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"I don't Want to Die Alone" Nurses' Perception of Ageism: A Qualitative Study

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Dilek BAYKAL¹, Necmiye ÇÖMLEKÇİ², and Gülbeyaz CAN³

Abstract

The aim of the study was to learn the perceptions and thoughts of nurses with whom older patients interact constantly. In this research, semi-structured interview was used. In a research hospital in Istanbul between March-June 2019, 16 volunteers were included in the study. Researchers led individual semi-structured interviews regarding nurses' perceptions, how they overcame those challenges, and need and expectations aging care (dying patients). All interviews were analysed using thematic analysis methods and synthesized into major themes. The research was planned based on the 32-item checklist (COREQ) guideline. Nurses (N = 16) reported three themes: (i) ageing perceptions (ii) care for dying patients, (iii) expectations and five subthemes emerged in this study. It is understood that nurses have a positive perception of ageing. In addition, nurses have expectations from the state (financial support, gerontology service etc.) and society (respectful, understanding etc.) to reduce the difficulties they experience while caring for dying patient.

Keywords

ageism, dying patients, perception, nurses, qualitative study

Corresponding Author:

Dilek BAYKAL, Department of Nursing, Faculty of Health Sciences, Istanbul Atlas University, Hamidiye No: 40 Kagithane/Istanbul 34408, Türkiye.

Email: dbaykal@hotmail.com

¹Department of Nursing, Faculty of Health Sciences, Istanbul Atlas University, Istanbul, Türkiye

²Department of Nursing, Faculty of Health Sciences, Bartin University, Bartin, Türkiye

³Faculty of Nursing, Istanbul University-Cerrahpasa Florence Nightingale Istanbul, Istanbul, Türkiye

Introduction

In the present century, because of rise in life expectancy, old age is becoming important all over the world. World Health Organization (WHO) defined older people as individuals aged 60 years and above. According to the World Health Organization (WHO), the population of older people in the world was 900 million in 2015, which has been estimated to reach 1.2 billion by 2025 and two billion by 2050 (WHO, 2018).

Ageing is influenced by complex changes, such as biological losses that lead to an increased risk of disease, and a decline in the physical, psychological, and social capacities of the individual (Colloca et al., 2020). As a result of the physiological, and psychological changes that accompany old age, older persons comprise the most vulnerable group to various diseases. For example, Americans 75% aged 65 years and above suffered from multiple chronic diseases (CDC, 2020).

Older people face ageism apart from the physiological and mental problems brought about by aging. Ageism was defined by Butler in 1969 as an individual's encountering negative perceptions and behaviors because of their age (Dahlke & Hunter, 2022). In 2019, it was accepted by WHO that ageism negatively affects the health and well-being of individuals and is an important public health problem (WHO, 2019). In addition, diseases that occur with ageing and the perception of approaching death with advanced age can affect the approach to these people. In the literature, it has been reported that ageism affects the well-being of the elderly negatively, causing depressive symptoms and low self-esteem (Marquet et al., 2019; Lyons et al., 2018). It is important to reduce ageism while older individuals receive health services in places such as hospitals and health care centers (Yakubu et al., 2022; Gholamzadeh et al., 2022).

Attitudes and perceptions of nurses, who have a key role in elderly care, affect the quality of care (Wanko et al., 2021). In studies conducted by Akpinar et al. reported in the literature that nurses' attitudes towards the elderly are positive and negative (Akpinar et al., 2018). However, it has been observed that studies qualitatively evaluating nurses' perception and thoughts of the ageing, difficulties that they faced in older care are limited (Lennox et al., 2019). For this reason, the evaluation of nurses' perceptions and attitudes towards the dying patients, as well as the evaluation of the problems and difficulties they encounter in older people care, will provide solutions that will increase the quality of older people care. The purpose of this study is to examine the feelings and thoughts of nurses about ageing and dying patients. Thus, the aspects of nurses' feelings and thoughts reflected in older people's care and dying patients will be shed light on.

Research Question

This study purpose to answer the following research questions:

- 1 What is the perception of nurses toward ageism?
- 2 What do nurses experience when caring for dying patients?

