

Original Article

Turkish Family Decision Making Process for Placing a Loved One with Dementia in Long-Term Care

Ozlem Kucukguclu, PhD

Professor, Department of Internal Medicine Nursing, Dokuz Eylul University Faculty of Nursing, Inciralti, Izmir, Turkey, ozlem.kguclu@deu.edu.tr

Hatice Mert, PhD

Associate Professor, Department of Internal Medicine Nursing, Dokuz Eylul University Faculty of Nursing, Inciralti, Izmir, Turkey, hatice.mert@deu.edu.tr

Burcu Akpınar Soylemez, PhD

Assistant Professor, Department of Internal Medicine Nursing, Dokuz Eylul University Faculty of Nursing, Inciralti, Izmir, Turkey, burcu.akpinar@deu.edu.tr

Correspondence: Burcu Akpınar Soylemez, Assistant Professor, PhD, Department of Internal Medicine Nursing, Dokuz Eylul University Faculty of Nursing, Inciralti, Izmir, Turkey, burcu.akpinar@deu.edu.tr

Abstract

Aims: This descriptive qualitative study was conducted in an attempt to understand the experiences of family members of people with dementia in the process of deciding to institutional their care.

Methodology: The data were collected from 15 caregivers using a semi-structured data form with in-dept interviews. The data were analyzed using qualitative content analysis.

Results: Three main themes identified were having difficulty providing care, seeking solutions to maintaining care at home, and difficulty in decision-making to place their family members in a long-term care facility.

Conclusions: Turkish families experiences difficulties about decision making process for placing their loved ones in a long term care. Results showed us that they need support in this process. Nurses should consider their feelings and support them.

Keywords: Caregivers, Dementia, Decision-making, Institutional care, Qualitative research

Introduction

Caring for a family member with dementia at home can be a strain on the caregiver and other family members. Sometimes family support is not sufficient requiring outside assistance. When outside assistance is not adequate or the caregiver has health problems, the family member with dementia must be placed a in long-term care institution. This study presents the difficulty families can have on making a decision to place a member in a long-term care institution. In the collectivistic Turkish culture, placing a family member in an institution can result in a stigma for the family. This research uses the term, patient, to

refer to a person requiring care at home or in an institution.

Background

Dementia is a syndrome causing progressive cognitive and behavioral problems. According to a study conducted in Turkey, dementia prevalence is 8.4% which increases in parallel with age. While the rate of incidence is 2.2% in the age range of 55-59 years, it is 30.4% in the age 75 and above (Arslantaş et al., 2009). A number of cognitive, functional, and behavioral problems complicate the home care and cause nursing home placement of patients with dementia (Gaugler, Krichbaum & Wyman, 2009;

Jennings et al., 2015). Many families institutionalize their loved ones with progressing dementia when it becomes almost impossible to care for them at home. However, many families have difficulty institutionalizing their loved ones with dementia due to the cultural, emotional, and economic concerns. The decision for institutionalization is made by families after considering all alternative methods (Chang & Schneider 2010, Kwon & Tae 2012). Even though there is a high tendency for older individuals to traditionally live with their families and children in Turkey, the recent change towards the nuclear family has increased the number of individuals requiring institutional care (Turkey Family Structure Survey, 2014).

The decision to institutionalize is a process with sociocultural dimensions and is affected by the characteristics of the patient and their caregivers (Gaugler, Krichbaum & Wyman, 2009; Verbeek et al., 2012; Kraijo, Leeuw, Schrijvers 2015). These characteristics for patients include cognitive impairment, age, sex, unable to perform activities of daily living, and behavioral and psychological symptoms. Characteristics for caregivers include age, sex, relation with the patient, health status, health-related quality of life, educational background, financial situation, and caregiver's burden and depression (Argimon et al., 2005; Gaugler, Krichbaum & Wyman, 2009; Gilley, McCann, Bienias & Evans, 2005; Drame et al., 2012; Stephan et al., 2014; Kraijo, Leeuw, Schrijvers, 2015).

