lueckenotte, 2006, p. 176-177). Hospitals can potentially be very dangerous places for older adults, who often present with atypical symptoms, and may be suffering with multiple comorbid conditions (Meiner & Lueckenotte, 2006, p. 177-178). The risk for adverse drug reactions is highest in the elderly, often as a result of polypharmacy, and older patients are also at an increased risk for falls. Elders are more susceptible to infection due to an inhibited immune response and may develop respiratory or urinary tract infections. Lastly, older adults also face the hazards of immobility, which can lead to muscle deterioration, atelectasis, and skin breakdown (Meiner & Lueckenotte, 2006, p. 177-178).

These problems are enhanced in patients with dementia who are commonly admitted for the same reasons as other older people, but may have difficulties expressing their needs, or settling in to strange new surroundings (Department of Health, 2010, p. 3). Patients with mild to moderate dementia in a hospital setting are two times more likely to experience an adverse event than a person without dementia (Watkin, Blanchard, Tookman, & Sampson, 2012, p. 79). “Slips, trips or falls” (p. 79) were most common, and 42% of those documented falls resulting in some form of injury (Watkin et al., 2012). The hospital setting is a dangerous environment for any patient, but for those with the additional diagnosis of dementia there appears to be at an even greater risk.

FINDINGS

One hundred and twenty-eight articles met the inclusion criteria of the integrated literature review and were analyzed further. A consort diagram of the search is provided in Figure 1 (Appendix A). A variety of methodologies were used to explore the experiences of hospitalized dementia patients: semi-structured interviews, observations and descriptions, case studies, chart reviews, summary articles and a literature review.

Experiences from the Patient's Perspective

Ten articles focused specifically on the experiences of patients with dementia. The studies used a variety of research methods, including semi-structured interviews, observations, chart reviews, and combinations of all three. Though all ten articles discussed experiences from the patient's perspective, only four included actual interviews with patients.

In a mixed-methods study, Tolson, Smith and Knight (1999) asked 213 patients with "coincidental dementia" (p. 1127) to describe the nursing care they received during their stay in one of four acute care facilities in the United Kingdom. These patients had been admitted for an acute problem, but also showed signs of dementia such as a decline in cognitive functioning. Interviews were held with patients and their caregivers to determine perceived good and bad aspects of care, and nursing charts were examined to review diagnoses and treatments. Only 41 of the study's initial participants actually took part in the interviews.

The four themes that emerged from the interviews included: "settling in", "visible love", "reaching me, reaching you", and "my condition" (Tolson et al., 1999, p. 1133). "Settling in" was described as the first hurdle, with some patients exhibiting restlessness and agitation as they

tried to become accustomed to their new surroundings. The ability for patients to share a connection with their loved ones was described as “visible love”, while the importance of communication between patient, family, and nursing staff was referred to as “reaching me, reaching you”. Lastly, “my condition” expressed the desire of the patient to understand the reason for their admission and their prognosis.

The perception of care given by the nursing staff in relation to the four recurring themes was generally positive, with the majority of nurses helping with settling in, visible love, and reaching me, reaching you (Tolson et al., 1999). However, the study showed that issues with communication lead to participants experiencing feelings of concern regarding their condition. Tolson et al. suggested when caring for patients with dementia, special attention should be given not only to the acute problem, but also to the unique issues that arise from caring for this vulnerable population.

Edvardsson and Nordvall (2008) studied the experiences of dementia patients in a specialized psycho-geriatric unit in Sweden. Six patients in various stages of dementia were interviewed in this phenomenological hermeneutical study. Results showed that patients were unsure of their location, and had little understanding of their illness, but often felt confident when discussing their earlier life. Some described feeling bored and devalued, and explained that they “don’t want to be a burden” (Edvardsson & Nordvall, 2008, p. 496). Patients also varied in their opinions of the pros and cons of sharing their environment with strangers. Some perceived fellow patients as threats, while others saw them as potential new friends.

In one of the few studies carried out in the United States, Morrison and Siu (2000) compared the treatment of pain in hip-fracture patients with dementia to that of hip-fracture

patients without cognitive impairment. Daily chart reviews were carried out to assess the pain management of all 97 participants, while the 59 cognitively intact patients were asked to rate their pain on a numerical scale. The study showed that almost half of the cognitively intact patients rated their pain as severe or very severe, yet “were prescribed unarguably inadequate analgesia for their level of pain” (Morrison & Siu, 2000, p. 244). Dementia patients received far less pain medication than the cognitively intact patients, with 76% of them receiving analgesia only when nursing assessments noted visible behaviors that they attributed to pain. The authors concluded that pain was undertreated in all of their participants, including the cognitively intact patients. The dementia patients, who were unable to verbalize their discomfort, experienced similar amounts of pain but received less analgesia.

Proctor (2001) used semi-structured interviews and the voice relational method to examine how four older women with dementia viewed their experiences at a day hospital in the United Kingdom. Patients described feeling powerless, ignored, and left out of the decision making process. Some felt intimidated by the doctors and nurses, whom they believed were better educated. This perceived hierarchy meant that patients sometimes found it difficult to express their needs or concerns to care staff.

Several articles used observational techniques to assess the experiences of patients with dementia in a variety of hospital settings. Cowdell’s (2010) ethnographic study observed the interactions between staff and 11 patients on an acute care ward specializing in the care of older adults. Three themes emerged and described the experience of being in a hospital, the patient’s interactions with staff, and their uncertainty about the future. Patients appeared to find the hospital environment loud and disturbing, exhibiting alarm at the sound of call-bells and

telephones. Some became distressed when receiving care from the nursing staff, especially when the care was provided on a schedule not congruent with the patient's normal routine. Many patients vocalized concerns about their current situation and their fears for their future, unsure of what was going to happen next – “ ‘[I] don't know what's happening to me...do I stay here forever?’ ” (Cowdell, 2010, p. 87).

Norman (2006) also explored patient interactions with staff through observation of eight patients who were assigned to a general hospital wards rather than on specialty geriatric wards. The researchers found that patients tried to express themselves in a variety of different ways in an attempt to control the care that they were receiving. The study also showed that nursing staff categorized patients as either positive or negative. Interactions and care provision varied based on which of these two groups the patient was perceived to belong. Positive patients were viewed as “compliant and relatively independent” (p. 458) while negative patients were sometimes not acknowledged at all (Norman, 2006).

Norbergh, Asplund, Rassmussen, Nordahl, and Sandman (2001) performed a small-scale study of 24 patients with dementia in a psycho-geriatric unit in Sweden. They used the Patient Activities Classification tool and free note taking to assess observed daily activities of dementia patients over a period of several hours in a variety of settings. The findings showed that patients spent over half of their time alone, only interacting with nursing staff when they came to perform activities of daily living. Socializing with other patients or family members usually consisted of watching television or drinking coffee.

A slightly larger study carried out by Perrin (1997) took place in nine dementia care units where 109 severely impaired patients were observed in group settings. Their interactions were

scored using two different tools: the Dementia Care Mapping Instrument and the Behavior Category Profile. The results were similar to those found in the study by Norbergh et al. (2001) with patients involved in limited social interaction, appearing withdrawn, and spending their time sleeping or eating (Perrin, 1997).

Watkin et al. (2012) carried out a mixed-methods study to examine the prevalence of reported adverse events in hospitalized older adults. The cognitive function of 621 patients was assessed to determine the presence of delirium or dementia. In addition, patient charts and adverse incident reports were reviewed. Patient family members also took part in non-structured interviews. Results showed that patients with mild to moderate cognitive impairment were significantly more likely to experience an adverse event, ranging from miscommunication errors to falls. The researchers also found that staff frequently failed to recognize cognitive impairment in their patients. Watkin et al. (2012) theorized that nurses are more likely to identify patients with severe cognitive impairment and therefore put interventions in place to prevent the occurrence of adverse incidents. They also suggested that severely impaired patients “are likely to be bed-bound” (p. 79) which may be a factor in reducing the number of adverse incidents occurring in this group (Watkin, et al. 2012).