3 What are the expectations of nurses to take better care of older people (dying patients)?

Methods

Study Design

The study was a qualitative research method.

Sample

One of the largest research hospitals in Istanbul was selected for the study. The purpose of this was to reach the nurses working in different services that care for the older people. Thus, it was aimed to reach nurses with different views.

Volunteers who have been working in internal diseases, surgical services and intensive care units, which healthcare is provided to older people intensively at least 1 year in a research hospital in Istanbul between March and June 2019 were included. Four of the nurses who met the inclusion criteria could not be interviewed because the appropriate meeting time could not be arranged, and two of them could not be interviewed due to increased workload. A total of 16 nurses were interviewed.

Procedure

Semi-structured interview is one of the qualitative research methods. In this research where the qualitative method was preferred, the form in which the socio-demographic characteristics of nurses were questioned was applied. Then, interviews were made with the semi-structured form. Before starting the research, the consensus was reached by gathering with the researchers the form to be used while conducting the interviews. In order to check the intelligibility of the semi-structured form, five nurses working in the same hospital were shown the forms, and their suggestions were received. Adjustments were made in line with their suggestions.

After the forms were become ready, interviews were held in the hospital setting with the nurses who agreed to participate in the study. During the interviews, the other researcher participated as an observer and the interviewer's notes were taken. The interviews took 15–20 min approximately. To permit maximum information on data, nurses with a wide mix of ages, clinical experiences, and education levels were recruited.

Data Collection

The interviews were conducted under the guidance of the "Semi-Structured Form", which was prepared by the researchers. The lead interviewer (XX) is a nurse scientist, female and university faculty member trained in qualitative study and previously led

similar qualitative studies. A research assistant (YY) trained in qualitative methods, female, she is also conducted interviews using the same interview protocol. The interviews were audio-recorded, and the notes of the interviewes were taken during the interviews.

The Semi-Structured Form

The interview form that is created by the researchers was designed to understand factors that may affect their attitudes and behaviors during the delivery of health services to the older people. At the beginning of the interview, in order to understand the feelings and thoughts of nurses towards the ageing, they were asked about "Where should older people in need of care be cared for", "Their thoughts on dying patient and whether these thoughts have changed after they started to give care to...", and "they were asked about their thoughts about their own old age". Lastly, "while they were caring for the dying patient the feelings, thoughts, and giving care difficulties that they experienced" were asked. At the same time, in order to solve the problems and the difficulties they faced and to care for the older people (dying patient) better, their expectations from the society and the state were asked to be learned. The negotiations were terminated when it was believed that they had reached sufficient saturation.

Data Analysis

The thematic analysis was used to analyse the interviews. Thematic analysis is the most appropriate method to reveal a particular topic focused on interview questions (Joffe, 2011).

Thematic analysis is a method for identifying, organising, and offering insights into patterns of themes across several items of qualitative data. Thematic analysis provides the systematic coding and analysis of broad theoretical concepts. The analysis procedure included: transcribing the whole interview; recognizing written data and identifying codes; searching, reviewing and identifying themes and ultimately produce findings. Transcriptions were analysed one to one with the themes being drawn out inductively. In order to reduce bias while creating themes, two researchers (XX; YY) independently coded themes. The voice recordings that were taken during the interviews were converted to text. An Excel table was created to organize the codes. The identified key themes and their sub-themes were linked to the theoretical literature upon completion of the analysis and not prior. The coding process was performed manually through repeated reading of and making notes on interview transcripts. It was ensured that the codes and related quotations had the capacity to explain the richness of the texts, as the literature suggests (Nikitas et al., 2019). By coming to all researchers together, it was ensured that the themes and categories are a true representation of the nurses' attitudes and behaviors towards the ageing and dying patient.