The severity of cognitive impairment of patients has been positively associated with nursing home admission (Coehlo, Hooker & Bowman 2007; Luppá et al., 2009). However, cognitive impairments were not the only reason for institutionalization. When cognitive impairments are accompanied by disruptive and aggressive behaviors with gradually reduced functional capacity it becomes more difficult to care for patients at home (Luppá et al., 2009). Turan and Yılmaz (2008) found significant correlation between the decision concerning the nursing home placement and the decline in the mini mental status of patients, presence of behavioral and psychological symptoms, inability of patients to maintain their self-care, sleep disorders, and the burden of caregivers. Stephan et al. (2014) underline the importance of factors such as the severity of dementia and behavioral problems of patients, their overall health status, and exhaustion of caregivers in deciding for

institutional care. Variables such as the severity and length of the illness, presence of psychiatric symptoms, age, educational background of caregivers, and home care expenditures affect the institutionalization of patients (Gaugler, Krichbaum & Wyman, 2009; Luppá et al., 2009; Stephan et al., 2014). Matsumoto & Inoue (2007) reported that the decision for institutionalization originated from factors such as urine and fecal incontinence, inability of patients to perform self-care and being housebound (Matsumoto & Inoue 2007). The burden on caregivers and their difficulty in care remarkably affected their decision for institutionalizing their patients. Caregivers experiencing burden and increased difficulty in providing care have a higher tendency to institutionalize patients (Gilley et al., 2005; Stephan et al., 2014).

Many studies originate from western countries and represent the data from the society where the study is conducted. However, findings from these studies may be beneficial in providing guidance for other cultures with different social, political, and economic structures. Turkey, a multi-ethnic and multi-religious state, combines a highly diverse and heterogeneous set of conditions that have been derived from various cultures. Turkish culture with traditional strong family ties has negative attitudes toward institutional care and can cause a stigma when a family member is placed in an institution. Therefore, research is needed that describes the experiences and decision making process that necessitate Turkish families to institutional care of their loved ones with dementia. This study was conducted to understand the experiences of families who had the need to place their patients in long-term care institutions. The findings will facilitate crosscultural comparisons and culture-oriented family care planning.

Methodology

This descriptive qualitative study reports the experiences and decision making process of families taking care of people with dementia necessitating their placement in long-term institutionalized care. The interviews were conducted in two nursing homes in a large city in western Turkey.

Participants

Purposeful sampling method was used to obtain participants for this study.

Criteria for Inclusion:

1. Being a family member who was the primary care taker before the institutionalization,
2. Voluntarily agreeing to participate in the study,
3. Able to speak Turkish, and
4. Agreeing to have the interview tape recorded.

The sample consisted of 15 family members who were the caregivers of their patients with

dementia before institutionalizing them. The ages of the family members were 34-63 years ($x=51,06$, $SD=7.52$); 5 of were male and 10 were female. Twelve family members were the children of people with dementia, 2 were daughter-in-laws, and 1 was a grandchild. Family had taken care of their patients at home from 2 - 11 years.

Following home care, the patients received institutional care from 1 month to 6 years (see Table 1).

Table 1. Characteristics of Family Caregivers

Subject	Years in Caregiving Role Before Placement	Time Since Placement	Caregiving/Kingship
1.	3 years	1,5 years	Son
2.	10 years	2 months	Son
3.	6 years	2 years	Daughter in law
4.	7 years	1 years	Son
5.	7 years	1 years	Daughter
6.	3 years	1,5 years	Daughter in law
7.	5 years	1 years	Daughter
8.	3 years	2 years	Daughter
9.	2 years	1 years	Grandson
10.	6 years	2 years	Daughter
11.	11 years	6 years	Daughter
12.	5 years	6 months	Daughter
13.	4 years	1 months	Daughter
14.	8 years	1 years	Son
15.	2 years	6 months	Daughter

Ethical Considerations

The Institutional Review Board of a large university in Turkey approved the study. Written permissions were also obtained from the institutions where the study was conducted. Before interviews began, participants were informed about the objectives of the study, that the information collected would be confidential and no individual would be identified, and that the interview would be tape recorded. Verbal and

written consents to participate were obtained and participants were informed that they could drop out of the study at any time.

Data Collection

The study was conducted in two nursing homes in western Turkey. A semi-structured interview form was used for in-depth interviews, lasted for 45-95 minutes, and were tape recorded. Interviews took place in a quiet room with no interruptions.

The interview questions were as follows: Can you tell us about your experiences in the process of deciding to place your family member in a nursing home? How did you feel about the decision-making process?

Data Analysis

The data were analyzed using qualitative content analysis. Fifteen audio-taped interviews were transcribed verbatim and the data were coded separately by two researchers and then the

codings of the researchers were combined. Following the codings, the common themes and sub-themes were identified.

