**IMPROVING CARE AND EXPERIENCE FOR HOSPITALIZED DEMENTIA PATIENTS THROUGH IMPLEMENTATION OF DEMENTIA ACTIVITY ROOM**

by

**Amrit Pal Kaur**

BDS, Baba Farid University of Health Sciences, India, 2010

MHA, Tata Institute of Social Sciences, India, 2015

Submitted to the Graduate Faculty of

the Department of Health Policy and Management

Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Health Administration

University of Pittsburgh

2018

UNIVERSITY OF PITTSBURGH

GRADUATE SCHOOL OF PUBLIC HEALTH

This essay is submitted

by

Amrit Pal Kaur

on

Month day, 2018

and approved by

**Essay Advisor:**

Wesley Rohrer, PhD, MBA

Associate Professor \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Health Policy Management

Graduate School of Public Health

University of Pittsburgh

Essay Readers:

Andrea L. Durst, MS, DrPH, LCGC  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Assistant Professor

Human Genetics

Graduate School of Public Health

University of Pittsburgh

Amy Kowinsky, RD LDN \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Improvement Specialist

Wolff Center of UPMC

Pittsburgh, Pennsylvania

Copyright © by Amrit Pal Kaur

2018

Wesley Rohrer, PhD, MBA

**IMPROVING CARE AND EXPERIENCE FOR HOSPITALIZED DEMENTIA PATIENTS THROUGH IMPLEMENTATION OF DEMENTIA ACTIVITY ROOM**

Amrit Pal Kaur, MHA

University of Pittsburgh, 2018

**ABSTRACT**

Dementia is a growing problem of public health concern because the decline in memory and other cognitive functions that characterizes this condition also leads to a loss of independent function that has a wide-ranging impact on individuals, families and healthcare systems affecting 1 in 20 over age of 65 and 1 in 5 over age of 80. Due to the complexity of the disease, these patients are often admitted to the hospital and fall victim to the fact that traditional hospital processes do not meet their needs.

The Dementia Activity Room piloted on unit 10E at Mercy, is the first room of its kind for this population in an inpatient setting at UPMC. The Dementia Activity Room involves the application of non-pharmacological interventions for patients with dementia. Patients with dementia who would benefit from additional supervision and stimulation go to the Dementia Activities Room for the day. It is staffed by nursing assistants who received special training on communication and engagement techniques for patients with dementia. Patients have several activity options, and families are engaged to suggest and participate in activities. Special focus is on insuring that the patients walk throughout the day and are supported with meals, adequate hydration, and in activities of daily living. The Dementia Activities Room is designed to improve both the care processes and the hospital experience of the patients with dementia and their loved ones. By creating a dementia-friendly atmosphere within the hospital, patients with dementia can be kept positively engaged, cognitively stimulated, and safe. Also, introducing this room in the hospitals has increased the confidence of caregivers, especially nurses and nurse assistants in taking care of patients with dementia.

TABLE OF CONTENTS

[1.0 Introduction 1](#_Toc526944332)

[1.1 WHAT IS DEMENTIA 1](#_Toc526944333)

[1.2 PUBLIC HEALTH RELEVANCE 4](#_Toc526944334)

[1.3 PROBLEM STATEMENT 6](#_Toc526944335)

[2.0 LITERATURE REVIEW 7](#_Toc526944336)

[2.1 Prevalence of Dementia 7](#_Toc526944337)

[2.2 Gaps in Care/Current Dementia Care 8](#_Toc526944338)

[2.3 Issues Faced by Caregivers (Nurses) 11](#_Toc526944339)

[3.0 DEMENTIA ACTIVITY ROOM 15](#_Toc526944340)

[3.1 Design and Implementation of the room 15](#_Toc526944341)

[3.2 Clinical Outcomes 17](#_Toc526944342)

[3.3 Nurse Satisfaction 20](#_Toc526944343)

[4.0 CONCLUSION 23](#_Toc526944344)

[5.0 RECOMMENDATIONS 24](#_Toc526944345)

[APPENDIX: CHARTS 27](#_Toc526944346)

[bibliography 32](#_Toc526944347)

List of tables

[Table 1. Clinical Outcomes - DAR Patients (80 and older) 29](#_Toc526944348)

[Table 2. Clinical Outcomes – non-DAR Patients (80 and older) 30](#_Toc526944349)

List of figures

[Figure 1. Clinical Outcomes - DAR Patients (65 and older) 27](#_Toc526944350)

[Figure 2. Clinical Outcomes - non-DAR Patients (65 and older) 28](#_Toc526944351)

[Figure 3. Nursing Satisfaction/Perception of Dementia Care Outcomes 31](#_Toc526944352)

# Introduction

Dementia is a chronic disease that is increasing in prevalence; as a result, it is imperative to design reliable processes to meet the care needs of patients with dementia. In the current state, the care that patients with dementia need is very different than the care they typically receive. This refers especially to the care that patients with dementia receive in the hospitals. On a busy nursing unit, patients with dementia are often left in their rooms alone for long hours and encouraged to stay in bed, because they may be a fall risk or are prone to wandering. This is then further reinforced by an alarm that sounds if they do try to get out of bed. A patient with dementia in this environment can easily become agitated, which can be perceived as disruptive, aggressive, or difficult. This essay explores the implementation of a Dementia Activity Room, one method of care that better supports the physical and emotional needs of these patients. This essay reflects my part of work in an ongoing quality improvement assessment project.

## WHAT IS DEMENTIA

Dementia is an umbrella term for a set of symptoms that are caused by disorders affecting the brain. This term is applied to a cluster of symptoms including memory loss, confusion, disorientation and other cognitive impairments serious enough to interfere with activities of daily life including self-care and decision making. A person with dementia may also experience changes in mood or behavior. Dementia is progressive, which means the symptoms will gradually get worse as more brain cells become damaged and eventually die.