A study by Sampson, Gould, Lee, and Blanchard (2006) compared end-of- life care given to dementia patients with care given to patients without dementia. The retrospective chart review took place on an acute medical ward in the United Kingdom. One hundred and twenty-two records were reviewed for diagnoses of dementia, provision of end-of-life care, and implementation of painful or invasive procedures. The results showed that patients with dementia were more likely to have urinary catheters and nasogastric tubes placed but were less

likely to have central lines inserted. They were less likely to have their religious faith listed in their chart. Only 9% of dementia patients were referred to palliative care, while 25% of patients without a diagnosis of dementia received similar referrals. Twenty-six percent of dementia patients were prescribed palliative medications versus 31% of non-dementia patients.

Experiences from the Family Caregiver's Perspective

When patients with dementia are unable to communicate their thoughts or needs, often their family members or caregivers are able to provide a wealth of knowledge to help guide care in health care settings (Miller, Campbell, Moore, & Schofield, 2004). Eight articles were found that discussed the experiences of these caregivers during the hospitalization of their loved one.

Douglas-Dunbar and Gardiner (2007) carried out an exploratory study to help develop support services for caregivers of hospitalized dementia patients in the United Kingdom. Semi-structured interviews were carried out with caregivers of nine dementia patients in a general hospital. The results showed that caregivers frequently felt that communication with the staff was poor throughout the entire hospital stay. Some explained that they had valuable information to share with the nursing staff, but that their attempts to share these details were ignored. Caregivers expressed an understanding of the heavy workload of their nurses, and were generally happy with the care that the patients received. However, some family caregivers did not believe that the nurses fully understood dementia, nor did they appreciate the stressors placed on the caregiver during the hospitalization. Results also showed that caregivers commonly felt the need to advocate for their loved one, believing that “they needed to be with the person with dementia

in order to ensure that their needs were met, [sic] especially for those patients where communication had become difficult” (Douglas-Dunbar & Gardiner, 2007, p. 29).

In another study from the United Kingdom, Gallinagh, Nevin, Campbell, Mitchell, and Ludwick (2001) used semi-structured interviews to explore caregivers’ experiences. Interviews were held with nine caregivers of elderly patients with dementia who had side rails used at some point during their hospitalization in an “older person ward” (Gallinagh et al., 2001, p. 391). The study found that all of the caregivers felt that side rails were being used as a safety measure, but four of them did not receive any explanation from staff for their use. Many believed that the use of side rails was to be expected when caring for a hospitalized older person. Results also showed that some caregivers expressed concern over the restrictive nature of the side rails and worried that they could accidentally cause harm to the patient. Though a few offered suggestions to improve the design of the side rails, none of the caregivers were able to successfully identify alternatives to their use.

Simpson, Scothern, and Vincent (1995) used grounded theory to survey caregiver satisfaction of eight different hospital wards in the United Kingdom. Forty-one dementia patients and their caregivers were interviewed within two weeks of their discharge, providing both qualitative and quantitative data. Results showed that caregivers often believed that information was being withheld from them and felt uncomfortable asking staff questions. Caregivers were more likely to be satisfied with the care provided by nursing staff if they felt that the nurse had a proactive attitude. The study also found that many family caregivers perceived that their loved one was different from the other patients and that there should be some separation between those in earlier stages of dementia and those in the later stages of the disease.

In a mixed-methods study carried out in Spain, caregivers' perceptions of palliative care were assessed using telephone interviews and chart reviews (Formiga, Olmedo, López-Soto, Navarro, Culla, & Pujol, 2007). Patients were divided into two groups: those who died from terminal heart failure (65 patients), and those who died from severe dementia (37 patients). Caregivers were questioned one month after the death of their loved one. Charts were also reviewed for data related to medical care and support given at end-of-life. Findings showed that caregivers of dementia patients were more likely to be satisfied with the amount of information received from staff and were offered spiritual support more frequently than caregivers of patients with heart failure. There was a significant difference in the perception of symptom control because only 46% caregivers of dementia patients rated it as adequate, and 51.5% of caregivers witnessed uncontrolled dyspnea (versus 60% and 41.5% respectively, as reported by caregivers of heart failure patients).

Another study that focused on end-of-life care for dementia patients examined the effectiveness of an intervention aimed to promote advance care planning (ACP) (Sampson, et al., 2011). Assessments were performed on 33 patients with severe dementia on an acute medical ward following their emergency admission. The assessment became the basis for an ACP discussion held between the authors and the patient's family caregiver. Follow-up meetings were held post-discharge to assist and advise them on making an ACP for their loved one. However, of the 33 patient-caregiver dyads that were assessed, only seven ultimately created an ACP.

The researchers found that recruitment was impeded by the stressful situations surrounding an acute hospitalization, with many caregivers choosing not to take part in discussions as a result of family conflicts or demonstrating a "general unwillingness to address

end-of-life care issues” (Sampson, et al., 2011, p. 206). Though few caregivers participated in care planning discussions, they all exhibited an interest in receiving further information on dementia and end-of-life issues. Sampson, et al. (2011) found that providing a selection of basic information about dementia was well-received by the caregivers who saw it as a way to prepare them for the terminal stages of the disease.

Miller et al. (2004) performed a quasi-experimental study of the Elder Care Supportive Interventions Protocol (ECSIP), a set of interventions designed to minimize discomfort in hospitalized older adults experiencing confusion. Within 48 to 72 hours of admission to a tertiary care hospital, 81 patients with a prior diagnosis of dementia were assessed with a variety of tools including the NEECHAM Confusion Scale, Katz Index of Activities of Daily Living, Functional Activities Questionnaire, and the modified Discomfort Screen-Dementia Alzheimer’s Type. Baseline data were also obtained from caregivers regarding the patient’s normal behaviors and routines. Staff members then put ECSIP interventions in place with steps taken to maintain a familiar environment, provide meaningful contact, and decrease physical discomfort. Patients were assessed again within 24 hours prior to discharge and the outcomes compared.

The results of the Miller et al. (2004) study showed no statistically significant reduction in discomfort levels. The study was able to provide limited information about patient demographics and cognitive function, but the implementation of the ECSIP was unsuccessful, due in part to poor implementation by the nursing staff. Though the intervention failed overall, the authors did find that the patients’ caregivers appreciated being involved in care planning, and were able to provide helpful knowledge regarding the patients’ needs.

In a 2011 article by Thompson, over 1400 people with dementia and their caregivers were asked to describe what could be done to improve the care given to dementia patients in general hospitals. Structured surveys were distributed to 1484 dementia patients and their caregivers as well as 700 practitioners. Many participants from both groups felt that staff education needed to be improved and that involving caregivers in the provision of care was beneficial to all involved. Practitioners stressed the importance of early assessment and recognition of dementia in acute care patients. Caregivers agreed that a skilled assessment would be helpful and also mentioned that they would prefer easily understood care plans and increased access to specialists. They described a variety of factors that they considered barriers to effective care including “poor communication, lack of understanding of needs, and frequent moves between wards” (Thompson, 2011, p. 14).

Webster (2011) also aimed to improve the care given to dementia patients in acute hospital settings by writing a summary article that described experiences of four hospitalized older adults and their family caregivers. Two of the case studies described how caregivers felt that small, individualized changes to the patient’s plan of care helped to ease their sense of anxiety. As in Thompson’s (2011) article, one caregiver stated that communication with the nursing staff was impeded by the patient’s repeated relocations within the hospital (Webster, 2011). Webster stressed the importance of “person centered care” (p. 86) when working with dementia patients, which focuses care on maintaining or even improving complete wellbeing, not just treating a single condition (2011).

Experiences from the Perspective of the Nursing Staff

In addition to patients and family caregivers, nursing staff are also an important part of the hospitalization experience. However, research into their experiences of caring for acutely ill dementia patients is sparse (Cowdell, 2010). Ten articles were found that discussed the opinions of nursing staff, their experiences of working with dementia patients, and interventions that have been put in place to improve the dementia care that they provide.

The study by Cowdell (2010) examined the experiences of both staff and dementia patients in an acute hospital setting by observing their interactions with each other. In addition to observations, this ethnographic study also included interviews with 25 registered nurses and 33 nursing assistants. Three themes were uncovered: philosophies of caring for people with dementia; the value that staff attached to their work; and the ability of staff to provide care. The results showed that staff developed their own theories of dementia care based upon their prior experiences and work environment rather than education. Staff categorized dementia patients based on these preconceived ideas. They viewed their work as “unskilled and not prestigious” (p. 87) and felt that society as a whole had a similar view of them and the work they perform (Cowdell, 2010). The study also found that nursing staff lacked confidence when providing psychosocial care to dementia patients, finding it easier to provide physical care instead.