Results

Three main themes identified were having difficulty providing care, seeking solutions to maintaining care at home, and difficulty in decision-making to place their family members in a long-term care facility (see Table 2)

Table 2. Themes and Sub-themes

Having Difficulty Providing Care	Disruption in family life Failure in receiving support Health problems of caregivers Increase of problems because of progression of disease Failure in coping with the new situation
Seeking Solutions to Maintaining Care at Home	Efforts of home care (care by siblings in turn) Seeking a caregiver support Seeking a professional support
Difficulty in Decision-Making to Place Their Family Members in a Long-Term Care Facility	Despair Ambivalent emotions Social pressure (cultural factors) Anxiety about the institution

Having difficulty providing care

Sub-themes identified were disruption in family life due to care responsibilities, failure to receive support from other relatives, health problems of caregivers, increased problems related to the progression of the illness, and failure to cope with the new situation.

Disruption in family life

Family members stated that they had a disruption in family life and a great difficulty due to the obligation of constantly being with the patient, conflicts with their partners, negative affects on children at home, conflicts between the people with dementia and other family members, and conflicts between siblings regarding the care.

When his health deteriorates, it bothers both the family and other people. I have started to go there so often that my family life has been disrupted (son, participant 4)

My sister has a little boy and my father is not so nice towards him. He affected from situation negatively (daughter, participant 5)

She wants my husband to turn off the TV in the evenings. She does not allow my husband to watch the TV (daughter, participant 7)

Failure in receiving support

Half of the caregivers stated that they received no support from their siblings to continue the care at

home, the caring responsibility was left to the same person, and they had no strength to take care of the patient alone.

From the very first day, my sister started complaining that he did not eat or take his medicine. They brought every single problem to me. And finally, my sister said; "I will no longer look after him, you can do what ever you want". That, indeed, was the end point (son, participant 1)

My sister brought my mother and said "I do not want this (pointing her mother), so do not call me again. Call me just in case something urgent happens". She left my mother in front of the door and went back (daughter, participant 10)

There is nothing as disturbing on earth as seeing four children refuse to take care of their mother. But I had to make that decision as I had no strength to take care of her alone (daughter in-law, participant 6)

Health problems of caregivers

Family members stated that they had or developed health problems and therefore, they had a difficulty in taking care of their patients.

My health deteriorated in that process and I took antidepressant medications. My blood pressure started to increase and I started to take antihypertensive medications. My sister had similar problems. She also took antidepressant medications due to the same reason (son, participant 4)

They kept giving me a hard time. And my distress caused my vitiligo (pointing her face) to spread all over my face (daughter, participant 10)

My wife had hemiplegia and my son was disabled. I, on the other hand, was receiving the treatment for my Behçet's syndrome. Our health posed an apparent obstacle (son, participant 1)

Increase of problems because of progression of disease

Almost all the family members stated that they had decided to institutionalize their patients in a nursing home when their patients could no more maintain their self-care (such as feeding, going to

the toilet, taking medicine), demonstrating aggressive behaviors, causing security problems like fire or getting lost, and behaviours like getting undressed unappropriately.

My father started to lose his control, forgot things and got lost. As he was unable to do things properly, he started to attack and hit me. I could see the monster in my father (son, participant 1)

He had left the oven on and the neighbors had seen it. The window was open. The neighbors told me that they had smelled gas (son, participant 2)

Failure in coping with new situation

Family members stated that they could not cope with the symptoms of the illness and majority of them took antidepressant medications as they were exhausted during that process.

Someone calls you and tells you "your mother has fallen on the street", "she has fallen ill", "your mother is missing". I mean, I repeatedly experienced these kinds of situations and they started to force the limits of my tolerance. I felt incapable of managing all these problems. Human beings have a limit of tolerance. Once it is exceeded, you get highly exhausted (daughter in-law, participant 3)

At night, he was always on my mind; whether he would get up, go to the window or out to the balcony, or to the door. Because he used to always go to the door. I was getting highly suffocated (daughter, participant 11)

Seeking solutions to maintaining care at home

Sub-themes identified were efforts for taking care at home (care by siblings in turn), seeking a caregiver support, seeking professional support.

Efforts for taking care at home (care by siblings in turn)

All the family members stated that they tried to take care of their patients with their siblings in turn before the institutionalization and thought that it would be better for them to be taken care of in their own social environment.

He lived in his house for approximately three years under our (me and my siblings) supervision and with the

support of his neighbors when he was left alone. He stayed with my elder sister in another city for a while (son, participant 14)

I still think that it will be better if he is taken care of in his own social environment and gets protected with love (son, participant 1)

Seeking a caregiver support

Family members stated that they tried to take care of their patients with the support of a caregiver at home when they were unable to maintain their self-care. However, as the caregivers had difficulty in home care, they usually ended up in long-term care.