Dementia is not a specific disease but a condition caused when the brain is damaged by other diseases. Alzheimer’s disease is the most common cause of dementia, but not the only one. Many diseases can cause dementia, including Alzheimer's disease, vascular dementia (due to strokes), Lewy Body disease, head trauma, fronto-temporal dementia, Creutzfeldt-Jakob disease, Parkinson’s disease, and Huntington’s disease. These conditions can have similar and overlapping symptoms.

Alzheimer’s disease is the most common cause of dementia. **“**Itaccounts for an estimated 60 to 80 percent of cases and in most people with the disease, those with the late-onset type symptoms first appear in their mid-60s" (Aging, 2017). The proportion of ethnic minorities among the elderly in the United States is increasing. The population of Hispanic elders is expected to double in 2010 and will be 11 times greater by 2050. Of the 80.1 million elderlies projected for 2050, 8.4 million (10.4 percent) will be black, as compared to 8 percent of elders in 1990” (Norman B. Anderson, 2004). With these changes, ethnic minority populations will bear an increased share of the economic and social burden associated with diseases that predominantly affect the elderly, such as Alzheimer's disease (AD). This presents the potential for a major public health issue because ethnic minorities may be at higher risk for AD and dementia than non-Hispanic whites (Norman B. Anderson, 2004). Sex and gender differences have been noted in prevalence, clinical manifestation, disease course, and prognosis. “The incidence of the disease is higher in women than in men, data from the Framingham Study, which enrolled a total of 2611 cognitively intact participants (1550 women and 1061 men) and followed up on many for 20 years, indicated that for a 65-year-old man, remaining lifetime risk of AD was 6.3% and remaining lifetime risk of developing any dementing illness was 10.9% ,corresponding risks for a 65-year-old woman were 12% and 19% ,almost twice that of men” (Podcasy & Epperson, 2016).

The most common early symptom of Alzheimer's is difficulty remembering newly learned information because Alzheimer's changes typically begin in the part of the brain that affects learning. As Alzheimer's advances, it leads to increasingly severe symptoms, including disorientation, mood, and behavior changes; deepening confusion about events, time, and place; unfounded suspicions about family, friends, and professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing, and walking. The brain Changesincludedeposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) (alz.org).

Behavior changes in patients with dementia due to various underlying diseases include:

* **RESTLENESS –** People with dementia are prone to developing many restless behaviors such as agitation, pacing and fidgeting. This behavior can be difficult for caregivers to deal with as it can take many forms and can be very tiring. There are multiple causes that can lead to restlessness in patients with dementia such as pain or discomfort, depression, side effects of medication, hunger, thirst, anxiety or boredom and communication problems.
* **REPITITIVE BEHAVIOR –** Patients with dementia often repeatedly do same activities, gestures, ask the same question or say same things over and over again. This can be exhausting for caregivers, who might become irritated and frustrated. Patients with dementia in turn may also become frustrated if their questions are not answered and they are left feeling anxious and insecure.
* **SHOUTING AND SCREAMING –** Patients with dementia may scream, shout, or use abusive language sometimes due to various reasons such as pain or discomfort, communication problems, response to a hallucination or an unsupportive environment. All these behavioral displays can prove to be very distressing for caregivers.
* **WALKING –** Patients with dementia tend to walk more in order to relieve boredom or anxiety, revisiting a past habit or due to confusion. This can be very stressful for caregivers if the patient with dementia stays out for long periods of time or leaves the home unexpectedly.
* **SLEEP DISTURBANCES –** Disturbance in sleeping patterns is very common in patients with dementia. They may get up repeatedly during the night and may be disorientated when they are awake. This disturbance in sleep pattern might make the person tired during the day leading to sleeping for long periods during day time and being awake at night.
* **SUNDOWNING –** Patients with dementia might exhibit certain behaviors at late afternoon or early evening such as agitation, aggression, or confusion. This pattern is called sundowning. This can happen due to number of reasons such as loss of routine at a previously busy time of day, too little or disturbed sleep or medications that worsen confusion and agitation.
* **HIDING, HOARDING AND LOSING THINGS –** Patients with dementia may hide, hoard, or lose things as an attempt to remain in control of their situation or they might be experiencing paranoia leading them to believe that their items might get stolen. This can be very frustrating for the caregivers who might have to spend lot of time trying to find lost things. (society, 2014)

## PUBLIC HEALTH RELEVANCE

Dementia is a syndrome that affects memory, thinking, behavior and ability to perform everyday activities. The number of people living with dementia worldwide is currently estimated at 35.6 million. This number will double by 2030 and more than triple by 2050. Dementia is overwhelming not only for the people who have it, but also for their caregivers and families. There is lack of awareness and understanding of dementia in most countries, resulting in stigmatization, barriers to diagnosis and care, and impacting caregivers, families, and societies physically, psychologically, and economically (International, 2012).

Due to the complexity of the disease, these patients are often admitted to the hospital for clinical care while traditional hospital processes and clinical interventions alone may not meet their needs. While every patient has unique needs, this population often requires direct non-clinical support including cueing and reminders to eat, to drink, and toileting. Patients with dementia like most older adults benefit from social engagement, redirection, and emotional support and they may require encouragement to walk and exercise so that they do not lose the ability to walk and move from one place to another.