Like Cowdell’s (2010) study, Nolan (2006) investigated the experiences of nurses who care for dementia patients. The seven nurses in Nolan’s study worked on a ward dedicated to treating acutely ill older patients and had prior experience of working with people with dementia. Nolan used hermeneutic interpretation to analyze the in-depth interviews, which took place over a period of three months. The results showed that the nurses struggled to encourage patient

independence due to time constraints, finding it difficult to balance the needs of all of their patients. The study also found that the nurses strove to create friendships with their patients in an attempt to promote trust and facilitate care. Nurses reported feeling a sense of accomplishment when this was achieved. The nurses in this study reiterated the belief that working with the patient's caregiver helped to establish a bond within the acute care setting and that this relationship was beneficial to everyone involved.

In a case study by Kelley, Siegler, and Reid (2008), nurses in a geriatric hospital in the United States discussed their experiences of treating pain in four elderly patients with dementia. The case study highlighted several issues found when trying to manage pain in this population. One patient was unable to use the patient-controlled analgesia (PCA) pump that had been provided for him, either because he failed to remember it was there or because he did not recall how to use it. This led to him being in considerable pain until the PCA pump was later replaced with an oral analgesic. The findings also showed that some patients were unable to recognize changes in their pain intensity, making it difficult to assess the effectiveness of the treatment being provided. Other patients were unable to recognize the potential side effects of these medications, such as constipation and urinary retention, causing these problems to go unnoticed for several days. Kelley et al. (2008) underscored the importance of thoroughly assessing pain in dementia patients and utilizing a variety of methods to provide accurate pain measurement.

Boockvar, Bella, and Marturano (2005) carried out a retrospective chart review that highlighted a common obstacle to providing appropriate nursing care to dementia patients – inadequate transfer documentation. One hundred and seventy four transfers from nursing homes to a hospital were examined for data relating to mental status, assessments, and demographics.

Results revealed that transfer documentation often contained little or no information related to the patient's current or former mental status. Of the patients sent without mental status information, over two thirds actually had a previous diagnosis of dementia. The researchers suggested that this lack of pertinent information made it harder for nurses to differentiate between delirium and dementia in their patients and that improved transfer documentation could allow for better communication between different locations.

Two articles studied the efficacy of two different interventions aimed to benefit hospitalized dementia patients. Williams (2011) used case studies to describe a newly implemented program called the "Butterfly Scheme" (p. 18), which was developed to improve the safety of dementia patients in the hospital setting. The intervention utilized caregiver knowledge of the patient's likes and dislikes to help nursing staff provide more individualized care. Both of the nurses in the study had implemented the scheme and described positive reactions from staff and caregivers. One nurse felt that the staff had a better understanding of their role in providing care to dementia patients and were able to provide better care thanks to the personalized information. Another nurse explained that the information provided by the caregivers helped to improve interpersonal relationships between all parties.

Wierman et al. (2011) described the Simple Pleasures intervention, designed to reduce agitation in hospitalized dementia patients. In this interventional study, 26 patients were assessed for cognitive function and agitation, and baseline information regarding their hearing and vision was obtained from their caregivers. Simple Pleasures items – various interactive objects used to target specific activities such as screaming, anxiety, and wandering – were distributed to each patient, and staff members were trained to encourage their use. The patients

were reassessed every 48 to 72 hours. No significant change in their agitation levels was noted. When asked, staff felt that they benefited from having the additional baseline information on each patient, and they appreciated having an alternative to the use of sedating medications and physical restraints.

Three summary articles discussed recommendations for the nursing care of dementia patients in acute hospital settings. James (2011) explained that hospital workers were unlikely to receive specialized dementia training, in spite of the prevalence of dementia patients in hospital admissions. The author suggested that patients with dementia often failed to receive non-clinical interventions because staff found it hard to communicate effectively and were hesitant to interact with patients as a result. Bridges and Wilkinson (2011) stressed the importance of communication in caring for dementia patients. They asserted that staff, patients, and family caregivers must communicate effectively to help determine the patient's individual needs. They also explained that communication between staff members is just as important; "Encouraging dialogue within nursing teams is key to learning from each other about what works, disseminating best practice, and identifying patients' needs" (Bridges & Wilkinson, 2011, p.46).

Nurses and other healthcare workers who care for dementia patients may be victims of violence secondary to dangerous agitation behaviors in this patient population. In Danesh, Malvey, and Fottler's summary article (2008), recommendations were made on interventions to prevent the occurrence of violence carried out against nursing staff by dementia patients. Strategies including employee education, environmental changes, and early identification of warning signs that could precipitate violence were identified as ways to minimize the risk of workplace injury to dementia caregivers.

Finally, Moyle et al. (2008) conducted an integrated review of the literature to describe best practices for providing acute care to dementia patients. The review included 31 theoretical and research based articles written between 1986 and 2006. Most articles focused on care models with few studies addressing best care practices in the acute care setting. The authors did find that early assessment and detection of dementia was an important factor in the provision of safe, appropriate care to this high-risk patient population. Results also showed that nursing staff often lacked knowledge and confidence when caring for dementia patients, that they sometimes negatively labeled them, and that they found communicating with dementia patients difficult. Findings also suggested that caregiver involvement was valuable to staff and helpful in reducing patient stressors.

DISCUSSION

The purpose of this literature review was to explore the experiences of hospitalized older adults with dementia, their family caregivers, and their hospital nursing staff. The information found within the 27 relevant articles provided a glimpse into these experiences and are discussed further in this section.

Experiences from the Patient's Perspective

Ten articles examined the experience of hospitalization from the perspective of the dementia patient. Four of these articles were carried out in a general hospital setting, while the participants in the remaining six articles were receiving some form of specialty geriatric care. In addition, only one of the ten studies took place in the United States; the rest were carried out in the United Kingdom and Sweden.

The disorienting aspect of hospitalization was discussed in three articles, with patients who were unaware of their new surroundings becoming alarmed by unfamiliar sounds and strange new routines (Cowdell, 2010; Edvardsson & Nordvall, 2008; Norman, 2006; Proctor, 2001; Tolson et al., 1999). These three articles explained that dementia patients often showed concern over their future, uncertainty of where they were, and poor understanding of what was going to happen next. Tolson et al. (1999), Proctor (2001), and Norman (2006) found that communication issues lead to feelings of powerlessness and apprehension, with some patients struggling to express their needs effectively.

Two observational studies found that dementia patients had very limited social interaction and spent a large amount of time alone (Norbergh, Asplund, Rassmussen, Nordahl, &

Sandman, 2001; Perrin, 1997). The patient's only access to socialization generally took place with nursing staff while activities of daily living were carried out, and the patient's remaining time was spent sleeping, eating, or watching television. Patients expressed feelings of boredom but did not wish to burden staff, whom they felt were often unavailable (Edvardsson & Nordvall, 2008).

Lack of appropriate palliative care was found in two articles using comparative methods to review care given to dementia and non-dementia patients (Morrison & Siu, 2000; Sampson et al., 2006). Grossly inadequate pain management was found in dementia patients who were unquestioningly in painful circumstances but unable to express their discomfort. In addition, dementia patients near end-of-life were more likely to receive uncomfortable invasive procedures but less likely to receive palliative care.

One research article found that patients with mild to moderate dementia were more likely to experience a reportable adverse event (Watkin et al., 2012). These adverse events included slips, trips, and falls, and often resulted in the patient being injured in some way. Watkin et al. (2012) believed that patients with mild to moderate dementia exhibited less obvious signs of cognitive impairment, making it harder for staff to recognize the condition and pre-emptively initiate appropriate protective safety measures.

Experiences from the Family Caregiver's Perspective

Eight articles examined the experiences of dementia patients' caregivers during their hospitalization. Six of these studies were carried out in general hospitals, while the remaining two took place in specialty wards. One study was performed in the United States, one in Spain, and the remaining six took place in the United Kingdom.

Poor communication between caregivers and hospital staff was a consistent finding described in several articles (Douglas-Dunbar & Gardiner, 2007; Simpson et al., 1995; Thompson, 2011; Webster, 2011). Caregivers reported feeling ignored and were sometimes untrusting of the nursing staff, doubting their knowledge of dementia and suspecting that information was being withheld. Many felt that they had useful information to share and wanted to be involved in planning care for their loved one (Miller et al., 2004). The results also showed that the hospitalization process was stressful for caregivers, making it difficult to carry out the research on one occasion (Douglas-Dunbar & Gardiner, 2007; Sampson et al., 2011).

