

# Challenges of Providing Nursing Care to Patients with Dementia: A Qualitative Study

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## Abstract

**Objective:** The aim of this study was to identify the challenges faced by nurses while providing care to patients with dementia.

**Materials and Methods:** This study was a descriptive and qualitative study conducted between 10 December 2017 and 1 March 2018. In-depth interviews were conducted with ten nurses. Data were analyzed using the inductive content analysis method.

**Results:** Four themes and eight subthemes were identified. The themes were: the perception of dementia, the meaning attributed to caring for patients with dementia, challenges of nursing care in dementia, and empowerment in care practices.

**Conclusion:** Nurses must understand the complex needs of people with dementia in hospitals and clinics. Because these patients need person-centered care that requires special communication and behavior. Nurses should be supported to provide this care to patients with dementia and manage the symptoms of patients with dementia. It contributes to providing individual and institutional support to nurses who care for patients with dementia, improving their communication skills, and coping with the difficulties and difficulties faced by nurses.

**Keywords:** Dementia, nurse, nursing care, qualitative study

## Introduction

Patients with dementia are often older adults with chronic diseases, have complex needs and symptoms, and are difficult to care for (1,2). Therefore, the care of these patients is a difficult and exhausting process.

In the care of patients with dementia, it is among the responsibilities of the nurse to regulate the environment and relationships to preserve the patient's functionality and stability, compensate for the losses associated with the disease, and to provide therapeutic environments that help maintain their privacy and quality of life (3). However, unsuitable hospital environments and an inadequate number of nurses are important barriers to patient management and the provision of quality care (4,5). However, nurses may not be well prepared or experienced in caring for patients with dementia. Several studies have shown that nurses have insufficient knowledge, skills, confidence, and

safety awareness about dementia and its care (2,6). Nurses who care for patients with dementia experience negative emotions due to memory and behavior problems (agitation, hallucination, confusion, etc.), which are the most common symptoms of dementia. Nurses have difficulty managing dementia-related symptoms and suffer from job dissatisfaction and experience feelings of fear, anxiety, frustration, burnout, weakness, and guilt; these lead to ineffective coping strategies to overcome the challenges faced (4,7).

Unfamiliar hospital environments and caregivers lead to anxiety, agitation, and aggressive behavior in patients with dementia, making nursing care more challenging (8). Therefore, it is recommended that patients with dementia are approached and provided with person-centered care. Person-centered care is a holistic and integrative approach designed to maintain the well-being and quality of life of people with dementia. The main purpose of person-centered care is to respect the

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**Received:** 23.06.2022 **Accepted:** 29.07.2022



**Cite this article as:** Çevik B, Kav S, Akgün Çıtak E, Akyüz E, Abbasoğlu A. Challenges of Providing Nursing Care to Patients with Dementia: A Qualitative Study. Eur J Geriatr Gerontol 2022;4(3):205-211

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patient's autonomy and maintain dignity even though his/her cognitive abilities are impaired. A patient with dementia whose personality is recognized and valued feels respected and honored in social settings; therefore, he/she acquires a sense of belonging, confidence, and comfort, and is willing to participate in activities. It takes time to develop person-centered care for patients with dementia; however, collaboration with the patient's family can facilitate this challenging aspect of care (8,9).

The relationship between the dementia patient and the nurse is critical in clinical settings because familiar caregivers and members are not present to help the patient. Nurses should be able to use appropriate interpersonal communication, empathy skills, and emotional intelligence to make a positive impression on patients with dementia (8,10). Training programs should, therefore, be held to improve the knowledge and confidence of nurses caring for patients with dementia. Research has shown that although nurses have a basic knowledge of the care required by patients with dementia, they know little about the early diagnosis of dementia, and effective communication strategies, and are unable to encourage the participation of patients in activities and manage treatment-resistant patients (8-11). Marx et al. (7) conducted a study to assess the level of knowledge and working status of nurses and reported that nurses had difficulty in managing the behaviors of patients with dementia, securing and providing care, and getting them to accomplish daily tasks. Fukuda et al. (3) reported that nurses caring for patients with dementia have difficulty managing patient behavior, reducing patients' and their families' anxiety and fear, communicating with patients, and providing care and safety due to shortcomings in hospital organizations, such as nursing shortages and inadequate cooperation with professionals in other medical fields.