When it comes to taking care of patients with dementia, the normal rules do not apply, and all the healthcare professionals need proper training and guidance to learn to support, motivate, and keep patients with dementia safe. Professional caregivers and the caregivers in the family both report that the need for training in dementia care to make their lives easier and enabling them to take better care of patients with dementia. (Powell, 2016)

“There is a need both to challenge poor practice and for positive development work with

healthcare professionals who work in acute hospitals with people with dementia and cognitive impairment so that they are equipped with the skills, emotional resilience, and organizational support to be effective in meeting the needs of people with dementia and cognitive impairment” (Philip Clissett, 2013).

## PROBLEM STATEMENT

In general, the care that dementia patients need is very different than the care they typically receive. On a busy nursing unit, dementia patients are often left in their rooms alone for long periods of time and often encouraged to stay in bed, because they may be a fall risk or are prone to wandering. A dementia patient in this environment can easily become agitated, which can be perceived as disruptive, aggressive, or difficult.

There is an opportunity to care for these patients in a way that better supports their physical and emotional needs. Physicians should see a more comprehensive and realistic picture of the patients, and so they can more easily implement a treatment plan to address the patients’ full range of needs, rather than addressing the complications that may have arisen during the patient stay from being in an environment not tailored to unique needs of dementia patients. Preventing complications would also decrease length of stay. Providing facilities and services more tailored to the needs of these patients should give more confidence to immediate caregivers such as nurses, nurse assistants and family members in providing care and support to patients with dementia.

# LITERATURE REVIEW

## Prevalence of Dementia

Dementia is a disease of concern because the decline in memory and other cognitive functions that characterizes this condition also leads to a loss of independent function that has a wide-ranging impact on individuals, families, and healthcare systems. Accurate national estimates of the current and future prevalence of dementia are essential for effective planning for the long-term care and medical costs that will fall to the Social Security, Medicare, and other insurance programs for elderly adults in the USA (B.L. Plassman, 2007).

According to WHO, the number of people living with dementia worldwide currently as of 2017 is estimated at 47 million and is projected to increase to 75 million by 2030. The number of cases of dementia are estimated to almost triple by 2050 (WHO, 2017). “The elderly population (those aged 65 years or older) in the USA is expected to double from approximately 35 million today to more than 70 million by 2030. With this rapid growth in the number of older Americans, prevention, and treatment of chronic diseases of aging will take on growing importance” (B.L. Plassman, 2007).

According to the study “Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study”, composed of 856 individuals aged 71 years and older evaluated for dementia using a comprehensive in-home assessment, the prevalence of dementia among individuals aged 71 and older was 13.9%, comprising about 3.4 million individuals in the USA in 2002. The corresponding values for Alzheimer’s disease (AD) were 9.7% and 2.4 million individuals. Dementia prevalence increased with age, from 5.0% of those aged 71–79 years to 37.4% of those aged 90 and older. The national prevalence of Alzheimer’s disease, Vascular dementia and all dementia increased with age, reaching 37.4% dementia prevalence among individuals aged 90 and older (B.L. Plassman, 2007).

Overall, Alzheimer’s disease accounted for approximately 69.9% of all dementia, while Vascular dementia accounted for 17.4%. Other types of dementia such as ‘dementia, undetermined etiology’, Parkinson's dementia, normal-pressure hydrocephalus, frontal lobe dementia, alcoholic dementia, traumatic brain injury and Lewy body dementia accounted for the remaining 12.7% of cases. With increasing age, AD accounted for progressively more of the dementia cases so that in the age 90+ group, AD accounted for 79.5% of the dementia cases compared to 46.7% among those aged 71–79 years (B.L. Plassman, 2007).

## Gaps in Care/Current Dementia Care

Healthcare professionals in acute settings are not always prepared to care for patients with dementia. They may lack both confidence and competence and have insufficient knowledge and skills in dementia care. Studies have reported that hospital environments and organizational structures are not dementia friendly and are inappropriate for patients with dementia. It has been shown that cultures of care in acute settings predominantly focus on safety and physical care and that following ward routines is usually prioritized over meeting individual patients’ needs. Hospitals are described as “systems under pressure” with insufficient time to provide optimal care for dementia patients. Thus, the capacity of staff in acute settings is a factor that limits the provision of appropriate care to dementia patients as they often represent a disruption of the hospital routine. (Christiane Pinkert, 2007)

The study “Caring for older people with dementia in hospital. Part one: challenges” was conducted on four focus groups to explore adult nursing students' experiences of caring for older people with dementia in hospital. This study findings highlighted the shortcomings in hospital care for people with dementia. Areas of concern include person-centered care, eating and drinking, social interaction, and dignity and respect. The Royal College of Psychiatrists’ audit found continuing problems, including insufficient training of staff and an impersonal environment that was not conducive to the needs of people with dementia. “The hospital's physical environment and organizational culture, deficits in the knowledge and skills of staff and students, and negative staff attitudes led to students struggling to provide care” (Baillie Lesley, 2012). Patients with dementia have complex needs that they usually do not express concretely and their unmet needs in acute hospitals often lead to problematic and challenging patient behaviors. Thus, for many dementia patients, a hospital stay has negative consequences. They have longer hospital stays and are at higher risk of functional decline during hospitalization (Christiane Pinkert, 2007).Inappropriateness of the hospital environment, and deficits in the knowledge, skills and attitudes of staff and students, lead to a struggle to provide care, particularly related to nutrition, mobility, and emotional needs and communication (Baillie Lesley, 2012).

The physical environment and organizational culture are perceived to be inappropriate for caring for older people with dementia. In one of the studies, students described how patients could not walk freely and safely in the hospital environment. There was also a lack of social space with limited opportunities for interaction and activities. There was nothing for dementia patients to do, when clearly, they needed something to stimulate them (Baillie Lesley, 2012). The organizational culture affected how people with dementia were treated. One of the nurses felt that dementia patients were not treated with respect or dignity possibly because of the lack of understanding and the time constraints, because wards are very busy environments and people with dementia often require considerable time to provide responsive care. Spending extended time with patients clashed with an organizational culture that valued speed as time was prioritized in favor of acutely ill patients (Baillie Lesley, 2012).