Other studies stressed the importance of a better relationship between caregivers and staff. Caregivers appeared most satisfied when nursing staff made small changes to individualize care (Simpson et al., 1995; Webster, 2011). Formiga et al. (2007) found that caregivers were generally satisfied with the end-of-life care provided and were more likely to be offered spiritual support. These findings contradicted those of Sampson et al.'s (2006) research, which found that dementia patients were less likely to have their religious preferences noted. One article showed that caregivers did not question their nurses about the use of side rails, though many had concerns over their safety and had not received an explanation for their use (Gallinagh et al., 2001).

Results showed caregivers believed that their loved one was different from other patients and that their dementia less severe (Simpson et al., 1995). Some felt that patients should be separated by the severity of their illness, with patients experiencing more severe dementia placed in a different area than those in the early stages. One article also found that caregivers seemed unwilling to address end-of-life issues during an acute hospitalization. They preferred instead to receive simple written information rather than taking part in a discussion (Sampson et al., 2011).

Experiences from the Perspective of the Nursing Staff

Of the ten articles that reviewed the nursing staff's experiences of working with hospitalized dementia patients, six took place in general hospitals, and four involved nurses working on specialty geriatric wards. Four were carried out in the United States, four in the United Kingdom, one in Australia, and one in the Republic of Ireland.

Some nursing staff felt that their work with dementia patients was viewed as unskilled and lacked prestige. The nursing personnel also reported pressure of time constraints and a lack of confidence in providing psychosocial care to dementia patients (Cowdell, 2010; Moyle et al., 2008; Nolan, 2006). Three articles discussed the importance of staff education, noting a lack of dementia-specific training in acute care settings and suggesting the need for education classes to promote recognition of aggressive behaviors in dementia patients (Danesh et al., 2008; James, 2011; Thompson, 2011). Cowdell (2010) and Norman (2006) both found that nurses tended to use their previous experiences to categorize dementia patients, varying the care they provided based upon group assignments.

Effective communication was a common theme in articles that addressed staff relationships with dementia patients. Five articles reported that good communication between staff and family caregivers helped nurses to provide better care to the patients and to establish beneficial relationship between all parties (Bridges & Wilkinson, 2011; James, 2011; Moyle et al., 2008; Nolan, 2006; Williams, 2011). Bridges and Wilkinson (2011) encouraged communication between nurses, explaining that nurses can learn from each other's experiences, and provide better care to their patients when they have open dialogue.

Four studies stressed the importance of thorough assessments when working with dementia patients, explaining that a lack of good assessment data can affect all aspects of care provided (Boockvar et al., 2005; Kelley et al., 2008; Moyle et al., 2008; Thompson, 2011; Wierman et al., 2011). Boockvar et al. (2005) found that inadequate transfer documentation made it difficult for staff to differentiate between delirium and dementia. The authors suggested that improved documentation could help staff with their assessment and treatment. Staff in two interventional studies appreciated having additional baseline data on their patients, saying that they benefited by being able to provide more individualized care (Wierman et al., 2011; Williams, 2011).

LIMITATIONS

Most research into the experiences of hospitalized dementia patients has been performed outside of the United States, primarily in the United Kingdom and Sweden. The findings of these studies may not be generalizable to the American acute care setting due to varied healthcare systems and cultural differences. In addition, many of the studies took place in specialized geriatric wards and dementia care units. The majority of dementia patients in the United States receive care in general medical-surgical units (Douglas-Dunbar & Gardiner, 2007).

Only four of the 27 articles used direct interviews with dementia patients to examine their experiences of hospitalization. The reason for this may lie in the ethical difficulties of carrying out research on these vulnerable individuals who may lack the ability to give the required informed consent (Tolson et al., 1999). Communication difficulties associated with dementia may also be a factor in limiting research in this population (Proctor, 2001).

Most of the studies utilized non-experimental, qualitative methods, with relatively small sample sizes, over short periods of time. The short-term nature of acute hospitalization makes longitudinal studies impractical, and a person's lived experiences cannot be measured for quantitative research. However, more rigorous qualitative research utilizing larger sample sizes could provide a better understanding of dementia patients' experiences.

RECOMMENDATIONS FOR NURSING

Practice

Effective communication is an essential element of dementia care within the acute care hospital setting. Patients and their caregivers are unsatisfied with the level of communication, feeling misled or ignored by the nursing staff (Douglas-Dunbar & Gardiner, 2007; Miller et al., 2004; Simpson et al., 1995). Nurses need to encourage successful dialogue between all parties, so that beneficial relationships can be formed, patient care can be improved, and customer satisfaction can increase. In addition, it is important to encourage communication between staff members, which helps to promote effective and safe nursing care. It also allows for the sharing of experiences and ideas, which can be used as valuable learning tools.

Nurses must strive to provide individualized care to their dementia patients. The process of mentally labeling a patient as positive or negative was found in two studies, and had a detrimental effect on the care provided (Cowdell, 2010; Norman, 2006). By humanizing the patient, and taking time to speak with them directly, nurses can better assess their needs, develop trusting relationships, and make the patient feel more valued. Making simple changes to the environment can also be beneficial for dementia patients. Easy-to-read signage can help to provide cues as to their surroundings, while using large clocks and calendars can help orient patients and minimize the confusing atmosphere of a hospital floor.

Though dementia patients are commonly seen in the acute care setting, cognitive assessments are rarely carried out effectively (Sampson et al., 2006). Hospital staff should strive to identify the cognitive status of all admissions, and continue to assess periodically, to ensure that appropriate treatment plans are put in place. Comprehensive pain assessments should also

be carried out frequently with dementia patients who may be unable to effectively communicate any discomfort they are experiencing. Nurses need to advocate for these patients by assuming the presence of pain in those undergoing known painful procedures and by requesting and providing appropriate analgesia.

Effective end-of-life care is also an important aspect of caring for dementia patients and is currently lacking in several areas (Formiga et al., 2007; Sampson et al., 2011). Nurses need to be prepared to provide palliative care to these patients, helping to control pain and preventing other distressing symptoms such as dyspnea. Knowing the patient's religious preferences and provision of spiritual support to the whole family may also provide comfort during this difficult time.

Education

Research has shown that dementia education in the general hospital setting is currently inadequate (Moyle et al., 2008). Staff often lack confidence in their abilities to provide care to dementia patients, struggling to communicate effectively and avoiding psychosocial aspects of care provision (Cowdell, 2010; Perrin, 1997). All hospital staff that provide care to older adults should receive regular dementia training to promote a better understanding of patients with dementia, and to explain the potential safety hazards that can occur as a result of working with this population. Nurses should receive additional training to assist in the early detection of cognitive changes in this vulnerable population, facilitating prompt diagnosis and treatment.

In addition to having a thorough knowledge of dementia, nursing staff who specifically work with older populations also need to have an understanding of appropriate palliative and

end-of-life care. Nurses have an opportunity to provide valuable information and resources to assist family caregivers with end-of-life issues, but should be aware that the acute care environment may not be the most suitable situation for this type of intervention. Providing nurses with the skills to share this knowledge, when appropriate, can help dementia patients and their caregivers plan for their future care.

Research

There is a need for further research into the experiences of hospitalized dementia patients. Many current articles come from outside of the United States and focus on nursing care provided in specialized dementia care settings. Possibly as a result of the ethical difficulties of studying people with dementia, there is limited research from the point of view of the patient.

More effort needs to be put into developing ethically sound methods of research that include dementia patients and allow their voices to be heard. Without information from the point of view of the patient, it is difficult to develop or evaluate interventions designed to improve their experiences of hospitalization. It is also important to carry out further research in acute care settings. Since dementia patients are more likely to be seen in an acute care setting than in a specialized dementia unit, future research should focus on the acute care environment to provide more generalizable findings. Finally, more research needs to be carried out in the United States. As so much of the current research is carried out in the United Kingdom where they have a nationalized health care system, it is difficult to relate the results to the United States where the health care system is so different. Studies carried out in the United States would add to the current body of literature, and provide more relatable information to American nurses. Finally,

there is an urgent need to develop best practices related to inter-facility communication and caregiver/family communication.

