Barriers to Patient-Centered Care for Dementia Clients in the Long-Term Living Setting

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Barriers to Patient-Centered Care for Dementia Clients in the Long-Term Living Setting

By

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Abstract

When caring for people with severe dementia, the concept of the person being central is increasingly advocated in clinical practice. Person-centered care acknowledges autonomy in all facets of care. Recent studies examine behavioral changes in individuals with dementia and how health care teams address these alterations. Health care providers are vital for effective holistic management. Therefore, this review focuses on the current knowledge regarding care goals, practices, and perceptions of the client battling with cognitive decline. A literature review ascertains that clients with dementia respond to interventions and have decreased negative health outcomes, when providers ensure values and needs are met in clinical practice. From the literature review, a qualitative pilot study was developed for future research. The qualitative phenomenological study aims to investigate the barriers that prevent health care providers from conducting patient focused care, illustrated by McCance and McCormack’s theory of patient centered approaches to nursing. The literature review and pilot study revealed how health care providers incorporate patient-centered care methods for older adults with Dementia.
Introduction

Dementia is a global issue, with increasing prevalence rates impacting health services and outcomes. According to the World Health Organization (WHO), approximately 50 million people worldwide have dementia. Older adults in long-term settings care are significantly affected by their treatment plan. While there are several initiatives that have been developed to improve quality of care, there is a lack of cohesive understanding about effective methods for the gerontologic population. Past research on patient centered care has shown challenges in attitudes and performance. The results of certain care practices such as infantilization, intimidation, stigmatization, and objectification are carried out in facilities (Clissett et al., 2012). Instead of visualizing the individual in a holistic manner, professionals stigmatize the abilities of their client.

Gradual deterioration in cognition, function, and behavior make individuals with dementia dependent on others for support with their activities of daily living. Person-centered care is widely recognized as the ideal approach for caring for people with dementia (Terada et al., 2011). However, health care teams are not grasping all opportunities or retaining knowledge about dementia from training programs into clinical practice. Implementation of person-centered approaches ensures respect of personhood despite cognitive impairment. Gerontologic nurses uphold the responsibility for recognizing deviations in behavior and determining appropriate interventions for continued care management.

Problem Statement

Dementia is a progressive disorder that impacts the cognition and mental processes of individuals. Health care providers are responsible for maintaining effective standards of care that improve the quality of life. With a growing prevalence of dementia, it is estimated to quadruple worldwide by 2041, with 81.1 million people affected (McKeown, 2010). Moreover, in long term
care settings, current practices diminish autonomy and affect the wellbeing of residents (Chenoweth et al., 2009). Integrated care approaches utilize education and staff to minimize the compromised behaviors of dementia. As health care professionals, it is critical to address personalized care in treatment plans. Family and health care provider collaboration can ameliorate perceptions surrounding individuals with dementia.

**Purpose Statement**

Therefore, the aim of the study is to investigate the efficacy of patient-centered care and current practices for individuals with dementia.

**Research Question**

The research question for this study is: How is patient-centered care utilized for clients with dementia in acute and long-term care settings?

**Literature Review**

The purpose of this project was to bring awareness of cognitive decline in older adults for health providers and to explore effective interventions to enhance personhood. The following literature review addresses information regarding patient centered care within the gerontologic community. An inquiry was conducted utilizing the key words: *dementia, patient-centered care,* and *quality of life.* To narrow down the search, the researcher combed through abstracts, pertinent information, and designs to select the main articles. Primary databases that were examined include: Google Scholar, Iceberg, and the Cochrane Library. Eight published articles were reviewed under the following subheadings: perceptions, gerontologic considerations, dementia care goals, and nursing implications.
Perceptions in Acute Settings

A repeated measures study by Surr et. al (2016) evaluated the efficacy of a specialist training program for acute hospital staff concerning improvement in attitudes, satisfaction, and emotions of caring efficacy. The sample was comprised of 40 acute hospital staff working in clinical roles, the majority of which were nurses. Patient centered care is a practice that views each person with dementia as an individual with a unique life story, attempts to comprehend the world through a different lens, and to provide a supportive social and physical environment. Dementia care in acute settings are largely task focused and delivered in an impersonal manner, which can lead to distress and longer hospital stays. The study highlights the main reasons for undesirable outcomes for people with dementia: unsupportive physical environment, unorganized ward culture, stigma and negative staff attitudes, and insufficient knowledge (Surr et. al, 2016).