After the themes were identified, they were read and approved by the participants to ensure the transferability of the findings and to allow readers to match the findings to

their own context. In the analysis, it was aimed to convey the presentation of concise, consistent and integrating data conveyed by the participants with themes. The expressions presented in the results section will be conveyed with themes and sub-themes. Beside of this, raw data excerpts that capture the gist of the issue are presented in italics. The results will then be linked to literature in the discussion section. The Consolidated criteria for Reporting Qualitative research (COREQ; Tong et al., 2007) guided the presentation of results (Table S1, in the supporting file).

Trustworthiness

We ensured qualitative rigor as defined by Lincoln and Guba (1985) by maintaining and documenting the credibility, transferability, dependability, and confirmability of all data through methods, bracketing of biases, triangulation of data sources. All the stages of the study were explained to the nurses in detail, and thus methodological reliability and rigor were ensured.

Ethical Considerations

Approval was obtained from the Non-Interventional Ethics Committee (date and number: 28.02.2019/42) for the study. Participants who accepted to participate in the study were informed and their written consent was obtained for the voice recording.

Results

Nurses' socio-demographic characteristics may be seen in Table 1. And, the identification and numbering of participants are shown in Table 1. Participants (P) and genders (M, F) were identified with abbreviations.

Socio-Demographic Characteristics of Nurses

The age range of nurses varied between 22 and 38. It was found that most of them were single (n = 12) and their working durations were 1–4 years (n = 14). Moreover, it was spotted that most of the nurses' male (n = 8) and all of them were university graduates at least. (Table 1).

Consensus was reached on three main theme and five subthemes of the main theme by the researchers (Table 2). These themes were refined after receiving feedback from participants.

Ageing Perceptions

In order to determine the perceptions of nurses about ageing, their thoughts on elderly care, whether these thoughts have changed over time, and their thoughts on their own old age were asked.

Р	Age	Gender	Marital Status	Education	Working Duration
I	38	F	Married	University	I0 ↑ years
2	26	M	Single	University	I-4 years
3	25	F	Single	University	I-4 years
4	34	М	Married	University	5-9 years
5	25	M	Single	University	I-4 years
6	24	F	Single	Ass. Degree	I-4 years
7	25	F	Single	University	I-4 years
8	23	F	Single	University	I-4 years
9	26	М	Married	Phd	I-4 years
10	23	М	Single	Phd	I-4 years
П	28	M	Single	University	I-4 years
12	31	М	Single	Phd	I-4 years
13	28	M	Married	University	I-4 years
14	22	F	Single	Ass. Degree	I-4 years
15	25	F	Single	University	I-4 years
16	24	F	Single	University	I-4 years

Table I. Socio-Demographic Characteristics of Nurses.

Participants: P Female: F Male: M

Table 2. Summary Table of Major Themes and Subthemes Which Arose From Interviews of Nurses.

Major Themes	Minor Themes Older people should be cared Mood changes When I get older		
Ageing perceptions			
Care for the dying patients			
Expectations	Expectation from the society Expectation from the state		

It was found from their statements it did not change in general and their attitudes towards the ageing were positive.

Older People Should be Cared

This theme shows the positive attitudes of nurses towards the older people. Most of the participants reported that the older people should be cared for with their families. The participant who stated that being with the older people would contribute to the development of their children:

"Certainly, there must be an elder in the family. Because of its benefit to children rather than the health. Growing up with older people adds positive things to one's character." (P4,34y, M)

The belief that the older people should be cared for by their children is one of the important cultural characteristics in Turkish society. While a nurse's response emphasizes this cultural feature, its importance for the psychology of the older people can be understood from its expression;

"I think they should be at home. Because I don't think their psychology will be good when they are left out or left in the nursery. We are eight siblings. It is nonsense that eight siblings cannot take care of two people, and it is not appreciated in our town." (P6,24y, F)

However, there were also those who had different thoughts about the older people at home and their care.

"If the elder can, she/he will be better at their own home. Because this is the place where she/he feels free. They are happier in their own home." (P5,25y, M)

The nurse who said that the care of the older people may vary according to the care need of the:

"It depends on the situation. If it needs a lot of care, of course they should be given care in the family, but are they becoming too spoiled this time? They either don't do the things they can do, or they don't prefer to do it." (P8,23y, F)

Mood Changes

Empathy is one of the most important features of the nursing profession. In this theme, it is understood that the attitudes of nurses towards the older people changed positively after they started their professional.