SUMMARY

As the population of elderly people in the United States grows, so will the number of people suffering from one of the many forms of dementia. People with dementia are hospitalized for a variety of reasons, often receiving care in acute care settings. Study findings show that communication between nursing staff, patients, and their family caregivers is lacking, resulting in inadequate care and dissatisfied consumers. The need to provide individualized care is paramount, and allows for trusting relationships to develop between nurses and their patients.

Based on the information gained from this literature review, it is clear that additional training is needed for all hospital staff to promote better interactions with dementia patients. Nursing staff also need to develop cognitive and pain assessment skills, and broaden their knowledge of end-of-life and palliative treatments.

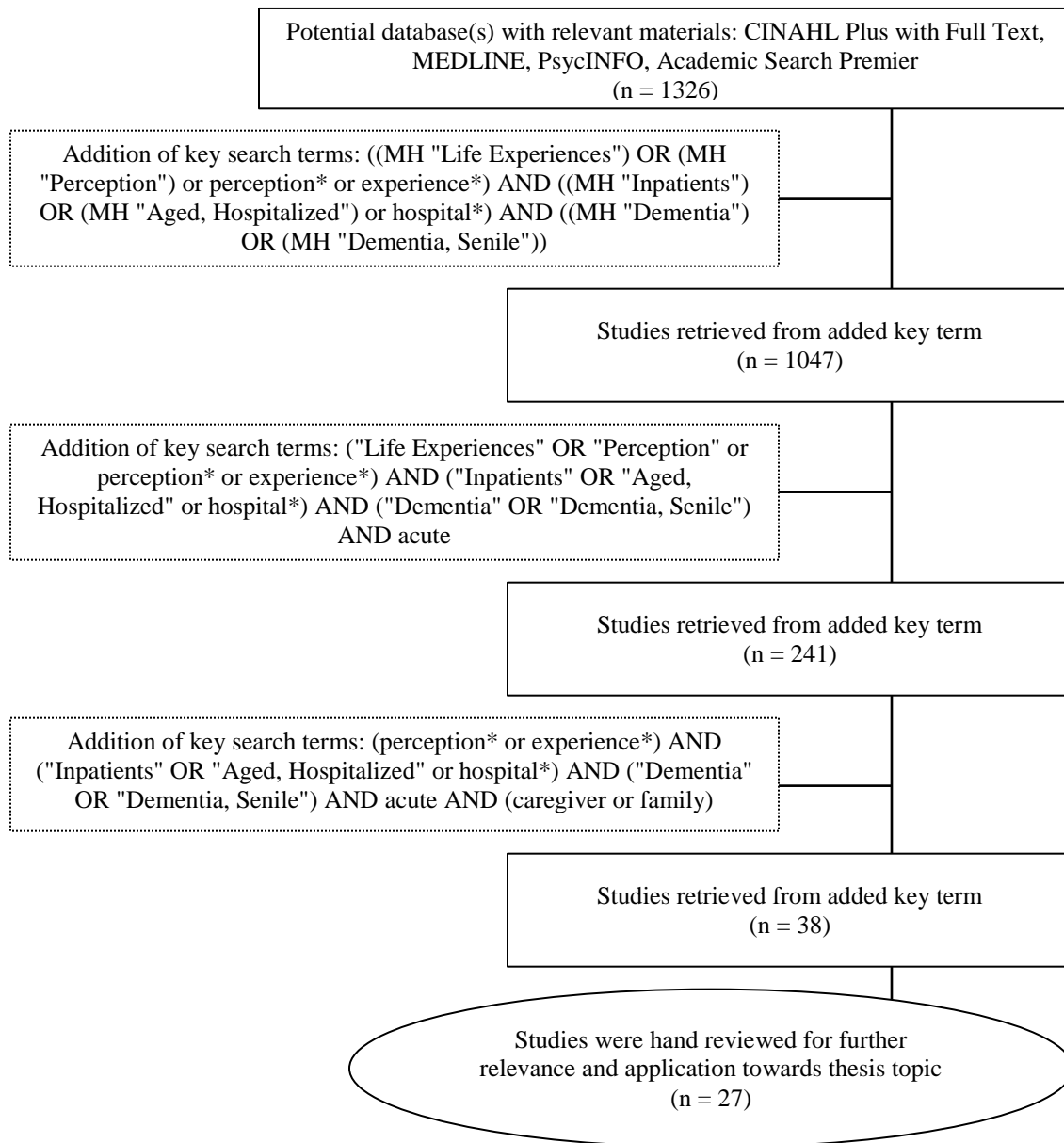
There is limited research from the perspective of the dementia patient, and further efforts must be made to find ethical ways to incorporate these patients in future studies. There have been few studies carried out in acute care settings, where the majority of dementia patients are seen. A large portion of current research has been conducted in specialty dementia care environments within the United Kingdom and Sweden. Future research should be carried out in acute care settings within the United States.

APPENDIX A: SELECTION METHOD OF LITERATURE

Figure 1: Selection Method of Literature

Key Search Terms: life experience, perception, inpatient, experience, aged, hospitalized, dementia, senile, acute, caregiver, family.

Limiters Used: English language, peer-reviewed.



APPENDIX B: TABLE OF EVIDENCE

Table 2: Table of Evidence

Exclusion Criteria: Focus on early-onset dementia or delirium; non-peer reviewed; non-English; published prior to 1990.

Inclusion Criteria: Patient sample suffering from dementia; English language; published after 1990; peer-reviewed.

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
Boockvar, Fridman, and Marturano (2005) "Ineffective communication of mental status information during care transfer of older adults"	United States	To discuss the content and accuracy of mental status information given during the transfer of a patient between a nursing home and a hospital.	174 admissions to one of two academic hospitals from one of five nursing homes. Patients had to have been hospitalized for over 24 hours and to have survived to discharge.	Retrospective chart review. Researchers examined transfer documentation for descriptions of mental status, then nursing home and hospital medical records were reviewed for demographic, medical, and cognitive assessment data.	None	Transfer documentation often contained little or no information related to mental status, especially in transfers involving patients with dementia. The lack of information may have contributed to the poor recognition of delirium in some patients. Transfer forms were worded poorly and often left out useful information such as communication data.	Care should be taken when completing transfer paperwork to ensure that thorough and accurate information is given in order to aid other providers with diagnosing and treating patients with dementia.
Bridges and Wilkinson (2011) "Achieving dignity for older people with dementia"	United Kingdom	To describe ways for nurses to promote dignity for hospitalized dementia patients.	None.	Summary article.	None	Communication between staff, patients, and caregivers was critical when trying to determine a patient's individual needs. It was also a	Staff should learn from their own experiences, and those of others, to facilitate their work with hospitalized dementia patients.

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
in hospital"						useful way for employees to identify and promote best practices when working with dementia patients.	Working with those closest to dementia patients can provide nursing staff with the knowledge to better care for them. Sharing knowledge of a patient during staff changeover is a vital to providing good care and preventing frustration for all parties.
Cowdell (2010) "The care of older people with dementia in acute hospitals"	United Kingdom	Investigate the experiences of patients and nursing staff in relation to the care delivered to and received by older people with dementia in an acute hospital setting.	11 people aged between 80 and 93 years old, who had previously been diagnosed with dementia and who had been admitted into a specialist ward for older people. 25 RNs and 33 nursing assistants who had worked with older people for over two months.	Ethnographic. Observation of interactions between staff and patients, as well as interviews and opportunistic conversations.	None	Patients found the hospital environment to be difficult and disturbing, became distressed by unpleasant care delivery, and were concerned about their future and prognosis. Their experience was mostly a negative one with minimal interaction between patients and the care	Attention should be focused on encouraging empathy in staff who work with dementia patients. Staff need to understand that patients with dementia may communicate differently, and that they should be listened to and learned from.