Staff sometimes failed to see the patient with dementia as a whole person as lack of knowledge about dementia apparently affected attitudes of the nurses because they felt out of their depth trying to provide care to patients with dementia. In some wards patients with dementia were treated as second class citizens and staff were unwilling to accept confused patients because of the extra workload. The main challenging areas were: nutrition, mobility, and emotional needs and communication. Helping patients with dementia to eat often takes time and patience, which is sometimes lacking. The nursing staff struggles to ensure that patients with dementia have enough to eat and drink. It’s difficult to feed some patients when they are sitting with their mouth closed refusing to eat and sometimes dementia patients fear that they are being poisoned. At mealtimes, patients with dementia are sometimes left until last to be helped because they take longer time to eat and by the time their turn comes the food is cold (Baillie Lesley, 2012).

Staff experienced difficulties in managing patients with dementia ambulating the ward, because of concerns about safety and falls. Patients were continually asked to return to their beds. Safety concerns meant the open nature of acute hospital wards was problematic for people with dementia who wished to walk around as the doors are open and people with dementia need to be monitored and if they will leave the ward, they must be accompanied by staff or family member. need to have somebody with them. Providing additional time for patients with dementia was often lacking because the emphasis was on the patient’s physical condition whereas it was the emotional support and responsiveness that were needed. Staff experienced difficulties in communicating with patients whose behavior was aggressive, anxious, or agitated (Baillie Lesley, 2012) .

Older people with dementia are often admitted to acute hospital wards for a range of reasons but the hospital environment and organizational culture may not be conducive to their care. The care environment is important for the development of person-centered relationships and hospitals were often not conducive to the needs of people with dementia, impersonal, disorientating and lacked areas for socializing. Some staff lacked the necessary knowledge, skills and attitudes to provide person-centered care for patients with dementia, leading to negative attitudes, which were reinforced by an organizational ethos that valued specialist, acute and physically orientated care (Baillie Lesley, 2012).

## Issues Faced by Caregivers (Nurses)

Dementia is a major public health problem. More and more patients with dementia are being admitted to acute care hospitals for treatment of comorbidities. Issues associated with care of patients with dementia in acute care hospitals have not been adequately clarified. Nurses in acute care hospitals may be unable to provide care adequate to meet the needs of patients with dementia. Nurses’ experience in caring for people with dementia in acute hospitals is characterized by frustration, overall job dissatisfaction and feelings of powerlessness and guilt. Despite a growing body of knowledge concerning the care of people with dementia in acute care settings, it remains unclear how nurses in acute hospitals provide care for people with dementia and what general conditions characterize the nursing care provided to these patients (Christiane Pinkert, 2007).

The case study “Issues experienced while administering care to patients with dementia in acute care hospitals: a study based on focus group interviews” was conducted in Japan. This was a qualitative study using focus group interviews in six acute in the western region of Japan and the participants were nurses in surgical and internal medicine wards. According to this study nurses in Japan face similar issues taking care of hospitalized dementia patients. The issues that nurses face in relation to dementia care, including responsibility for patients, frustrations with regard to time, frustrations with regard to lack of organization, divided tasks, and working alone. The various problems and difficulties faced by nurses were interactive and caused a burdensome cycle, and nurses did their best to adapt to these conditions despite feeling conflicted. (Risa Fukuda, 2015)

The nurses in this study indicated difficulties cooperating with nurses in other wards and frustration at having to use coercion or restraint while caring for patients with dementia. Nolan

described structural inadequacies of acute care hospitals as a setting for dementia care, nursing staff frustration due to limitations on care imposed by structural inadequacies, and complications from the continually changing needs of people with dementia. Furthermore, Borbasi, Jones, Lockwood, and Emden clarified that time pressure, overwork, lack of resources, and lack of knowledge/understanding of dementia health care professionals (Risa Fukuda, 2015).

Previous Japanese studies have revealed that nurses had difficulties accepting dementia patients and their situations. The tensions associated with routine work with these patients, conflicts with their families, and treatments unique to dementia care were all challenging; the nurses feared the increased accident risk and spent more time administering care only to patients with dementia. Problematic patient behavior affects many individuals, including the families and hospital roommates of patients with dementia. Therefore, families and hospital roommates may also require nursing care for fear, anxiety, and frustration related to the problematic behavior of patients with dementia (Risa Fukuda, 2015).

The findings show that nurses face great uncertainty in caring for people with dementia in acute hospital settings and that each nurse reacts in different ways to address this uncertainty. The results also underline that, even for nurses who provide some form of person-centered care, the hospital environment imposes several contextual constraints. Hospitals must minimize constraints to give every nurse the chance to perform person-centered care. Furthermore, it is important to sensitize nurses and give them sufficient training and education to enable them to care for people with dementia (Christiane Pinkert, 2007).

There is evidence to suggest that specialist wards for patients with dementia can benefit patients, caregivers, and staff. It is recommended that universities ensure that nursing students are well prepared and supported throughout their pre-registration education to nurture confidence and positive attitudes towards caring for people with dementia in any setting (Baillie Lesley, 2012)

I searched the literature specific to the implementation of dementia care rooms in hospital settings but except for The University Hospital in Heidelberg, Germany which created a dementia unit dementia room within hospital settings, I was unable to find literature that addresses this model of care.