"I haven't seen my family elders except my grandmother. So, I couldn't spend much timewith them, but after I started to my profession, I began to understand the chronic diseases of the older. After seeing an old man, I looked back over my life. That's why; this profession made me empathize with the older people." (P15,25y, F)

"There has been a change because when I first graduated 15 years ago, I was inexperienced. I feel sad for the older people." (P1, 38y, F)

When I get Older...

This theme explains the expectations and perceptions of nurses when they are old. Those who care for the elderly today will be the elderly of the future. In this respect, it is understood that nurses are afraid of being alone in their thoughts about old age.

"I don't want to be alone. I think people are afraid of being alone. Even now, it's scary." (P3,25y, F)

"Of course, I would like them to support. So, maybe I might want to have a child. The feeling of loneliness is not nice." (P6,24y, F)

However, there were also nurses who reported that they had no expectation.

"I want to die without be in need. They said three days in the bed then to depart. That's my motto." (P9,26y, M)

"Everybody's personal life is important. Rather than being dependent on others, I would like to live in a proper place with people who are equivalent to me." (P15,25y, F)

Care for the Dying Patients

The emotions, thoughts, and care difficulties they experienced while caring for the dying patients were asked. In general, it was determined that the patients had difficulties due to the physical and cognitive deficiencies. These difficulties they experience may affect the perception and attitude of the older people. However, It was understood that nurses did not complain despite the difficulties they experienced.

"We sometimes have trouble on communicating. Some of them not hear or understand you." (P2,26y, M)

"It is difficult to position the older persons the neurology service. Especially if you're small like me." (P16,24y, F)

"They cannot turn right and left. Hip dressings are a bit difficult because their muscle strengths are weak a bit. It is hard to communicate. Also, their rehabilitation is difficult." (P12,28y, M)

It was determined that migrations originating from the Middle East have affected nurses in recent years.

"Sometimes, problem can be language. If the patient was a Syrian, you may not be able to communicate and help" (P3,25y, F)

Nurses also expressed the problem she experienced because the elder's generally do not have enough information about their health problems. They stated that it is difficult to care for dying patients who do not know about their health problems.

"We ask what disease you have. She says I don't have a disease. Then, I ask do you use any drugs. She says I use blood pressure medicine, for example." (P15,25y, F)

Expectations

As in the whole world, the workload of nurses is quite high in Türkiye. Due to this workload, the attitude towards the older people may be negatively affected. For this reason, nurses were asked about their expectations from the society and the state in order to better care for the older. These expectations may be affected by nurses' attitudes and perceptions towards the older people. This theme was examined in two subthemes as expectations from the society and the state.

Expectation from the Society

It was understood that the expectation of nurses from the society were to respect for the older people.

Generally, it was seen that they had expectations from society regarding respect for the older.

"I would expect them to be more respectful and more understanding." (P6,24y, F)

"Of course, the new generation is treating older people badly. They are making disrespectful, unpleasant sentences and accusations. Of course, there is a generation gap. Scientific boards that provide guidance training on this may be created." (P10,23y, F)

Expectation from the State

In this sub-theme, it was understood that there were different opinions on the need to improve economic, social and health services for the older people. It was understood from the opinions of the nurses that they found the services provided to the elderly inadequate and that they thought that the older people should live better.

"Currently, for example, someone is taking older aid from government and care for the dying patient. Does he really take the money and care for the patient, or just show it on paper and spend that money elsewhere? The state should control this." (P4,34y, M)

"Salaries can be paid higher so that they do not have financial problems. Health care team can be sent to their homes and their necessary controls can be made so that they are not dependent on anyone. It can be ensured that they are in touch with the hospital, and it can be controlled." (P3,25y, F)

"I think nursing homes can be a little better. Their loneliness can be reduced a little more, not only staying there but also social activities can be done." (P6,24y, F)