The person-centered care training program for acute hospitals (PCTAH) was designed by the authors to fill in the knowledge gaps of staff training needs. Compromised of two levels of training, followed by a pre and post questionnaires were distributed after sessions. Modules focused on patient-centered care, types and impact of dementia, identification of and meeting people’s emotional needs, effective communication, and redefining supportive behaviors to meet physical health needs. A repeated measures ANOVA was performed to ascertain staff feelings in relation to attitudes and caring efficacy when working with people with dementia. However, the data violated assumptions of Mauchly’s test of Sphericity, causing an increased probability of a Type II error. An adjusted comparison of these findings demonstrated that a foundation level of training is effective in changing attitudes but does not seem to be sufficient enough to bring about change in satisfaction or caring efficacy (Surr et al., 2016).
The article, *Challenges of achieving person-centered care in acute hospitals*, by Clissett et. al (2013) explores approaches to care for older adults in acute settings. A qualitative study was conducted with twenty-nine participants over the age of seventy with cognitive impairment. Data collection consisted of observations lasting between one to two hours and interviews in patient’s homes with family caregivers. Researchers adopted a priori framework that complemented the categories of: identity, inclusion, attachment, comfort, and occupation.

A core problem that arose from the study was the admission of a confused older adult created a disruption from normal routines that impacted the client and the caregivers. Health care professionals promoted feelings of attachment and inclusion featured in accounts of good practice and missed opportunities. For instance, the continuity of staff, communication skills and recognizing meaningful relationships to the person with dementia enhanced positive outcomes. Balance between the need to complete tasks and sustain relationships with clients proved to be more important for people with dementia. Moreover, environments created venues for older adults to feel part of the ward and be involved with decision making. A hallmark of patient-centered care is that the person is valued; evidence suggested that the quality of life for people with dementia arose out of emotional ties of inclusion (Clissett et al., 2013).

Perspectives on individuals with dementia dictates holistic care approaches. Staff employed in acute hospitals report lack of knowledge, skills, and confidence in caring for people with dementia (Surr et al., 2016). Both articles reveal preconceived notions of cognitive decline in older adults and ways in which staff can disregard opportunities to engage clients in their care. Clissett (2013) asserts that preserving the identified of the individuals with dementia provides a greater sense of who they are. Both research articles, identify the stigma behind caring for older adults and methods of mitigating poor health outcomes by implementing minor changes in the
nurse-client relationship. Perception in patient-centered care varied in health care settings, and people with dementia occupy one quarter of acute hospital beds (Surr et al., 2016). Acute care for people with dementia should be designed to maintain personhood.

**Gerontologic Considerations**

Gilmore-Bykroskyi’s (2015) study, *Caregiver Person-Centeredness and Behavioral Symptoms in Nursing Home Residents with Dementia: A Timed-Event Sequential Analysis* illustrates the temporal variations of care management among clients with dementia. Motor agitation, care resistance, and repetitive actions are a few of the behavioral symptoms that can arise with dementia. As a result of these behavioral changes, distress, caregiver burden, and worsening turnover among nursing home employees ensues. The study design utilized video observations of caregiver-resident mealtime interactions between twelve nursing home residents with dementia and eight certified nursing assistants from two memory care units. Institutional Review Board Approval was obtained from the University of Wisconsin-Madison to conduct the study. Researchers utilized the validated Pittsburgh Agitation Scale tool to measure caregiver person-centeredness through tasks completion and client behavioral symptoms. This article provided insight on the behavioral domains of individuals with dementia if care is not managed. Aggression was noted as threatening gestures, while resisting care was observed as pushing away and avoidance (Gilmore-Bykroskyi et al., 2015).