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
						<p>staff.</p> <p>Nurses developed their own personal philosophies about caring for dementia patients based on their previous experiences.</p> <p>Nursing staff felt that their work was undervalued by others and required little skill, and many felt more confident providing physical rather than psychosocial care due to lack of education.</p>	
<p>Danesh, Malvey, and Fottler (2008)</p> <p>“Hidden workplace violence: What your nurses may not be telling you”</p>	United States	To discuss the occurrence of workplace violence perpetrated by dementia patients against nursing staff, and to suggest strategies for preventing it from occurring.	None.	Summary article.	None	<p>While receiving nursing care, dementia patients may become violent with staff.</p> <p>Violence towards nurses may affect the ability of a company to recruit and retain staff.</p> <p>Violent acts such as hitting, pinching, hair pulling, biting, and scratching are</p>	<p>Nursing staff should be prepared for the possibility of violent behaviors from patients with dementia, and should report any such occurrences to the appropriate people.</p> <p>Employers should understand the potential safety risks of working</p>

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
						<p>often not reported by staff members who view these problems simply as part of the job.</p> <p>Employers have an obligation to provide a safe working environment for their staff members.</p> <p>Frameworks for managing potentially violent situations are available, promoting prevention, training, and employee feedback.</p>	with dementia patients, and should utilize available tools to provide a safe working environment for their staff.
<p>Douglas-Dunbar and Gardiner (2007)</p> <p>"Support for carers of people with dementia during hospital admission"</p>	United Kingdom	To develop support services for the caregivers of dementia patients admitted to a general hospital.	Caregivers of 9 dementia patients in a district general hospital.	Qualitative semi-structured interviews, occurring following the patient's discharge.	None	<p>Caregivers said that communication between them and the staff was poor, and that they often felt ignored. Some understood the heavy workload of their nurse, but also felt that the nurses did not fully understand dementia, or the stress that</p>	Nurses should work to develop a therapeutic relationship with caregivers and dementia patients, encouraging their input and acknowledging the valuable information they can provide.

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
						hospitalization placed on the caregivers themselves. Caregivers felt the need to advocate for the patient, and believed that they had valuable information to share with the nursing staff, but were often ignored.	Nurses should also be aware that hospitalization can be stressful both on the patient and their caregiver, and offer support accordingly.
Edvardsson and Nordvall (2008) "Lost in the present but confident of the past: Experiences of being in a psycho-geriatric unit as narrated by persons with dementia"	Sweden	To speak with people with dementia and discover their experiences of being in a psycho-geriatric unit.	Six people with mild to severe dementia.	Phenomenological hermeneutical. Interviews, featuring open-ended questions, took place 1-3 weeks after admission to a psycho-geriatric unit.	None	Patients felt "lost in the present" - unsure of where they were or how ill they may be - yet "confident in the past" - frequently referring to their previous life (Edvardsson & Nordvall, 2007, p. 494). They described feeling bored and devalued, and discussed some of the pros and cons of having to share a living environment with strangers.	Staff should create more time to listen to patients with dementia to better understand their needs, and to help them feel valued. Patients desire to know where they are and why they are there - this can be achieved through the use of environmental cues.

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
Formiga, Olmedo, López-Soto, Navarro, Culla, and Pujol (2007) "Dying in hospital of terminal heart failure or severe dementia: The circumstances associated with death and the opinions of caregivers"	Spain	To determine perceptions of palliative care provided to heart failure and dementia patients in two Spanish acute tertiary hospitals.	Caregivers of 102 patients over 64 years old who died from terminal heart failure (65 patients) or severe dementia (37 patients) in two teaching hospitals.	Mixed method. Charts were reviewed for information related to medical care given and support offered. One month after the death of the patient, phone questionnaires that included open ended questions were conducted with their caregiver to determine their level of satisfaction.	None	Caregivers of dementia patients were more likely to be satisfied with the information they received, and were offered spiritual support more frequently. However, they felt that there was less symptom control and inadequate management of dyspnea. In contrast, caregivers of heart failure patients generally felt that symptoms were adequately managed, witnessed little uncontrolled dyspnea, but were rarely offered spiritual support.	When providing end-of-life care to a patient, it is important to communicate with the caregiver and keep them informed about the treatment being given. Knowing the desires of the patient prior to their hospitalization can help to improve end-of-life care. Controlling symptoms such as pain and dyspnea can help to minimize the potential suffering of dying patients, as well as ease the worries of their caregivers. Staff caring for older adults should receive palliative training to better prepare

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
							them for dealing with terminal cases.
Gallinagh, Nevin, Campbell, Mitchell, and Ludwick (2001) "Relatives' perceptions of side rail use on the older person in hospital"	United Kingdom	To explore the perceptions of relatives whose family member had side rails used during their care in an older person ward.	Caregivers of 9 elderly patients in a dedicated older person ward.	Semi-structured interviews. Adapted version of the Family Interview Guide was used, replacing the word "restraint" with "side rails" to elicit responses from caregivers about their thoughts on their use.	None	Caregivers all felt that the side rails were being used as a safety measure, though almost half never received an explanation from staff for their use. Some felt they were assistive devices for the patient. Three caregivers expressed concern about them being restrictive, and some were concerned about their potential for causing harm. None of the caregivers were able to list alternatives to the use of side rails, but some were able to give suggestions for improving them.	Staff should discuss the use of side rails with patients and their family members, mentioning the reason for their use, the potential problems that can arise from their use, and any alternative measures that can be taken.
James (2011) "How can we improve care in general hospitals?"	United Kingdom	To provide a summary of recommendations for nurses to use in improving care of dementia	None.	Summary article.	None	Hospital workers were unlikely to receive dementia specific training unless they worked in a mental health setting, yet over one	All staff within the hospital setting should receive dementia specific training, not just nursing staff. In addition, easily

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
		patients in acute hospital settings.				<p>third of acute hospital admissions have cognitive impairment. Patients with dementia often did not receive non-clinical interventions as staff were hesitant to involve them or found communicating difficult. Hospitals were often busy, noisy and disorienting to people with dementia.</p>	<p>understood information related to caring for dementia patients should be made available for employees and families, twenty-four hours a day.</p> <p>Complementary therapies, such as massage, may be beneficial to patients with dementia.</p> <p>Simple and cost effective changes can be made within the hospital environment to make it more dementia friendly, including large clocks and calendars, appropriate signage, designated quiet areas, and pictorial menus.</p>

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
<p>Kelley, Siegler, and Reid (2008)</p> <p>"Pitfalls and recommendations regarding the management of acute pain among hospitalized patients with dementia"</p>	United States	To review previous cases where nurses cared for older adults with dementia in an inpatient geriatric hospital, and to analyze the problems that arose trying to treat their pain.	4 adults, aged 70 years and older, with dementia and pain.	Case study. A review of experiences from clinical practice where pain was a factor in the treatment of a dementia patient.	None	<p>Patients with dementia were not always able to remember when to take, or when to request medications. They were often unable to understand or recognize changes in their pain intensity. They often did not recognize side effects of pain medications such as constipation or urinary retention.</p>	<p>Patients should be rigorously assessed for pain and its cause.</p> <p>Patients should be frequently reminded of the side effects of the medications they are being given, and staff should anticipate potential side effects and treat accordingly.</p> <p>Use of pain scales along with the observations of all staff members working with the patient can help provide accurate pain measurement in patients with dementia.</p> <p>All care providers should keep an open mind when diagnosing and treating this patient population.</p>

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
Miller, Campbell, Moore, and Schofield (2004) "Elder care supportive interventions protocol: Reducing discomfort in confused hospitalized older adults"	United States	To test the Elder Care Supportive Interventions Protocol (ECSIP), a set of interventions designed to minimize discomfort for hospitalized older adults experiencing confusion.	81 adults over the age of 64 who were admitted to medical and surgical units of a tertiary care hospital. Patients had to have been admitted from a nursing home and have a prior diagnosis of dementia or chronic cognitive impairment.	Quasi-experimental design. Within 24 hours of admission, data relating to patients baseline behaviors and normal routines were obtained. Patients were then assessed using NEECHAM confusion scale, Katz Index of ADL, and DS-DAT within 48-72 hours, and again within 24 hours prior to discharge.	Steps were taken to maintain a familiar environment, provide meaningful communication, sensory input, and decrease physical discomfort. Employees also received a two hour training class.	No statistically significant reduction in discomfort was noted; however staff had not been implementing the interventions as required. Many family members stated that they appreciated being able to share their knowledge with staff regarding the patient's likes and dislikes.	Family members are a good source of information and are generally interested in being involved with care, providing insight into a variety of patient needs.
Morrison and Siu (2000) "A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture"	United States	To compare the treatment of pain in hip fracture patients who have dementia, with those who have no cognitive impairment.	97 patients over the age of 70 who were admitted to a large teaching hospital with the diagnosis of hip fracture. Patients were excluded if they also had a diagnosis of cancer, multiple internal injuries, a previous hip fracture, were unable to speak English, or were delirious. Based	Descriptive/comparative. Cognitively intact patients were approached daily and asked to rate the severity of their pain on a numeric scale. Patient's charts were reviewed daily for information related to pain medication, including the name of drugs used, the dosage, and frequency.	None	Almost half of the cognitively intact patients rated their pain as severe or very severe, yet many of them received an inadequate amount of pain medication. Cognitively intact patients received almost three times the amount of analgesia as those with advanced dementia, yet many still reported their	When working with dementia patients hospitalized for potentially painful reasons (i.e. a hip fracture), nurses should frequently assess for symptoms of pain, and provide analgesia. If a procedure or illness has been shown to cause pain in a