"I would like to have a separate section of gerontology or palliative centre in hospitals, for example. I would like people to work here who love the older (dying patients), have energy, both physically and in time, will provide to assistance them." (P15,25y, F)

"Families are usually unconscious. There are many families that are concerned, but it is not possible to give care when their socio-economic status and cultural level is very low." (P13,28y, M)

Discussion

With this study, it was provided an overview of nurses' attitudes, behaviors and thoughts towards the ageing and dying patients. It was understood from the statements of nurses that their attitudes towards old age and the dying patients were generally positive. They also stated that they expect their children to take care of them, when they get older. They also have expectations from the society and the state, even if just a tad, about the management of the providing care for the ageing or dying patients process better.

It was found that at the young age group of nurses, they were single, and their working durations were short. It was observed that the participants have similar socio-demographic characteristic with studies conducted with nurses (Burnes et al., 2019). In addition, it was understood that most of the nurses participating in the study consisted of nurses and all of them were university graduates at least. The fact that all participants have at least a university degree can be attributed to the regulation promulgated in 2010 (Nursing, 2010).

Nurses stated that the elder should be cared for in the family and likewise, they want to be with their families when they get older. It was reported in the literature that living with the older affects the desire to live with their family in the future (when they get older) (Guest et al., 2019). Similarly, in the "One Roof, Two Generations" program was reported that this contributes to improving health in general, strengthening emotional bonds and positive perception about ageing (de Jong Gierveld et al., 2012). Indeed, creating opportunities to bring the young and older person together, although not under the same roof, will reduce generational conflict. It was stated that bringing young people together with the older will be effective even in choosing old age-related professions in the future (Isaacowitz et al., 2021). The underlying reason why the nurses participating in this study stated that they respected the older and wanted to be cared for on their families can be attributed to spending time with the older.

Even though spending time with the older leads to the development of positive emotions, the diseases that surge with the ageing increase their needs and make their care difficult. In our study, it was found that nurses experienced difficulties related to physical and cognitive disability in older and dying patient care most. In a similar study, it was stated that older care was found difficult due to chronic diseases, the complexity

of medical treatment and communication problems (Kydd & Fleming, 2015). Moreover, a decrease in physical function develops on at least 30% of the older patients while staying in the hospital, and their dependency increases (Lennox et al., 2019). In a study conducted with nurses working in the emergency room, it was stated that they had difficulty meeting expectations of the older patients (Boman et al., 2019). However, establishing a social and emotional bond with the patients not only ensures that their hospital experience is positive but also makes them feel that they are respected (Molina-Mula & Gallo-Estrada, 2020). The fact that the nurses in this study established social and emotional bonds with the patients made us think that they did not complain although they had difficulties in providing care. Caring for the dying or older patient may lead to spring different feelings and attitudes in nurses. In a conducted study, it was stated that nurses wanted to help young patients rather than older, those with acute diseases rather than those with chronic diseases (Skirbekk & Nortvedt, 2014). Furthermore, it was also reported that nurses talk the older in simple words and spend less time to them (Šaňáková & Čáp, 2019). However, in this study, it was understood that caring for the older in nurses contributes to their development of positive emotions. It was considered that the underlying reason for the positive attitudes of nurses towards the ageing in this study results from the cultural characteristics. In the traditional Turkish family structure, it is significant to live with older until the last day and to care for them. In the studies conducted in Turkey about attitudes towards the aging, similar to the results of this study, it was stated that they respected the older and were patient while caring for the older (Polat et al., 2014). Apart from this, the fact that most of the nurses are middle-aged and single may have caused their attitudes towards the older people to be positive. In a study conducted with university students in Türkiye, it is reported that as the age increases, the sense of social responsibility increases and it is also affected by many variables such as family, friends and environment (Quadir & Koç, 2022). The middle age of the nurses participating in this study may have caused their social responsibilities and positive attitudes towards the older people. In addition, the fact that nurses are single can be attributed to the fact that they have no additional responsibilities and develop positive feelings about caring for the dying patients.