Significant findings from the research revealed that particular task-centered actions may serve as antecedents to undesirable behaviors. Caregiving is often dominated by routines and completion of orders, causing undermining of a resident’s preferences, goals, or status. Compromising and dismissive behaviors from caregivers decreases responsiveness and limits effective care for the older adult. However, findings suggested that the more immediate influence
of caregiver actions on adverse symptomology is somewhat delayed due to variations in the onset of caregiver events or resident response to stimuli (avoidance (Gilmore-Bykroskyi et al., 2015).

Similarly, *Person-centered care and quality of life of patients with dementia in long-term care facilities* by Terada (2013) evaluated quality of life of elderly patients in geriatric health service facilities and hospitals. Researches aimed to elucidate patient center care among patients with dementia. Common aspects of person-centered care include: striving to maintain personhood despite cognitive ability, collecting and applying personal experiences of life and relationships, involving family members, and offering shared decision making. Therefore, care for people with cognitive loss is a process dependent on social psychology and pathological process (Terada et al., 2013).

The relationship of staff-rated quality of life measures to resident characteristics varied by the care setting. Analysis determined that the quality of life ratings by nursing assistants in long-term care facilities are related to their own attitudes towards clients with dementia and their own knowledge to address care needs (Terada et al., 2013). In a hospital setting, the person-centered scores correlated with cognition and activities of daily living status. This finding suggests a lack of systemic person-centered care approach in hospitals. A limitation of the study was the quality of life data was higher in which staff members had a positive affect and interaction with clients they worked closely with. Nonetheless, dementia focused care and quality of life are interrelated.

Person-centered care employed by health care teams is integral in comprehending the baseline of care that is currently being delivered. Both articles complement each other by highlighting adverse behavioral symptoms that are inevitable in dementia. Health care professionals establish a rapport with their clients and implement patient-centered care that is
effective as seen in Terada et. al’s study. The gerontologic community bolsters autonomy and evidence-based practice to preserve the functional status of the aging adult.

**Dementia Care Goals**

In the qualitative study, *Patient and Caregiver Goals for Dementia Care* by Jennings et al. (2017), researchers formulated focus groups to identify various concerns and intentions for health performance. Among the objectives discussed, each was classified within five domains: medical care, physical quality of life, social and emotional quality of life, access to services and supports, and caregiver support. Five focus groups with forty-three participants were included. This research article is valuable in comprehending the gaps in dementia care and what those desired to achieve despite their prognosis.

Dementia is a disorder in which all decisions need to be considered within the progression of the disease, the aims and preferences, and the potential alternatives to achieve them. In regards to medical care, participants yearned to receive high quality dementia care while limiting burdensome care near the end of life. Moreover, early-stage dementia individuals emphasized the significance of sustaining physical functioning and engaging in meaningful activity (Jennings et al., 2017).

As the disease progressed older adults plan to live at home. However, caregivers were concerned over safety, affordability, and autonomy of their loved one to make decisions. Furthermore, caretakers expressed growing concerns over fraud and financial abuse. Accessing services and support over legal affairs and managing stress due to responsibilities poses as other issues when caring for individuals with dementia (Jennings et al., 2017). Minimizing conflict and controlling external factors, ameliorates the cognitive decline that infiltrates all aspects of health. Thus, solidifying goals that people with dementia and their caregivers establish expectations and
methods on attainment. Early identification of needs enables professionals to apply patient-centered care for older adults with dementia.

A qualitative study, *Patient-centred care training needs of health care assistants who provides care for people with dementia* by Foster et al. (2018) described the care responsibilities in geriatrics. The aim of the research was to explore whether the education health care assistants received related to working with people with dementia equipped them with necessary skills to conduct patient-centered care. In order to garner a broader scope of practice, researchers focused on specific barriers: challenges of providing person-centered care, skills of communicating with staff and their families, and the link between these skills and their training. Thus, a comprehensive understanding of the methods and attitudes towards dementia care promotes realistic goals for the future (Foster et al., 2018).