This case study conducted by me is an observational case study and the methodology included discussion with key informants and analysis of the data. This was one of the projects that I worked on during my residency at Wolff Center of UPMC. This project is a collaborative quality improvement initiative by Wolff Center of UPMC and UPMC Mercy hospital. The analysis included analyzing the survey conducted to assess the satisfaction and confidence of nursing staff in taking care of patients with dementia before and after the implementation of the Dementia Activity Room. Patient data was analyzed to assess the difference in various clinical parameters of patients with dementia who went to the activity room and the ones who did not. Some of the limitations of this study were not having more sophisticated or refined methods to assess the average food intake (lunch and dinner) and the severity of agitation of the patients with dementia. People involved with this project are also trying to come up with methods to analyze sleep patterns of patients with dementia in order to assess if the patients who spend the day in the activity room had a better sleep cycle or pattern as compared to the patients with dementia who did not go to the room.

# DEMENTIA ACTIVITY ROOM

## Design and Implementation of the room

The Dementia Activity Room was started as collaboration between Wolff Center of UPMC and UPMC Mercy on unit 10E. It evolved into multidisciplinary team-based effort including geriatric medicine, nursing, pharmacy, occupational therapy, transport, school of nursing, and others. The Dementia Activity Room is located at UPMC Mercy on unit 10E, a medicine progressive care unit and it has a beautiful view of the river and the bridges. The room is full of natural light having three windows and is comfortable and well decorated. The room has one common table for patients to sit around and engage in conversation and different activities. The grant to design this room at UPMC Mercy hospital was given by Beckwith Institute. A semi-private room was converted into multi-purpose activities room for the dementia patients. The timeline of the room since it opened:

* The room opened on 11-21-2016, Monday-Friday from 10am-6:30 pm. Initially, all patients were encouraged to stay in the room for the entirety of the day.
* From 1-4-2017 the room changed to an AM session and a PM session and nurses were given guidelines on criteria and on best types of patients for AM session vs. PM session.
* From 3-20-2017 hours of the room changed to 11am to 7pm.
* From 6-9-2017 the room started opening on Saturdays from 11am to 3pm.
* From 7-14-2017 the transport personnel started bringing patients to the room. Nurses used to do this before

The room now operates from 11am- 7pm from Monday to Friday and 11am- 3pm on Saturday and Sunday for morning and evening sessions. The nurses make daily determination of which patients will go to the Dementia Activity Room. The room is staffed with a care attendant (sitter) and a volunteer.

This is the first room of its kind for dementia patients in inpatient setting at UPMC. In the planning for the initial implementation, many ideas were borrowed from similar settings in the long-term care facilities. There is an activities room for traumatic brain injury patients at Mercy, who face similar risks if left alone in their rooms. In my research, I didn’t find any dementia rooms or rooms based on similar concept in inpatient hospitals settings with one exception of dementia room at The University Hospital in Heidelberg, Germany. The University Hospital in Heidelberg, Germany created a dementia unit dementia room within hospital settings with environmental features allowing for safe and unrestricted ambulation through the unit and the creation of a home like atmosphere.

Patients who come to the room are those who suffer from dementia or other cognitive impairments. Age is no bar for the patients to visit the room provided they don’t have any communicable infections. The patients for the morning and evening shifts are determined by the nurses on daily basis based on their sleeping pattern. The dementia patients who spend all day sitting in bed or sleeping are encouraged to visit the room during morning sessions while the patients who have trouble sleeping at night are preferred for evening sessions.

The Dementia Activity Room provides a dementia friendly environment where patients with dementia go during the day and are encouraged to engage in activities to provide cognitive stimulation, feeling of engagement, enjoyment, self-care, and healing. Some of the activities include crafts, music, games, conversation starters, manicures, tactile activities, flower arranging, etc.

Specific goals of the DAR include:

1. Promoting well-being through fun and meaningful activities

2. Preventing agitation and aggression

3. Promoting nutrition and hydration

4. Preventing complications and loss of functional status.

Some of the other ideas behind the room are to reduce length of stay of dementia patients, to reduce wandering and incidents of fall. The idea is to prevent these patients from experiencing loss in functional status that often occurs in dementia patients during the hospital stay. Also, by encouraging families to help design meaningful activities, families now feel more confident in the care of their loved ones.

In this room, patients are monitored and attended to by nursing assistants who are able to give them the attention and the focus that they need to promote overall well-being. Not only does the extra attention enhance patient safety and satisfaction, it also marks a more cost-effective use of staff as one person can take of many dementia patients simultaneously. It also leads to increased nursing staff satisfaction because nurses now know that these patients are receiving the attention that they are unable to provide in a five-patient assignment.

## Clinical Outcomes

The analysis for clinical outcomes was initially done on patients with dementia above the age of 65 and later on the patients with dementia above the age of 80. Among the patients with dementia who visited the Dementia Activity Room, those above the age of 80 showed significantly better results as compared to the patients above 65 in the terms of average length of stay, food intake, agitation score, discharge disposition and medication intake.

The patients who were initially considered for the analysis were selected based on age (>65) and history/diagnosis of dementia, delirium and AMS (Altered Mental Status). More than three hundred patients used the room in first nine months and the group who benefited the most from the room are 80 years and older.

A comparative analysis was done between dementia patients who went to the room (DAR patients) and the dementia patients who did not (non-DAR patients). The idea was to make an assessment based on various parameters whether the dementia patients who went to the room had better clinical outcomes as compared to those who did not go to the Dementia Activity Room.