In Turkey, patients with dementia are hospitalized or admitted to appropriate clinics according to the health problem experienced. Although nurses working in hospitals and clinics

provide care to patients with dementia, little is known about nurses' experiences of caring for patients with dementia and the associated problems. Therefore, the aim of this study was to explore nurses' perceptions of the challenges they face in the care of patients with dementia in hospital and clinical settings.

## Materials and Methods

### Design and participants

This descriptive qualitative study focused on offering a realistic perspective on the difficulties encountered by nurses while providing care for patients with dementia in hospital settings. Participants were recruited from a university hospital using snowball sampling. Participation was voluntary. Data collection was terminated when further data did not provide any new information or insight. The study sample consisted of ten nurses. The inclusion criteria were as follows: (a) The participants should have a bachelor's degree; (b) the participants should have had at least one year of work experience in an adult ICU and/or inpatient clinics; (c) the participants should have had cared for at least one patient(s) with dementia; and, (d) the study required voluntary participation. A profile of study participants is presented in Table 1 and outlines the information regarding their age, gender, education status, working place, and employment year.

### Data collection

After obtaining permission from the institution, data were collected between December 10, 2017, and March 1, 2018. A semi-structured interview form consisting of five questions was used (Box 1). Participants were informed about the procedure, confidentiality of the data, and that the interviews would be audio-recorded. The interviews were conducted by two researchers (first and third author) in a quiet room. Each interview lasted 35 minutes (minimum: 20 minutes; and, maximum: 50 minutes) on average. One researcher conducted the interviews while the other observed and took notes. New

**Table 1. Demographic features of the nurses**

Participant	Age	Gender	Education status	Years of employment	Working place
N1	39	Male	Undergraduate	12	Intensive care
N2	35	Female	Undergraduate	14	Intensive care
N3	50	Female	Undergraduate	27	Clinic
N4	37	Female	Undergraduate	14	Clinic
N5	40	Female	Undergraduate	20	Intensive care
N6	28	Female	Undergraduate	4	Clinic
N7	24	Female	Undergraduate	1	Intensive care
N8	28	Female	Undergraduate	4	Clinic
N9	30	Female	Undergraduate	9	Clinic
N10	24	Female	Undergraduate	2	Clinic

participants were recruited until data saturation was reached, and ten nurses were interviewed in total.

**Statistics**

Data were analyzed using qualitative inductive content analysis. The interviews were transcribed with no corrections. To ensure confidentiality, participants were coded as N1, N2, N3, N4.... N10. For analysis, first, three authors separately coded the transcripts line-by-line to ascertain the meaning of the sentences during analysis. Similar conceptual expressions were grouped into a list of codes, classified, and labeled. Finally, subthemes were combined and the main themes were created (12).

**Trustworthiness:** During each interview, the researcher summarized the interview and asked the participant if he/she had anything more to add. The interview was terminated after the participant confirmed that he/she did not have anything further to add. Participants read the themes and subthemes and confirmed the validity of the same, with no further recommendations. Themes and subthemes were discussed by a research team to improve reliability. The methods were reported in accordance with the principles of consolidated criteria research qualitative research (13).

**Results**

They all had bachelor's degrees. Nine of the participants were female. Six of them worked in inpatient clinics, and the remaining worked in adult ICUs. Participants' mean age was 33.5±8.2 years (minimum: 24 years; maximum: 50 years), and they had a mean of 10.7±8.4 years (minimum: 1 year; maximum: 27 years) of work experience. Data analysis yielded four themes and eight sub-themes. The themes were: (1) the perception of dementia; (2) the meaning attributed to caring for patients with dementia; (3) challenges of nursing care in dementia; and, (4) empowerment in care practices. The second theme comprised two sub-themes: (1) Difficulty in providing care; and, (2) uplifts of caregiving. The third theme consisted of four subthemes: (1) Inability to communicate; (2) difficulty in managing patient behavior; (3) burden of care; and, (4) inability to manage time. The fourth theme comprised two subthemes: (1) Individual empowerment and (2) administrative empowerment (Table 2). The themes and subthemes are discussed in the following section.