At the residential care facility thirty-four caregivers were interviewed due to their close relationship with recently deceased individuals with dementia. Respondents noted that building a meaningful rapport takes time and time is not something the caregivers have an abundance of. Trusting relationships emanated warmth and guided de-escalation situations. Moreover, a common theme that arose was a commitment to help the residents feel happy, despite care being difficult. Supportive staff and communication are paramount in structure and time management. Often, feedback on caring techniques and approaches allowed staff to reflect on ways to improve. Health care assistants remarked that they were usually the first to notice changes in physical changes in health, but their communication with the family often was lost in the translation among the hierarchy of organized facilities. Lastly, several of the health care assistants interviewed indicated that they had lacked training in palliative or dementia care, but learned through experience or being mentored by a veteran colleague. Majority of the training offered to health care assistants was
focused on the more technical side of their profession. Quality of care relies on strong communication skills, among residents alike, coupled with a strong sense of empathy and compassion (Foster et al., 2018).

Each qualitative study was current and encompassed the roles of health care providers in their management of tasks and personalized care for residents with dementia. Health care assistants play a huge role in the care team, and their insights contributes to the current knowledge of training practices and personal insights in caring for the geriatric community. As well as, the goals individuals with early onset dementia value and their caregivers when strategizing care.

**Nursing Implications**

The cluster-randomized trial – *Caring for Aged Dementia Care Resident Study (CADRES)* of person-centred care, dementia-care mapping, and usual care in dementia by Chenoweth et al. (2009) studied improved outcomes through various provisions of care. Due to the complexity of dementia, integrated care approaches are required to maintain well-being and quality of life. Dementia care mapping is a process of implementing person-centered care by systemic observation that is relayed to staff to augment planning of care. Mapping requires extensive training, is labor-intensive, and costly. Secondary outcomes examined include: decreased need-driven dementia-compromised behaviors, reduction of psychotropic drugs or restraints and rates of accidents or injuries. Results revealed that person-centered care and dementia-care mapping both reduce agitation in people with dementia in residential care. (Chenoweth et al., 2009)

CADRES bolsters knowledge on current practices utilized in long-term care. In a cluster randomized controlled trial, urban residential sites were assessed before and after months of intervention. Fifteen cares sites with two hundred eighty-nine residents were randomly assigned care models. The Cohen-Mansfield agitation inventory was used to measure the outcomes of the
primary outcomes of the study. Compromised behaviors such as disturbed sleep-wake cycle, screaming, and pacing can diminish through the use of patient-centered care models. Traditional focus of nursing on physical features of activities of daily living resulting in neglect of psychosocial needs, leaving many people with dementia alone and emotionally distressed (Chenoweth et al., 2009). This research highlights interventions put into place that can improve quality of care for long term care residents battling with cognitive alterations.

McKewon et al. (2010) investigates how life story work is: understood, developed in practice, experienced by all participants and affects the delivery and outcomes of care. Nurses caring for people with dementia exercise the tools at their disposal. Often, health care providers enact person-centered care and do not recognize it or desire to use it, but are unsure how to implement the practice. Life story works asserts a dynamic approach to care by engaging the person with dementia about their life through artifacts and detailed information about their life. Therefore, life story work is one method that can invigorate person-centered care (McKewon et al., 2010).