The initial sample was patients age 65 and older. And the clinical criteria selected were:

1. Average length of stay
2. Discharge disposition
3. Average lunch and dinner intake
4. Severity of Agitation

The analysis didn’t show any significant clinical evidence that dementia patients who were going to the room were being benefited more clinically as compared to the patients who didn’t go to the room. The average length of stay for DAR patients was 5.66 days and for non- DAR patients was 5.33 days. DAR patients that were discharged to home were 12.5% and 11.83% non-DAR patients were discharged to home. Average lunch intake for DAR patients was 58.08% and for non- DAR patients was 57.79%. Average diner intake for DAR patients was 61.65% and for non- DAR patients was 57.28%. The severity of agitation in the DAR patients was none (65.63%), mild/moderate (21.12%) and severe (6.25%). The severity of agitation in the non- DAR patients was none (75.27%), mild/moderate (17.20%) and severe (7.53%).

Later, the sample of patients above the age of 80 was taken for analysis and this showed better results. And some additional criteria were included:

1. Average length of stay

2. Discharge disposition

3. Average lunch and dinner intake

4. Severity of Agitation

5. Antipsychotics usage

6. Pain medications usage

The average length of stay for DAR patients was 4.6 days and for non- DAR patients was 4.9 days. 54% of DAR patients were discharged to home and 42% non- DAR patients were discharged to home. Average lunch intake for DAR patients was 60% and for No DAR patients was 57%. Average diner intake for DAR patients was 59% and for non-DAR patients was 53%. The severity of agitation in the DAR patients was 43% and in non-DAR patients was 33%. Percentage of DAR patients and non- DAR patients used antipsychotic medication was 41% but the dose/patients/day was lower for DAR patients as compared to non-DAR patients. DAR patients that used pain medication were 2& and 18% non- DAR patients used pain medication. Additionally, weight loss of more than one kilogram during admission was seen in 33% of DAR patients and 75% in non-DAR patients.

## Nurse Satisfaction

A survey was conducted to assess the satisfaction and confidence of nursing staff in taking care of the dementia patients pre and post Dementia Activity Room. This survey showed very significant positive shift in the confidence and satisfaction of the nursing staff post Dementia Activity Room.

When asked if they were confident in their unit’s ability to prevent falls in patients with dementia, 58.33% agreed or strongly agreed pre-DAR and 78.95% agreed or strongly agreed post-DAR. When asked about the confident in their unit’s ability to make sure patients with dementia have the support they need at meals, 29.17% agreed or strongly agreed pre-DAR and 57.9% agreed or strongly agreed post-DAR.

Pre-DAR 20.83% nurses and 48.63% nurses post-DAR felt confident in their unit’s ability to make sure patients with dementia get enough to drink during the day. Pre-DAR 63.50% of nurses and post-DAR 73.68% nurses worried that something bad will happen to the dementia patients when they are left alone in their rooms.

Their confidence in processes to keep dementia patients calm, safe and cognitively stimulated increased significantly post implementation of the Dementia Activity Room. Pre-DAR 41.66% nurses felt that their processes on this unit did a good job of keeping dementia patients safe whereas the number increased to 73.86% post the implementation of DAR. Their confidence in processes on this unit do a good job of keeping dementia patients calm at all times increased from 33.34% to 57.90% post- DAR. Their confidence in processes on this unit do a good job of keeping dementia patients cognitively stimulated at all times showed the most significant increase from 8.33% to 84.21% post- DAR. When asked if they had a loved one with dementia, would they feel confident that they would be kept safe on 10E, 45.83% agreed pre-DAR and 73.69% agreed post-DAR.

***Few of the comments from the nurses post-DAR are quoted below:***

“I believe stimulation and care taker interaction during daylight hours is very important for our dementia patient's nutrition, cognition, safety and overall well-being. 10E's DAR enables us to provide this to a much greater extent than was possible prior to its opening.”

“Many of our patients have benefited from the dementia activities room, as well as many of our staff. It is a safe place for them to go and I often find they are calmer once the day is through.”

“I have found that the dementia room has been very helpful with restless patients in their rooms. It provides them opportunities to be cognitively stimulated and interactive. I also have found that they sleep better at night and rest which then gives them more energy the next day which is just a good cycle to continue.”

“So many patient's families state that they enjoy the DAR and will request to come to 10E on their loved one's next admission.”

“It is extremely helpful to have extra staff and also the help with bathing and feeding.”

“Expand it to patients who are just anxious and bored of sitting in their rooms.”

“I would not feel confident in safety if they were left in their room all day alone. I would feel very confident if I knew they were in a room interacting with other people and keeping more of a normal schedule and environment.

From the feedback that the nurses got for the patients and the family members, the nurses felt that both patients and their family members were happy and satisfied with the DAR. According to nurses one of the patient’s family member though that the special attention and care that the patients were receiving in the DAR was spectacular and hoped that this program continues to grow. Many patients as reported by the nurses were really happy to spend time in the DAR as they enjoyed the view of the room and the activities in the room. Many of the patients’ family members had positive things to say about the room such as they feel better about the care being received and they were happy that the patients were up and about instead of sitting in their rooms all day long.

# CONCLUSION

A dementia activities room is a way to truly change the paradigm of how we care for this population in the hospital. This approach allows us to care for these patients differently in a way that meets their unique needs. They are not the same as everyone else and should not be treated that way. The approach marks a shift from the traditional medical model and marks a more social/emotional approach – we need to actively look for ways to engage the patients’ hearts, minds, and cognitive abilities. By shifting the focus to this approach, we can have positive impacts on patient outcomes.

This project has helped me learn and explore a lot about the issues faced by patients with dementia and the caregivers both professional and family members. I understood the magnitude of the problems involved in providing adequate care to the patients with dementia in hospital settings. Majority of the problems are faced by nursing staff who despite their best efforts are not able to provide needed care due to lack of training, organizational structure, and facilities. The issue is not limited the kind of care patients with dementia receive during hospital stay but it is much deeper than that in the terms of consequences due to inadequate care. The lack of required care in hospitals can be translated to increased risk of complications, additional financial burden, and deterioration of the health status of patients with dementia.