<b>Box 1. Questions on the semi-structured interview form</b>
1. What does dementia mean to you?
2. What does care for patients with dementia mean to you?
3. What kind of challenges (psychological, physical etc.) do you face when caring for patients with dementia?
4. How does caring for patients with dementia affect you?
5. What are your recommendations for nurses caring for patients with dementia?

**Perception of dementia**

Participants were asked what the word "dementia" meant to them. They associated it with deterioration in cognitive processes (7/10), forgetfulness (6/10), difficult patients (6/10), and need for caregiver support (5/10) (Table 3). Participants shared the following experiences regarding their perception of dementia:

..... "To begin with, they are difficult patients; not being able to communicate, there is no way to establish a social... how should I put it? not being able to connect the patient socially to a... The fact that he/she refuses to eat, has no conception of time... It is tough, because, his consciousness is not completely intact, so it is hard to involve him in activities, which increases our workload and exhausts our patience." (N1)

....."Old, forgetting what he/she does and inability to adapt to the environment..."(N6)

....."I can refer to it as a deterioration in cognitive processes....." (N4)

....."The patient's consciousness has deteriorated completely... he isn't adapting to the external environment." (N1)

Most participants associated dementia with a deterioration in cognitive processes and forgetfulness. Nurses who define dementia as a deterioration in cognitive processes have more experience in the profession. Nurses with less experience in the profession (4/6) and those working in ICUs (3/4) stated that patients with dementia are difficult patients and in need of specialized care due to symptoms resulting from a deterioration in cognitive processes.

**Meaning attributed to caring for patients with dementia**

This theme consisted of two sub-themes: (1) Difficulty in providing care; and, (2) uplifts of caregiving.

**Difficulty in providing care**

Participants stated that they had difficulty meeting the care needs of patients, communicating and performing activities

<b>Table 2. Categories</b>
<b>Themes and subthemes</b>
1. Perception of dementia
2. Meaning attributed to caring for patients with dementia
a. Difficulty in providing care
b. Uplifts of caregiving
3. Challenges
a. Inability to communicate
b. Difficulty in managing patient behavior
c. Burden
d. Inability to manage time.
4. Empowerment
a. Individual empowerment
b. Administrative empowerment

**Table 3. Nurses' perception of dementia**

Perception of dementia	N1	N2	N3	N4	N5	N6	N7	N8	N9	N10
Forgetfulness	√	√		√		√	√	√	√	√
Deterioration in cognitive processes	√	√			√				√	
Need for caregiver support			√	√	√		√		√	√
Difficult patient	√	√	√	√		√		√		√

with them, and concentrating their attention socially and mentally on the reality of the world due to fluctuations in their consciousness and orientation; this caused them to spend most of their time with those patients and sometimes be subjected to physical or verbal violence. One particular nurse characterized her experience as follows:

....."Trying to persuade them is another challenge, there are some things that have to be done, such as vascular access and drawing blood, but the patient just wouldn't let you." (N8)

**Uplifts of caregiving**

Four participants were satisfied with their job because they knew that patients with dementia needed them and they were able to help the patients. Earning the trust of patients with dementia, cooperating with them and paying more attention to their needs made these participants happy.

....."I love caring for patients with dementia because I know that they need me. Helping them, communicating with them and caring for them make me happy... I give them some time to get to know me... I know that I have to spend more time with them." (N2)

"...I feel satisfied knowing that I have been helpful to them..." (N4)

" ... When I see the positive changes in the facial expressions of the patient I cared for, I feel satisfied." (N5)

**Challenges of nursing care in dementia**

Participants were asked about the challenges they faced while caring for patients with dementia. All participants stated that it posed both physical and psychological challenges, which were grouped under the subthemes of "inability to communicate", "difficulty in managing patient behavior", "inability to manage time", and "burden of care".