The above literature review, scrutinized person-centered care as a holistic alternative to conventional care practices. Each category complemented the other by highlighting perceptions concerning individuals with dementia and implications within the gerontological community. Furthermore, dementia care goals and nursing implications analyzed current knowledge and practice. Personhood is a product of relationships with others that can be nurtured or diminished, depending on whether the person is being valued or depersonalized. Patient-centered care can be learned by use of education and staff support. Few trials have shown the effectiveness of person-centered care in reducing need-driven dementia-compromised behaviors and improving quality of life.
Overall, each research study provided robust data from study designs and mixed methods. Within each category, the articles formulated the same conclusions that patient-centered care is an effective and beneficial practice, but is not actively utilized in acute and long-term settings. Further studies can determine which tools of patient-centered care can be adopted to increase a sense of personhood with clients diagnosed with dementia. Care practice improvements can be established for longer periods of time to record staff confidence in care models and patient satisfaction in treatment.

**Theoretical Framework**

McCance and McCormack (2010) proposed a patient-centered model of care that encompasses the ideas found in this researcher’s review of current literature. The Person-Centred Nursing Framework was formulated from previous empirical research regarding person-centred practices with older adults and the experience of caring within nursing. Four constructs are highlighted within the framework regarding: prerequisites, care environment, processes, and outcomes. *Prerequisites* focus on the attributes of the nurse such as being professionally competent and being able to demonstrate clarity of beliefs and values. The *Care Environment* highlights the context in which care is delivered which includes systems that facilitate effective shared decision making. Moreover, *Person-centred Processes* concentrates on delivering care through a range of activities. Lastly, *Outcomes* are the results of effective practices. In order to reach the center of the framework, each category works symbiotically to reach desired outcomes. The relationships between the constructs is displayed by the pictorial representation is Figure 1.
The Person-Centered Nursing Framework is a relevant tool to the gerontological community, especially towards older adults with dementia. Previous studies utilize McCormack and McCance’s framework to promote an increased understanding of person-centered care, to generate practice-derived information and to identify barriers and subsequent interventions in practice. McCormack and McCance (2010) define person in their research as “all those involved in a caring interaction and therefore encompasses patients, clients, families/carers, nursing colleagues, and other members of the multidisciplinary team.” Therefore, the emphasis on holistic care is showcased in this study as the focus of this research are the challenges that prevent health care professionals from carrying out patient-centered care. Perceptions of older adults with dementia and how the nurse responds to changes in behavior is reflected in the various factors featured in the framework. The idea is supported McCance and McCormack’s theory that a collaborative network ameliorates individual care management.

McCance’s model of Person-Centered Nursing provides a comprehensive view of patient-centered care. Health care providers are responsible for implementing appropriate care practices.
This researcher’s proposed research will focus on addressing one or more of McCance et. al’s components of patient-centered care.

The Project

Study Design

The purpose of this paper has been to investigate current practices for patient centered care for older adults in various health settings and address health care providers’ perceptions on care management and education. A review of the literature displayed some of the perceptions of health care providers as they interact with older adults with dementia.

With the knowledge of nursing education and gerontological goals obtained from the literature review, a qualitative study was proposed to answer the question: What are the barriers and challenges that inhibit health care providers from carrying our patient-centered care for older adults with dementia in long-term care settings? Moreover, what are the most commonly used methods used to address patients with dementia and how effective do health care providers perceive these interventions to be? This proposal incorporated further inquiries within the literature review and investigation of dementia care management.

McCance and McCormack’s Person-Centred Nursing Framework illustrates all of the findings the literature proposed, and provides this researcher with the base for further inquiry. While not every factor will be addressed, every question examined will pertain to one or more of the constructs.

Methods

This researcher proposed to use these findings to continue the study of barriers to patient centered care of dementia clients in the long-term living setting through a semi-structured
phenomenological interview process. Phenomenology allows a researcher to analyze an individual’s lived experience in relation to what is being studied. This method focuses on the emotions and sentiments of the participants. Descriptive phenomenology aims to bracket common conceptions identified within the interviews.

Participants

A purposeful, convenience sample was selected from voluntary health care providers from an undisclosed skilled nursing facility in the East Bay. The anticipated sample size was five health care professionals in varying roles such as: Director of Nursing, Registered Nurse, Certified Nursing Assistant, and Licensed Vocational Nurse. This sample size and skill mix was chosen to ascertain perspectives on Dementia care within their scope of practice. Each participant coordinated a time before or after their shift for the interview.