According to me the Dementia Activity Room is a great initiative of going beyond the clinical and pharmacological interventions while taking care of patients with dementia. This room is modelled after the care provided in long term facilities and it should not be that difficult to replicate this model into hospital settings.

# RECOMMENDATIONS

Based on my findings, analysis and observation of care providers I came up with following recommendations:

* Implement a better system for getting the patients to the dementia activities room. Currently the nurses bring the patients down to the room, but they have so many tasks at the mid-morning time that opening the room and getting patients there is not their highest priority. When the care attendant is bringing the patients to the room, they can only bring one patient at a time and then they must stay there with him. So, it would be good to have designated personnel and a more systematic and defined process of bringing patients to the DAR
* As mentioned before, the activities in the room include crafts, music, games conversation starters, manicures, flower arrangement, etc. We would like to extend the concept of activities to more “real life” meaningful activities as many of the participants would like to do painting, cooking, baking, etc. “Cognitively stimulating activities like reading, drawing, making music, and playing chess or bridge, may, by enhancing cognitive reserve, constitute a promising alternative to preventing cognitive decline via standardized cognitive trainings” (Valentina Tesky, 2012).  It has been found that keeping patients with dementia active in hobbies and interests that gave them pleasure in the past help in stirring memories, fostering emotional connection with others, encourages self-expression, and lessens anxiety and irritability. Some of the general activities suggested for patients with dementia (at home, long-term care facilities, hospitals) are singing songs, listening to music, painting, knitting, gardening, cooking, baking, etc. (Wegerer, 2017)
* Keep the room open overnight for the patients who have trouble sleeping at night. If the room is kept open overnight, the patients with dementia who have trouble sleeping at night can find something engaging to do rather than just sitting in bed. One facility practicing this concept for sleep disturbed seniors is Hebrew Home at Riverdale, New York. Caregivers of people with dementia often experience chronic sleep deprivation because their loved ones suffer from a condition known as sundowner's syndrome which is manifested as anxiety, anger, fear, hallucinations, and paranoia. (Botek) “The disruptive sleep patterns of a senior with sundowner's can be similar to those of an infant who is reverse cycling” (Botek). The night care program was created in response to one common caregiver issue- debilitating lack of sleep. Come up with better ways to measure sleep as currently there is no formal way to evaluate the sleep.
* Training nurses to enable them to take better care of patients with dementia. Patient with [dementia](http://go.galegroup.com/ps/i.do?p=AONE&u=upitt_main&id=GALE|A228508984&v=2.1&it=r&sid=summon) do not receive the best care in the hospitals because [nurses](http://go.galegroup.com/ps/i.do?p=AONE&u=upitt_main&id=GALE|A228508984&v=2.1&it=r&sid=summon) lack the training to do so. Lack of knowledge about dementia affects attitudes as the caregivers as they feel out of their depth trying to provide care to patients with dementia. There is a need for training and awareness education to help all nurses deal with the 25 per cent of hospital patients over the age of 65 who have the disease (Blakemore, 2010).
* Collaborate with daycare at UPMC Mercy for some intergenerational program. Participation in intergenerational programs can have a positive impact on quality of life and well-being in patients with dementia. Over time, there has been growing interest in bringing the younger and older generations together with intergenerational programs, especially in the field of dementia care. Intergenerational programs can have a positive impact on children and older adults’ well-being and perceptions of one another. Intergenerational programs provide a structured and secure environment for purposeful and meaningful exchange to take place between older adults and children (Bethany Galbraith, 2015).
* Provide more opportunities for pet therapy sessions. Pets in dementia communities are becoming commonplace with some facilities hiring pet coordinators to aid in the care of residents’ pets. While companionship is an obvious benefit of pet therapy sessions, a well-timed pet visit may also [help with anxiety](https://www.alzheimers.net/11-24-14-anxiety-increase-cognitive-decline) and depression in patients with dementia. There is some transition from emotionless to joyful when a pet enters the room, especially if it triggers pleasant memories (Napoletan, 2017).  “Pet therapy is efficient in improving depressive symptoms and cognitive function in residents of long‐term care facilities with mental illness” (ATTI, 2010).
* Expand the dementia activity room to other units of the hospital. The goal in near future is to expand the DAR to other units of UPMC Mercy. There have been instances where physicians from other units wanted the patients to unit 10 E, so that they to visit and avail benefits of DAR. There has been a debate whether to have one big DAR for all the patients with dementia in the hospital, but I feel that it would be better to set up a separate DAR for all units, at least medical units to begin with in the hospital.

**APPENDIX: CHARTS**



Figure 1. Clinical Outcomes - DAR Patients (65 and older)



Figure 2. Clinical Outcomes - non-DAR Patients (65 and older)

Table 1. Clinical Outcomes - DAR Patients (80 and older)

|  |  |  |  |
| --- | --- | --- | --- |
| ALOS for DAR | 4.69 |  |  |
| Discharge disposition | Count | Average LOS | % |
| Home (home, family, ALF, PCH) | 15 | 3.12 | 27% |
| Home care | 15 | 4.25 | 27% |
| SNF | 25 | 5.63 | 45% |
| IPR | 0 | N/A | 0% |
| Acute transfer | 0 | N/A | 0% |
| Hospice | 1 | 11.52 | 2% |
|  |  |  |  |
| Avg lunch intake | 60% |  |  |
| Avg dinner intake | 59% |  |  |
|  |  |  |  |
| Agitation | 24 | 43% |  |
|  |  |  |  |
| Meds (doses per pt per day) | # of patients | doses/pt/day | % of pts |
| Average pain med dosage | 1 | 0.25 | 2% |
| Average delirium med dosage | 23 | 0.47 | 41% |
|  |  |  |  |
| Agitation |  |  |  |