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
			on a Mini Mental State Examination, patients were considered to have advanced dementia (38) or be cognitively intact (59).			pain as severe or very severe. Approximately three quarters of all patients only received pain medication on an as needed basis.	cognitively intact person, it is recommended that nurses assume pain would also be present in dementia patients undergoing the same procedure or illness. Nurses should advocate for their patients and request continuous pain medications for those in painful situations, rather than administering them as needed.
Moyle, Olorenshaw, Wallis, and Borbasi (2008) Best practice for the management of older people with dementia in the acute care setting: A	Australia	To review literature related to the care of people with chronic confusion as a consequence of dementia in the acute care setting.	31 papers.	Literature review. Analysis of peer reviewed theoretical and research based literature released between 1986 and 2006, with a focus on care models and/or principles of care.	None	Early assessment and detection of dementia patients was important. Nursing staff often lacked knowledge and confidence when caring for dementia patients. The patient's inability to communicate effectively sometimes lead to	More research needs to be done to identify and evaluate care models aimed at helping hospitalized dementia patients. All staff should receive dementia related training to encourage early detection and

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
review of the literature"						practitioners negatively labeling them. The involvement of family caregivers was beneficial to staff and helped them to reduce patient stressors. Few studies had been carried out to determine best care practices for dementia patients in acute care settings.	appropriate care. Nurses should involve family members and caregivers when caring for dementia patients, and be willing to make changes to accommodate the individual patient's needs.
Nolan (2006) "Caring connections with older persons with dementia in an acute hospital setting: A hermeneutic interpretation of the staff nurse's experience"	Republic of Ireland	To describe the experiences of nurses who care for dementia patients in acute hospital settings.	7 nurses working in a unit dedicated to the care of acutely ill older people within a large acute hospital. All of the nurses were female and had worked with dementia patients for at least two years.	Hermeneutic interpretation. In-depth, conversational interviews took place over a period of three months, until data saturation was achieved.	None	Nurses struggled to encourage patient independence due to limited time and multiple demands. They strove to create a friendship with dementia patients to promote trust and facilitate care, feeling a sense of accomplishment when this was achieved. Nurses explained working with patients' caregivers made it easier to establish a bond in an acute care setting, and	Utilizing the knowledge of a dementia patient's caregiver not only provides nurses the information to facilitate care provision, but can also promote bonding between nurse, caregiver and patient, which can be beneficial to everyone involved.

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						described this relationship as beneficial to the caregiver and the patient.	
<p>Norbergh, Asplund, Rassmussen, Nordahl, and Sandman (2001)</p> <p>"How patients with dementia spend their time in a psycho-geriatric unit"</p>	Sweden	To increase our knowledge of institutionalized dementia patients by describing the daily activities of patients on a psycho-geriatric unit.	24 patients with dementia on a psycho-geriatric unit, admitted for assessment and treatment of psychiatric symptoms.	Observational. Researchers observed patients at ten minute intervals over several hours and categorized their activities using the Patient Activities Classification tool, along with free note taking.	None	<p>Patients spent over half of their time alone, and almost a third of their time with nursing staff performing activities of daily living. Those with the ability to communicate more effectively, those with difficulties eating, and those in restraints, all spent more time with nursing staff than others. Socializing with other patients (16%) and family members (1%) took up the remainder of the time, though these activities generally involved watching television together or drinking coffee in the day room.</p>	<p>It is important for nursing staff to recognize the need for psychosocial care as well as physical care when working with all dementia patients.</p> <p>By encouraging family involvement in the care of patients, nurses can include them in decision-making, and learn more about the patient, therefore improve the level of care being provided.</p>

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Norman (2006) "Observations of the experiences of people with dementia on general hospital wards"	United Kingdom	To observe the processes and care provision that occurs during the hospital stay of patients with dementia, and to consider their responses.	8 patients with dementia, as identified by nursing staff, who had been admitted to one of three general hospital wards.	Grounded theory. Observation of interactions between staff and patients.	None	Patients used a variety of different ways to express themselves, doing so in an attempt to control the care they were receiving. Nursing staff often grouped patients into positive or negative groups which affected both their interactions and the type of care given.	Nurses should consider the actions of patients with dementia as their way of communicating. Care planning should prioritize the need of the patient to express their individuality in order to improve their hospital experience.
Perrin (1997) "Occupational need in severe dementia: A descriptive study"	United Kingdom	To demonstrate the occupational needs of elderly persons in hospital and residential settings who have severe dementia, and to identify the therapeutic approaches which serve to meet those needs.	109 severely impaired persons in nine dementia care units (hospitals, residential homes, and dementia care units).	Patients were observed in group settings and their interactions and activities were scored using a Dementia Care Mapping Instrument and a Behavior Category Profile.	None	There was a shortage of social interaction, with most patients spending their days sleeping, withdrawn, and not committing to their environment. Patients appear to live within a shrunk environment - a "plastic bubble" (p. 940) - that caregivers must be able to penetrate in order to engage them (Perrin, 1997).	Less focus should be put into the larger surroundings of a room, and more attention given to the world directly surrounding the patient. Nursing staff need help understanding ways of interacting with severely demented patients outside of basic activities of daily living.

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
Proctor (2001) "Listening to older women with dementia: Relationships, voices and power"	United Kingdom	To find out how older women with dementia viewed the services they received at a day hospital, to understand their world view, and to investigate the possible difficulties of interviewing people with dementia.	4 women with dementia who attended a day hospital.	Voice relational method. Semi-structured interviews.	None	Patients described feeling powerless and left out of the decision making process. Some were afraid of giving wrong answers and had difficulties expressing themselves. Relationships with care staff were generally positive. However, patients sometimes felt uncomfortable voicing their own opinions or asking questions to those they perceived as being more powerful than them.	Promoting a dialogue with patients and listening to their views helps them to feel valued.
Sampson, Gould, Lee, and Blanchard (2006) "Differences in care received by patients with and without dementia who died during	United Kingdom	To examine the care received by terminal patients on acute medical wards, and to identify any differences between care given to patients with dementia and those without.	122 patients over 70 years of age who died on an acute medical ward. 35 with a diagnosis of dementia, 65 listed as cognitively intact, and 22 with no cognitive status listed in their charts.	Retrospective chart review. Case notes were analyzed for information related to dementia diagnosis, demographic information, end-of-life care, and the implementation of painful procedures.	None	Dementia patients were less likely to have their religious faith listed in their files. They were more likely to have urinary catheters and nasogastric tubes, but less likely to have central lines inserted. They were also less likely to be referred to palliative	Efforts should be made to identify the cognitive status of all hospital admissions, and to determine the spiritual needs of any terminal patient. Nurses need to understand the

Article	Country	Purpose	Sample Size/Type	Study Design	Intervention	Results/Key Findings	Nursing Implications
acute hospital admission: A retrospective case note study"						care or to be prescribed palliative medications.	terminal nature of dementia and promote the use of palliative care to their patients when needed.
Sampson et al. (2011) "Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention"	United Kingdom	To assess the use of an intervention aimed at improving end-of-life care for patients with dementia.	Patients with severe dementia who were undergoing an emergency hospital admission at an acute medical ward. 33 patient/caregiver dyads were assigned to an intervention group (22 dyads) or a control group (11 dyads).	Interviews using framework analysis. Assessments of each patient and interviews held with caregivers provided data for review in order to determine palliative needs and advance care planning requirements. Follow up interviews took place up to six month after discharge.	Basic information on dementia, the role of palliative care, and advance care planning was given to each caregiver, with follow up meetings scheduled to assist and advise caregivers in making an Advanced Care Plan.	Recruitment was impeded by the stressful situations surrounding an acute hospitalization and short hospital stays. Most of the elders receiving care were bed-bound, all were incontinent of bowel and bladder, all needed feeding assistance, and over half were at risk of developing a pressure ulcer. 95% suffered from mild to moderate pain. Caregivers chose not to make Advanced Care Plans due to family conflicts and an unwillingness to accept the likelihood of future problems. However, all caregivers exhibited an interest in getting	Nurses should encourage able patients to work with family members to make plans for their future care while they are still able. Nursing staff can provide end-of-life education to caregivers of dementia patients, ideally at a time prior to an acute hospitalization, when they are more likely to be receptive to receiving such information. Nurses should be aware that involving caregivers in advance care planning during an