Ethical Considerations

No identifying information were linked to individual participants. All information was kept confidential. Raw data was stored on a recording device with a secure passcode. After transferring the data to a computer that is password protected, the original recording was deleted. Recordings were transcribed verbatim, with the exception of any names mentioned. All transcribed recordings were seen by the researcher and advisor only. Printed transcripts of audio recordings were kept in a locked box at the researcher’s residence, and shredded or deleted within one year of study completion.
Data Collection

The research will use an interactive interview process to ascertain the participant’s experiences and sentiments. The study was approved by the Institutional Review Board for the Protection of Human Participants (IRBPHP application #10882). Table 1 includes proposed demographic related questions and Table 2 includes interview questions with corresponding rationale. The semi-structured interview guide was categorized into four main sections: demographics, perceptions, scope of practice and patient-centered care definition. Upon completion of interview process, the researcher performed a content analysis on repeated phrases or words. Upon completion, the researcher met with her faculty advisor to analyze common themes and major concepts.

Table 1 Demographics

<table>
<thead>
<tr>
<th>Question</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is your professional role at this facility?</td>
<td></td>
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<tr>
<td>2. How long have you been caring for the geriatric population?</td>
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</table>

Table 2 Interview Questions and Researchers’ Rationale

Questions were developed from the literature review and the qualitative studies. The researcher formulated questions with the guidance of advisor.

<table>
<thead>
<tr>
<th>Interview Questions</th>
<th>Rationale</th>
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<tbody>
<tr>
<td>According to the Alzheimer’s Association, Dementia is defined as an overall term for diseases and conditions characterized by a decline in memory, language, problem-</td>
<td>To open the discussion and provide the insight on the patients the participant cares for.</td>
</tr>
<tr>
<td>Question</td>
<td>Explanation</td>
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<td>------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------</td>
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<tr>
<td>solving and other thinking skills that affect a person’s ability to perform every day.</td>
<td></td>
</tr>
<tr>
<td>Describe the clients you work with.</td>
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<tr>
<td>What is a typical day like for you?</td>
<td>This statement may encourage participant to begin talking about their role without feeling interrogated.</td>
</tr>
<tr>
<td>Describe the team dynamic on your unit.</td>
<td>Looks at the care environment that health care providers are exposed to and their emotions as mentioned in the theoretical framework.</td>
</tr>
<tr>
<td>How do you feel about the safety and support measures in place on your unit?</td>
<td></td>
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<tr>
<td>How do you feel about your profession and caring for clients with dementia?</td>
<td>Gives the researcher insight on background and how the participant views older adults with Dementia.</td>
</tr>
<tr>
<td>How do your personal beliefs and culture influence your role as a health care provider?</td>
<td>This question is the first to address the research question about potential barriers to patient centered care or perceptions regarding care management. This question corresponds to the Prerequisites construct.</td>
</tr>
<tr>
<td>Describe the training you received to treat older adults with dementia? (For example, nursing school, in-services, CEU courses)</td>
<td>These series of questions reflect the scope of practice and educational background that the subjects were exposed to. Gives the researcher a basis of what interventions are successful. Participant responses will indicate current methods have you found to be useful or</td>
</tr>
</tbody>
</table>
practical when working with older adults with dementia?

What methods do you believe to be beneficial in your practice?

Conversely, what does not go well?

| How do you define the idea of patient-centered care? |
| What are your thoughts on this definition of patient-centered care, “Providing care that is respectful of, and responsive to, individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions?” |
| Provides insight on what the subject perceives to the hallmark components of patient-centered care. The definition provided allows subjects to reflect on their role and may encourage expression of a time they witnessed or engaged in patient-centered care. |

| In what ways, do you practice patient centered care? |
| An open-ended question will allow the subject to recall a particular experiences or moments in their practice. |

| How are family members and patients involved in care-giving decision making? |
| As featured on the Person-Centred Nursing Framework, this question aims to address the collaboration between health care providers and families. |
What barriers do you believe hinder your ability to perform patient centered care?