Table 2. Clinical Outcomes – non-DAR Patients (80 and older)



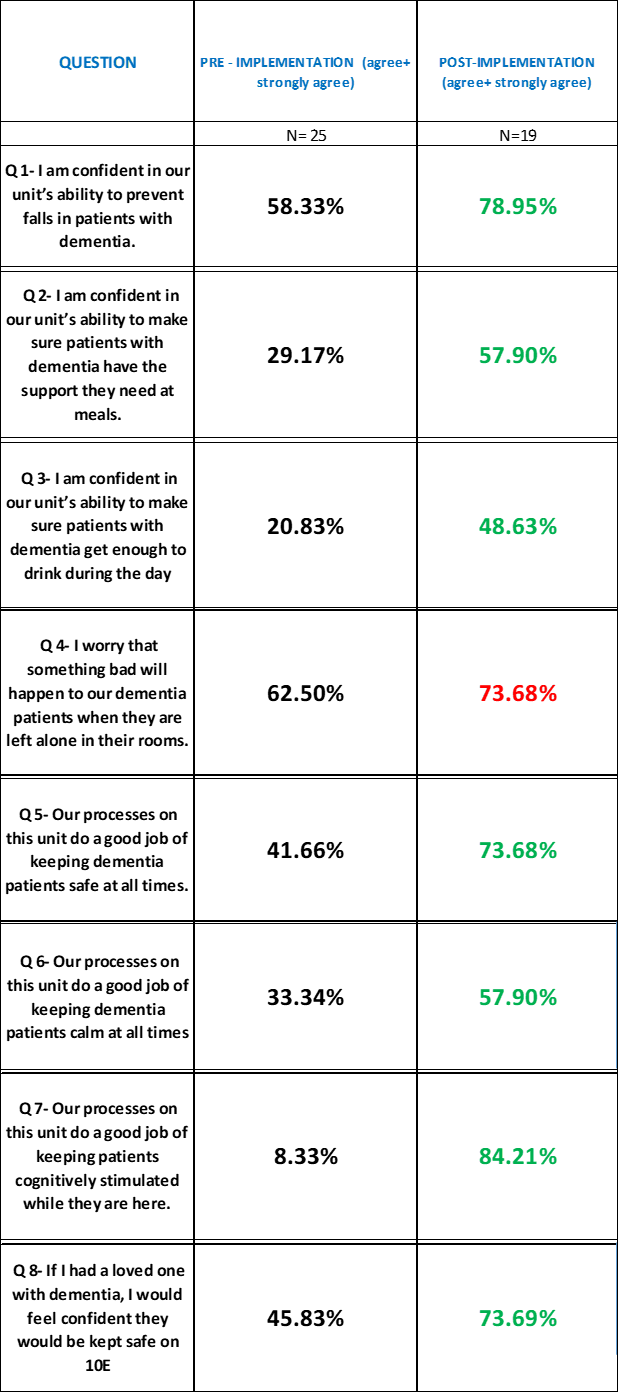


Figure 3. Nursing Satisfaction/Perception of Dementia Care Outcomes

# bibliography

Aging, N. I. (2017). *What Is Alzheimer's Disease.* alz.org. (n.d.). *Alzheimer's & Dementia.* Alzheimer's Association.

Atti, F. M. (2010). Pet therapy in elderly patients with mental illness. *Journal of Japanese Psychogeriatric Society*.

Baillie Lesley, C. J. (2012). Caring for older people with dementia in hospital Part one: challenges. *Nursing Older People*.

Bethany Galbraith, H. L. (2015). Intergenerational Programs for Persons With Dementia: A Scoping Review. *Journal of Gerontological Social Work*, 357-378.

Blakemore, S. (2010, June). All nurses need specific training in dementia care: awareness education is vital to improve the care of hospital patients, Angela Rippon tells RCN congress. *Nursing Older People*.

Botek, A.-M. (n.d.). One-of-a-Kind Night Care Program Helps Dementia Caregivers. *Ageingcare.com*.

Christiane Pinkert, E. F. (2007). Experiences of nurses with the care of patients with dementia in acute hospitals: A secondary analysis. *Journal of Clinical Nursing*.

International, W. H. (2012). *Dementia: a public health priority.*

Napoletan, A. (2017, September 4). How Can Pets Benefit Alzheimer’s? *alzheimer's.net*.

Norman B. Anderson, R. A. B., and Barney Cohen, editors. (2004). *Critical Perspectives on Racial and Ethnic Differences in Health in Late Life*. Washington DC: National Academies Press (US).

Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., … Wallace, R. B. (2007). Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study. *Neuroepidemiology*, *29*(1-2), 125–132.

Podcasy, J. L., & Epperson, C. N. (2016). Considering sex and gender in Alzheimer disease and other dementias. *Dialogues in Clinical Neuroscience, 18*(4), 437-446.

Powell, A. (2016, October). Dementia training for caregivers: is it important? The Caregiver Space.

Risa Fukuda, Y. S. (2015). Issues experienced while administering care to patients with dementia in acute care hospitals: A study based on focus group interviews. *International Journal of Qualitative Studies on Health and Well-being*.

Society, A. (2014). Changes in Behaviour. London.

Valentina Tesky, J. P. (2012). Cognitively stimulating leisure activities: A new approach for

patients with mild cognitive impairment (MCI). *The Journal of the Alzheimer's Association*.

Wegerer, J. (2017, March 29). 10 Stimulating Activities for Alzheimer’s Patients. *alzheimer's.net*.

World Health Organization (WHO). (2017). *10 facts on dementia.*