**Inability to communicate**

Seven participants stated that they had difficulty communicating with patients with dementia during their care and medical treatment, in the absence of family, or when the patients were agitated. The experiences of some participants are directly quoted as follows:

....."Patients never understand the procedures, and it is very difficult for us to explain them all. Patients are always agitated,

and they don't get us... My biggest communication problem is that they talk about things that never actually happened." (N9)

....."I have a hard time communicating (with patients with dementia), they snap at me...They forget the things that we talked about an hour or a day before, we always have to say the same things over and over again." (N6)

Participants who had difficulty communicating with their patients stated that they did not know how to communicate with them and were tired of having to say the same things repeatedly. They also stated that from time to time, there were some misunderstandings due to deterioration in orientation and perceptions. Families believe what patients say, and therefore, arguments break out or nurses find themselves in a situation where they have to defend themselves.

**Difficulty in managing patient behavior**

Five participants reported that they had difficulty managing patient behavior. Protecting agitated patients from falling or trauma, while ensuring their own safety, led to nurses' often subjection to verbal and physical violence.

....."We try to help them, but they react negatively like they hit us or display aggressive behavior." (N1)

....."It is a challenge for me, I am scared because I don't know how they will react. I am especially scared when it is a challenging physical task." (N2)

**Inability to manage time**

Eight participants reported that they had difficulty managing time when there were patients with dementia in their clinics and that it took a lot of time and effort to care for them and to manage their agitated behavior, due to changes in their cognitive processes (8/10). They also stated that they had difficulty ensuring the safety of patients and managing time during their shifts because they had to say the same things repeatedly during treatment and care.

....."I don't want to care for a patient with dementia that I have to deal with during my shift. I'd rather have completely dependent patients instead of patients with dementia because I can care for and treat them and plan their safety easily. But it's not the case with patients with dementia. I just can't leave the patient's room and can't spend any time with my other patients" (N5).

### Burden of care

Seven participants suffered from the burden of care because they had to say the same things to patients with dementia repeatedly, and spend most of their time with them. They stated that they were not able to leave their patients with dementia despite their busy shifts, experienced communication problems and had to deal with other patients who did not appreciate the care they provided and the conflicts that arose thereby. They felt exhausted because the care they provided was not visible and they always had to persuade their patients to undergo care and treatment. They stated that they suffered from stress during their shifts since they had to provide safety and physical care for patients with dementia, with whom they were unable to communicate effectively. This resulted in fatigue and exhaustion.

"...We sometimes don't know how to approach our patients. Sometimes I have to give them a command, and sometimes I raise my voice, I mean it's not like I yell at them, but I find myself in conflict situations, which is exhausting to me..." (N6)

### Empowerment in care practices

Participants were asked what their recommendations would be for nurses caring for patients with dementia. Their suggestions were grouped under two sub-themes: Individual empowerment and administrative support.

#### Individual empowerment

Participants stated that they had difficulty caring for patients with dementia and that they should be empowered in that regard. They recommended that communication techniques with patients with dementia be developed (8/10), care is provided by experienced nurses (5/10), and nurses be supported during physical care (4/10). They stated that nurses caring for patients with dementia should be calm and patient, which requires good communication skills and experience in patient-centered care.

....."Nurses should be provided with training on how to approach patients with dementia and how to communicate with agitated patients who refuse treatment and how to make them feel safe." (N6)

....."Be patient, trying to provide treatment and care over and over again ..... Every dementia patient is unique ... try to understand as a person and establish a contact point." (N3)

#### Administrative empowerment

According to participants, what should be done managerially are as follows: Patients with dementia should stay in clinics designed especially for them (8/10); their families should stay with them (7/10); experienced medical teams should provide care for them (7/10); health professionals should be provided with in-service training on caregiving for patients with dementia at regular intervals (5/10); and, the care needs of patients with

dementia should be taken into consideration when planning the care process and organizing the workforce or the required number of nurses (4/10).