What conditions do you think might help overcome those barriers in the future?

This question addresses the research question as it has to do with difficulties carrying out patient-centered care. Subject responses will identify challenge and subsequent interventions.

Are there any insights or ideas that you would like to add concerning caregiving techniques that you utilize for patient centered care?

This final statement allows the participant to mention anything the researcher may find relevant or provide information that was forgotten.

<table>
<thead>
<tr>
<th>Findings</th>
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<tbody>
<tr>
<td>A total of 5 participants volunteered to participate in this study. Three of the five were registered nurses, one as a Director of Nursing, and one an Administrator. The registered nurses ranged in experience from three years to over twenty years. All the participants have had caregiving experience for the geriatric population prior to their current profession. From the content analysis five significant themes emerged: Strategies for Supporting Patient-centered Care, Cultural Pride, Barriers to Care, and Dementia Care Tools.</td>
</tr>
<tr>
<td>Throughout the interviews, patient-centered care for Dementia clients was a recurring theme that was coupled with interventions. Strategies of supporting patient-centered care focused on collaboration among licensed professionals as well as families to design effective plans of care.</td>
</tr>
<tr>
<td>Example 1: “Listening, informing, and involving patients and families, especially in their care and focusing attention to each and every patient.” (Subject #3)</td>
</tr>
</tbody>
</table>
Example 2: “Engage with these patients in a way that shows them that they are safe and that they are being taken care of and share these techniques with their caregivers or even learn from their caregivers.” (Subject #5)

Example 3: “…but to work with all the health care professionals, create a plan that is not only goal-oriented but also including what is important to them.” (Subject 5)

The four individuals in direct contact with clients with dementia recounted their cultural background and upbringing influenced their role as a health care provider. While one attributed their personal background caring for a family member influenced their capacity working with older adults with dementia.

Example 1: “Well as a Filipino, when we were growing up we take care of the elderly. We really take pride in taking care of our elderly who have Dementia, they are our family.” (Subject # 2)

Example 2: “I mostly work with Filipinos. We were all trained to do our job as we have the culture of being loving and respectful to elders.” (Subject # 3 )

Example 3: “My best training was my 12 ½ years of hands on training with my father who actually had Dementia/Alzheimer’s. There’s only so much you can learn from a book, so much more you can learn being in the situation and learning by trial and error.” (Subject # 1)

All five individuals experienced challenges to performing patient-centered care which included knowledge, lack of time, and the need for self-care among providers. Table 3:

<table>
<thead>
<tr>
<th>Education</th>
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<tr>
<td>“Families in denial of what they know about their families and they do not want the service method or plan.” (Subject #2)</td>
</tr>
</tbody>
</table>
“First time in the Dementia arena... less education on how to care for them.” (Subject #1)

**Time Constraints**

“I have 37 patients to attend to.” (Subject #3)

“Sometimes caregivers will be in a rush to get them to do something because they have so many people.” (Subject #1)

“You’re so busy working task by task and inundated with these patients.” (Subject #5)

“You don’t get that one-on-one chance to get to know them on a person level.” (Subject #5)

**Compassion Fatigue**

After describing incidents where caregivers received behavioral backlash, participants noted methods of coping. “Going out and breathing” (Subject #2)

“Okay, with a clear mind, what am I going to do next.” (Subject #5)

Assessment of Dementia care techniques allowed this researcher to better understand how nurses as managers of patient care, are connected with optimizing indicators of quality of life to benefit client outcomes. The majority of participants stated that communication was an integral aspect of understanding clients with Dementia. In addition, introducing familiar objects from home and reorienting clients when they are confused. Participants noted that personable care was beneficial in maintaining personhood for their patients.