It was found that nurses have expectations such as economic or social support from families of the patients, society, and state while providing care to the older or dying patients. When the elders apply to the hospital, usually there is a family member with them. Having family relatives with them is important to obtain information from the patients. Existing diseases and deterioration in cognitive function due to dying process can prevent obtaining detailed information about the patient (Nikki et al., 2012). Lack of sufficient information about the patient may cause problems in the diagnosis and treatment process (Raney et al., 2017). Moreover, patient relatives play a role in providing much care of the patient, including daily living activities (Rossinot et al., 2019). Similarly, it was observed that the nurses in this study have expectations from the patients' relatives. In addition, they stated that they wanted a gerontology service or palliative centre to provide better care for their patients. In a study conducted in a similar way, nurses stated that they approve to have gerontology wards that are serving

only older patients (Deasey et al., 2016). Considering the expectations of the nurses from the state, they generally stated that they found the assistance provided to the older sufficient. However, it was understood from their discourses that they are issues that they expect to be fixed. Türkiye is a country where access to health care services provided at the national level as European countries. Although healthcare utilization is provided as a horizontal equity principle in European countries, sometimes it is not possible to meet the needs completely (Or et al., 2009). In Türkiye, government support is provided to those who care for the older by the Ministry of Family, Labour and Social Work, and their treatments administered a hospital by Republic of Türkiye Social Security Institution. On the other hand, the number of palliative care centres where dying patients are cared for is quite low. As in the case of France, there may be missing parts. It is considered that the issues that nurses expected to be fixed are related to these missing parts.

Conclusions and Recommendations

Understanding the feelings and thoughts of nurses in the process of providing care to the older or dying patients may contribute to increasing the quality of care services. In this study, it was understood that the perceptions of nurses towards the older or dying patients were generally positive.

According to the findings of the study, it is understood that patients do not have knowledge about their diseases, they are alone, and they experience physical and psychological difficulties. Nurses have expectations from society and the state to be able care for older or dying patients better and more comfortably. It is thought that workloads will decrease when these expectations are met. Therefore, good planning and arrangement in solving the existing economic and social problems of older or dying patients will also reduce the workload of healthcare professionals. While many health care systems are used for the older persons in developed countries, in developing countries such as Turkey, healthcare is provided by informal caregivers. This situation leads to a decrease in the quality of the healthcare service provided to the older persons or to encounter various difficulties in the absence of a caregiver.

Study Limitations

This study has some limitations. One of them the study was conducted in one hospital. This makes it difficult to generalize the results to general population. In the qualitative method, it is not known how much of the participants want to explain while their opinions and experiences are included. Sometimes problems such as not being able to remember the experiences of the participants and not wanting to share them fully arise from the nature of qualitative research.

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ORCID iD

Dilek BAYKAL https://orcid.org/0000-0001-5965-9318

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Author Biographies

Dilek Baykal, received the PhD degree in Istanbul University, department of Internal Medicine Nursing, Türkiye, in 2018. She current research is concerned with neurology, caregiver burden, quality of life and older care. She currently works as an assistant professor at the Department Nursing of Health Sciences, Istanbul Atlas University.

Necmiye Çömlekçi. Continued the PhD studying in Istanbul University-Cerrahpasa, department of Internal Medicine Nursing, Türkiye. She was worked extensively in the

areas of oncology, symptom management, and older care. She currently works as an research assistant at the Department of Nursing of Health Sciences, Bartin University.

Gulbeyaz Can continued the professor degree in Istanbul University-Cerrahpasa, department of Internal Medicine Nursing, Turkey, in 2018. She was worked between 2005 and 2010, she was an oncology nurses' representor at the National Cancer Advisory Board of the Turkish Ministry of Health and took an active role in establishing of the palliative care standard of Turkey. Her primary responsibility is patient education and counseling. She has many contributions to the literature on cancer, palliative care, and other research topics. The focus of her studies is an evidence-based symptom management in oncology. "Leman Birol Award" in 2005 by the Turkish Oncology Nursing Association and "The International Award for Contributions in Cancer Care" by ONS in 2018 was given to Can for her contributions to Oncology Nursing.