....."Family members should definitely stay with patients with dementia in the intensive care unit because patients trust their families and express their needs to them more than they do to us." (N4).

### Discussion

This study investigated nurses' perceptions of patients with dementia and provided insights into nurses' experiences and recommendations for care processes in hospitals and clinics. The findings revealed that nurses associated dementia with deterioration in cognitive processes, forgetfulness, need for caregiver support, and difficult patients. In particular, experienced nurses defined dementia as a deterioration in cognitive processes and forgetfulness, while others associated dementia with difficult patient(s) and need for caregiver support. Nurses who do not have sufficient theoretical knowledge and/or practical skills to manage the behaviors of patients with dementia, label them as "difficult patients". Therefore, experienced nurses can manage the behaviors of patients with dementia, and care for them successfully. These results are similar to the findings of other studies that reported that caregivers of patients with dementia associated dementia with forgetfulness, irritability, hyperactivity, and aggression (10-13). Clinical management and care of patients with dementia is difficult because of the behavioral and psychological symptoms of dementia.

Nurses are responsible for ensuring the physical, social, spiritual well-being and safety of patients with dementia. Hospitalization of patients with dementia has different negative implications for patients, their families, and nurses (10,13-15). Nurses experience frustration and negative feelings resulting from not having enough resources, opportunities, or abilities to perform quality care for patients with dementia. Additionally, a lack of knowledge of the complex needs of patients with dementia causes frequent emotional exhaustion and stress for nurses. Nurses who work with a deficit in knowledge and skills might feel a sense of professional failure and frustration while providing care for patients with dementia (10,13). Previous studies have also highlighted that nurses with adequate knowledge of dementia and its characteristics can provide better nursing interventions (10,14-18). In their study, Scerri et al. (19) investigated the effect of person-centered dementia care on employees' knowledge and attitudes in acute hospital wards; they stated that training programs were necessary to improve nurses' knowledge attitudes and interpersonal skills. Pinkert et al. (14) reported that it is important to sensitize nurses and provide them with sufficient training and education to enable

them to care for patients with dementia. In this study, nurses expressed those various types of educational activities relating to dementia care (engaging in role-play, watching videos, studying case examples, etc.) helped them develop abilities and strategies, such as viewing reality from the patients' perspective.

Dementia-related behavioral symptoms such as communication problems, conflict, and aggression during care have negative effects on nurses (1,2,10,13,15). Ostaszkiwicz et al. (16) argue that nurses are constantly at risk of physical and verbal abuse, and thus feel insecure and worthless while handling dementia patients. McPherson et al. (18) reported that nurses who work in inpatient dementia care wards experienced work stress caused by structural and interpersonal factors such as the nature of dementia patients, lack of resources, high demand, aggression, and fear. In this study, nurses stated that they suffered from stress and the burden of care because they had to say the same things to patients with dementia over and over again and spend most of their time with them. In addition, they were not able to leave their patients with dementia, despite their busy shifts. Moreover, nurses stated that they experienced difficulty in communicating with patients with dementia and managing their behavior because they do not comprehend as well as other patients. Thus, it is more time-consuming to assess their needs (e.g., pain identification).

Another sub-theme in study was "uplifts of caregiving", which plays a key role in protecting nurses from stress and fatigue; research shows that nurses experience stress, emotional overload and burnout when caring for patients with dementia (2,6). Nurses are less likely to be personally affected by patient behavior if they can associate it with the symptoms of dementia because; in this way, they can feel satisfied with the care they provide and manage the symptoms of dementia (17). Nurses in this study were aware that patients with dementia needed them and stated that they wanted to help patients with dementia and gain their trust and that they were satisfied with their job because they provide meticulous care that maintained patient dignity.