**Communication**

“Therapeutic touch... touch on the shoulder or holding their hand, getting to their level, looking them in the eye, showing them that they matter, that you care, and that you’re focused on them in that moment” (Subject #5)
“We are not welcoming any visitors right now, but that doesn’t mean we cannot update family members on the phone or we can’t help connect patients with their families via iPad and Facetime” (Subject #5)

“Speaking softly ... stepping back and putting themselves in their shoes and how scared they may be” (Subject #1)

“One-on-one talk with the resident to know them better...because if you don’t know them, how can you treat them well or engage with them.” (Subject #2)

Care Environment

“Encouraging patients to bring things from home, photos of grandchildren and family.” (Subject #4)

“Having things in certain areas for orientation, writing down information for hard of hearing patients.” (Subject #3)

Reorientation

“Every time you walk into the room you have to reintroduce you have to tell them what your role is ....” (Subject #4)

“Redirecting the resident, go with them, go with the flow.” (Subject #2)

“They forget something you told them 5 minutes ago or yesterday ... one of the biggest things you have to do I think is to step into their world” (Subject #1)

Strengths and Limitations

Multiple limitations exist for this study. Due to the COVID-19 pandemic, interviews were not conducted in person. Instead, the researcher conducted interviews through video which may have impacted the ability to pick up on nonverbal behaviors or cues for further inquiry. Moreover,
due to the focus on various health care providers, it may have been beneficial to focus on one group such as registered nurses. Due to the researcher creating the semi-structured interview, more open-ended questions would have allowed for more open dialogue or refinement of the question guide. Finally, participant perceptions on patient-centered care is subjective and possibly inconsistent. Although, the sample size was appropriate for this study, more participants could lead to more consistent findings to represent the general population.

A strength to this study was the recruitment process. Participants volunteered to take part in the study and scheduled a time to meet with the researcher at their convenience. In addition, certain aspects of the interview guide encouraged participants to reflect on their practice, role as a health care provider, and background. The responses were detailed and opened avenues to capture changing attitudes and questions for further research.

**Conclusion**

Health care provider’s significant barriers to patient-centered care for dementia clients in the long-term care setting includes education, time constraints, and caregiver fatigue. Dementia is a cognitive decline that impacts activities of daily living. A network of collaborative professionals and families alike contribute to effective care management. Registered nurses can address these challenges through various communication methods, establishing a welcoming environment, and reorienting confused patients. One participant summarized the significance of patient-centered care, “They no longer see themselves as a patient and you’re like their nurse or caretaker, you’re on the same level and they start to feel safe.”

Moving forward, more research needs to be conducted on the topic of patient-centered care for Dementia clients. Knowledge on this topic and further investigation can improve job satisfaction and coordinate care outcomes. Further research can examine the emotional
implications of patient-centered care for adults with early onset dementia and their personhood. Due to the vulnerable population, more research is required on the impacts of practice on the gerontological community. Continued research can ascertain approaches, possible shortcoming in training, and universal beliefs regarding patient-centered care.

This review demonstrated the knowledge currently available on patient centered care in acute and long-term settings. There are several methods to employ in care for older adults with dementia. The literature review showcased current approaches such as life story, dementia care mapping, and task-oriented behaviors. Despite the study focusing on dementia clients, the results are applicable in the treatment of all patients. Patient-centered care can be incorporated to future education to increase health care provider skill and compassion towards vulnerable populations.
References


Häikiö, K., Sagbakken, M. & Rugkåsa, J. Dementia and patient safety in the community: a qualitative study of family carers’ protective practices and implications for services. *BMC*


Yasuda, Mami, and Hisataka Sakakibara. “Care Staff Training Based on Person-Centered Care and Dementia Care Mapping, and Its Effects on the Quality of Life of Nursing Home Residents with Dementia.” *Aging & Mental Health*, vol. 21, no. 9, Sept 2017, pp. 991-996. EBSCOhost, Doi:10.1080/13607863.201