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						further information about end-of-life issues and dementia.	acute hospital admission may be very difficult.
Simpson, Scothern, and Vincent (1995) "Survey of carer satisfaction with the quality of care delivered to in-patients suffering from dementia"	United Kingdom	To discover the opinions of patients and caregivers of the care they received at a hospital for the mentally ill. Also, to see how their perceptions of high quality care relate to those of the service provider, and to review the use of a questionnaire in this situation.	41 dementia patients and their caregivers were interviewed within two weeks of their discharge from one of eight different hospital wards, where they had stayed following an emergency admission or for respite care.	Grounded theory. Interviewers utilized a questionnaire that obtained both qualitative and quantitative data.	None	Caregivers often believed that information was being withheld and felt uncomfortable asking for more details, sometimes feeling misunderstood by medical staff. They were more likely to be satisfied with the care provided if they felt that the nurse had a proactive attitude. Caregivers felt that there should be some separation between patients at different stages of dementia.	Better two-way communication between caregivers and nursing and medical staff is needed to ensure all parties understand each other. Staff attitudes can have a big impact on the hospital experience for caregivers. Where possible, nurses should take into consideration the stage of a patient's dementia when placing them with a roommate.
Thompson (2011) "What works, and what we need to do to improve acute	United Kingdom	To find out what works well, what makes it difficult, and what needs to happen to	700 practitioners and 1484 people with dementia and their caregivers.	Structured surveys.	None	Practitioners stated that involving family members in care was beneficial, that staff training should be more practical and	Staff should be skilled in dementia care and have time to provide the care that is needed.

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hospital care"		support better care for people with dementia and their families in general hospitals.				interactive, and that improving the identification and assessment of dementia patients would improve the care given. Caregivers also felt that staff education and family involvement was important, and that clearer care plans, increased access to specialists, and a skilled assessment would all be helpful.	Caregivers and staff should work as partners. Early assessment and identification of dementia is important. Care plans should be individualized. The hospital environment should be changed to suit patients with dementia.
Tolson, Smith, and Knight (1999) "An investigation of the components of best nursing practice in the care of acutely ill hospitalized older patients with coincidental dementia: A	United Kingdom	Examine, from the consumer's perspective, the components of best nursing practice in the care of acutely ill hospitalized elderly people who coincidentally suffer from dementia.	213 people aged 65 years and older who were consecutive admissions from two acute medical and two acute care of elderly people wards, and who had scored 23 or less on a Mini Mental State Examination.	Interviews were held with willing participants who were prompted to describe aspects of both good and bad nursing care. Nursing records were examined to review past diagnoses and treatments.	None	Four themes were discovered: Settling In - adjusting to unfamiliar surroundings; Visible Love - the need to demonstrate a bond between family members and the patient; Reaching Me, Reaching You - remembering and relating to people and events, as well as feeling that the nurse understands; and My Condition -	Formal assessments of patients' cognitive abilities should be made to allow appropriate nursing interventions to be implemented. Good nursing care, as viewed by consumers, integrates both acute care and dementia care.

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multi-method design"						trying to understand the acute illness that lead to the admission, as well as any chronic problems, including dementia (Tolson, Smith, & Knight, 1999, p. 1133).	Communication between nursing staff and families encourages positive adjustment and a feeling of involvement.
Watkin, Blanchard, Tookman, and Sampson (2012) "Prospective cohort study of adverse events in older people admitted to the acute general hospital: Risk factors and the impact of dementia"	United Kingdom	To identify the prevalence of reported adverse events involving older patients during an acute hospital admission, to identify any factors present during admission (i.e. dementia or delirium) that could predict the occurrence of these events, and to determine whether these events effected the risk of mortality during the admission.	621 people over the age of 70 who had an unplanned admission to a general hospital, remained hospitalized for at least 48 hours, spoke sufficient English, and were not experiencing persistent delirium.	Chart review, non-structured interviews and observations. Patients were assessed with a variety of tools to determine the presence of dementia or delirium. A review of hospital notes, occupational therapy reports, and discussions with caregivers were used to determine demographic data, length of stay, mortality information, pressure sore risk, co-morbidities, and the severity of the acute illness.	None	Patients with delirium or mild/moderate cognitive impairment were significantly more likely to experience an adverse event. Staff frequently failed to recognize cognitively impaired patients. Most of the incidents that occurred involved "slips, trips or falls" (p. 79), and almost one half of those incidents resulted in the patient being "injured" (Watkin, Blanchard, Tookman, & Sampson, 2012, p. 79). No significant association was found between	Routine cognitive screening should be implemented to help staff identify patients at risk for experiencing an adverse event. Staff should receive training to help them better understand dementia, and to provide them with information that can help them care for cognitively impaired patients.

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				Hospital records documenting reported adverse events were also reviewed.		patient mortality and adverse events.	
Webster (2011) "Improving care for people with dementia in acute hospital: The role of person-centered assessment"	United Kingdom	To demonstrate how person-centered assessments improve the care given to dementia patients in acute hospital settings.	4 hospitalized older adults and their caregivers.	Summary article including case studies.	None	One caregiver stated that communication between caregivers and nursing staff was impeded by the fact that patient was frequently relocated within the hospital. Others described small personalized changes to the plan of care eased their sense of anxiety. One situation highlighted the difficulties that arose from lack of interdisciplinary communication, and from failing to ask the patient his desires. Patient-centered practice involves understanding needs of dementia patients, and focusing care on maintaining or improving well being, not just	Working with patients and their caregivers enables nurses to provide person-centered care by helping to maintain daily routines and finding effective ways to solve problems that arise. All staff need to work together to improve knowledge and acquire the skills needed to care for dementia patients. Nurses should utilize person-centered assessments to see the "person behind the patient" (p. 92) and therefore provide more effective and

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						treating a single condition.	individualized care (Webster, 2011).
Wierman, Wadland, Walters, Kuhn, and Farrington (2011) "Nonpharmacological management of agitation in hospitalized patients with late-stage dementia: A pilot study"	United States	To assess the feasibility of using Simple Pleasures interventions in a hospital setting, and to determine what impact they have on reducing agitation in hospitalized patients with late-stage dementia.	26 patients with baseline dementia who had been admitted to a hospital from a long term nursing home.	Descriptive. Patients were evaluated within 24 hours of admission, then again every 48-72 hours for one week. Baseline data were obtained from the nursing home, then a variety of assessment techniques were used throughout the week.	Simple Pleasures items were distributed to each patient, and staff trained in how to encourage their use.	No statistically significant change in agitation levels was noted. Staff stated that they benefited from having more baseline information on each patient, and appreciated having an alternative to sedating medication and restraints.	When working with agitated dementia patients, staff and family members appreciate having alternatives to restraints and pharmacological treatments.
Williams (2011) "Hospital programme for dementia-specific care"	United Kingdom	To demonstrate the effectiveness of a new program designed to improve the safety of patients with dementia in a hospital setting.	One nurse consultant at a general hospital, and one senior nurse from an elderly care ward.	Case studies of newly implemented programs	Caregivers of patients with dementia provided detailed information about their loved one's likes and dislikes etc. The patients were then identified by a butterfly symbol on	One nurse felt that staff members reacted positively to the program and felt they had a better understanding of their role in providing care to dementia patients. The nurse also believed that staff benefited from the data given by caregivers and were able to better care	Simple interventions that involve communication with caregivers, and the clear identification of patients with dementia, can improve both staff and family members hospital experiences.

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					their charts to remind staff to review the information given in order to provide individualized care.	for their patients with the more personalized information. The other nurse felt that caregivers were able to provide insight into the patient's behaviors, helping to improve the interpersonal relationships between everyone involved. The nurse also believed that caregivers also appreciated the program and felt that it was put into place for the safety of their loved ones.	

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