The results of this study showed that experienced nurses expressed more positive statements regarding the care processes of patients with dementia. Previous studies have similarly reported that experienced nurses communicate with dementia patients more easily, have less difficulty in managing routines, and cope with patients and their relatives (2,6,8,20). Burns and Mellpatrick (8) expressed that nurses indicated that having long and persistent contact with dementia patients gave them the ability to realize patients' pain and other needs through their behavioral symptoms, which is quite challenging for less experienced workers or staff. Nurses encountered with dementia patients for the first time in the clinic may feel that lack the expertise required to care for such patients. Therefore, nurses who have had previous experience in providing care for people with dementia can provide more appropriate care.

Sensing and understanding the patients' emotional and physical expressions are ways to extend high-quality care (14,17,19). In addition, viewing the dementia patient as a person and providing holistic care for them were the two most important elements that positively improved care processes. Furthermore, person-centered care is stressed on as the foundation of care for patients with dementia. Therefore, it is recommended that patients with dementia be admitted to specialized clinics (15,17-19). In this study, nurses expressed those demented patients should be in clinics specially designed for them and that the number of nurses required should be outlined in the care plan. However, in Turkey, there are no dementia-friendly hospitals where such patients can be hospitalized. Additionally, due to the increasing number of patients with dementia, nurses in acute hospitals face great uncertainty when caring for patients with dementia.

Nurses who care for patients with dementia should be supported both emotionally and physically. Research shows that nurses caring for patients with dementia should receive guidance and support from experienced nurses and training on effective communication techniques (10,11,14,19). Nurses who are supported and valued by other health professionals and the institution(s) they work for, experience more job satisfaction and less fatigue. Nurses supported by their institutions and managers experience high levels of satisfaction, which, in turn, increases patient satisfaction (21). Sjögren et al. (17) stated that higher levels of person-centered care are associated with higher levels of satisfaction with work and care, lower levels of job strain, and a more supportive psychosocial climate. According to the participants, administrative empowerment can be achieved by ensuring that patients with dementia stay with their families in clinics specifically designed for them and are provided with care by experienced teams and nurses who undergo in-service training at regular intervals, on the caregiving requirements of patients with dementia. Research also suggests that nurses or healthcare teams caring for patients with dementia receive education and training on aspects of dementia, such as psychotic symptoms and depressive characteristics of dementia, behavioral disorders, and maladaptive aggressive behavior management and communication skills (8,16,17,19).

### Study Limitations

The most important limitations of our study are that it was conducted in a single-center institution and its small sample size. The common aspects and solutions of the difficulties experienced by nurses in the care of patients with dementia can be revealed through studies conducted in large samples and multi-centre institutions.

### Conclusion

Achieving person-centered care for patients with dementia in acute hospital settings is complex, and multiple factors need

to be addressed. Most nurses lack the specialist knowledge and skills required for dementia care. The findings of the study revealed that nurses face many different challenges while taking care of patients with dementia. Nurses stated that they suffered from psychological, communication, and time management problems while providing care to patients with dementia, and that experienced and trained nurses should care for patients with dementia. Participants had difficulty communicating with their patients and managing their behavior. Providing them with education and training programs on these issues can help them understand dementia and help them assess patient behavior and manage the behavioral symptoms of dementia. It can also help them adopt an empathic approach to challenging behavior and develop the skills necessary to cope with related stress and emotional problems.

### Acknowledgment

We would like to thank the administration of the University Hospital, which granted the necessary permissions for the implementation of the study, and all nurses who participated in the study.

### Ethics

**Ethics Committee Approval:** Ethical principles were maintained throughout the study. Permission (KA17/313) was obtained from the Medical and Health Sciences Research Board of Başkent University and from the Ethics Committee of Başkent University prior to the study.

**Informed Consent:** Informed consent was obtained from them prior to participation.

**Peer-review:** Externally peer-reviewed.

### Authorship Contributions

Concept: B.Ç., S.K., Design: B.Ç., S.K., Data Collection or Processing: B.Ç., E.A.Ç., E.A., A.A., Analysis or Interpretation: B.Ç., E.A.Ç., E.A., A.A., Literature Search: B.Ç., S.K., E.A., Writing: B.Ç., S.K.

**Conflict of Interest:** No conflict of interest was declared by the authors.

**Financial Disclosure:** The authors declared that this study received no financial support.

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