I decided that she could no longer live alone. So I hired a caregiver and I moved them to my home. It was not possible for me to cope with it alone, but she refused the hired caregiver. She just pushed her and reacted. She could not get adapted to her (the caregiver) in the house (daughter in-law, participant 3)

If I hired a caregiver and took care of my mother at home with her, it would be okay. But I could not find a skilled caregiver. I was mentally, physically, and financially destroyed with the incompetent caregivers (daughter, participant 5)

Seeking professional support

Caregivers stated that they sought professional support with the suggestions of doctors and other relatives when the dementia progressed. A nutrition problem emerged and caregivers could no longer take care of them at home.

An eating problem emerged as the dementia progressed. The paid caregiver could not take care of my mother under the new conditions. Needs of my mom started to change. And as we thought that the caregiver would not meet them, we decided to employ a more professional caregiver (son, participant 2)

I don't have the opportunity of taking care of my mother at home, which forces me to have professional care support. My sister and I did not have appropriate conditions for good care. Because we were not professional. We didn't exactly

know what to do. My mother's problem was not only her old age. If so, we could manage it. But she needed professional care as she had Alzheimer's disease (son, participant 14)

I am not a professional. I can't properly direct her emotions and thoughts. I can't meet all her needs (daughter, participant 5)

Difficulty in decision-making to place their family members in a long-term care facility.

Sub-themes identified were despair, ambivalent emotions, social pressure (cultural factors, anxiety about the institution.

Despair

Family members stated that even though they made a great effort to delay institutional care, they had no opportunity for care at home and desparately, they had to do it.

I objected and still object to the institutionalization, but I had to accept it. I wish I had better opportunities. I wish my wife and my child were not disabled and I could take care of her (he cried) (son, participant 1)

We institutionalized my mother in the nursing home as we were desperate and wanted her to be comfortable. We would not even consider it if she did not have the Alzheimer's disease (son, participant 14)

Ambivalent emotions

Family members stated that they constantly felt instability in the process of deciding to institutionalize the patient. They also stated that they considered the idea of institutionalization within themselves, but never expressed this idea verbally. Those mentioning the idea of institutionalization, on the other hand, experienced ambivalent emotions.

I constantly felt instability in the process of decision-making. One moment, I get so angry that you consider nursing home care. But five minutes later, I regret it. My decision and emotions had changed frequently. Sometimes I wanted to shout but I never did it (son, participant 1)

My logic tells me to do so, whereas my heart does not... (daughter, participant 15)

Her care needs changed and increasingly continued. We had heard about private nursing homes, but we still had qualms. But of course it was not easy to make that decision as we were her children (son, participant 4)

For six whole months, I struggled terribly with my logic and my heart. It was such a great dead-end (daughter, participant 13)

Social pressure (cultural factors)

Family members stated that their patients could not maintain their self-care, requiring professional support and better care; however, they had to delay that decision due to social pressure, refused to institutionalize them, and experienced a great dilemma in making that decision. In the Turkish culture, making a “decision for institutionalization” might be interpreted as “getting rid of the individual”. Thus, some of the caregivers used the statement “get rid of” during the interviews. Adult children who lives in Turkey stated that they had a great difficulty in deciding to institutionalize their patients, whereas their Turkish siblings or relatives living abroad in a different culture could easily make that decision.

I guess we were raised in a different perspective; we were raised with a sense of obligation to take care of our parents. My brother lives in Germany. As soon as he was informed about my father's diagnosis, he immediately recommended the nursing home (son, participant 1)

We are raised within the Turkish society and adopt the culture of that society. I mean, institutionalizing my mother would be considered a disaster by the society. They would say, ‘why have eight children failed to look after their mother and why have they left her in a nursing home?’ (son, participant 14)

Unfortunately, our society perceives the decision of institutionalization as getting rid of that person. I have recently heard one of our statesmen saying “we have to look after our parents forever and we should never leave them in a nursing

home”. Noone wants to get rid of anyone. But when you are desperate, you begin considering places where health assistance is provided. Undoubtedly, there is an abundance of social pressure, family pressure in our culture in this process (son, participant 2)

Anxiety about the institution

Almost all family members stated that they had anxiety about “not receiving good care in the institution”.

Before placement, we got a list of five – ten private nursing homes that were close to our house and convenient for us. Then we visited them one by one and evaluated concerning how they were providing care. You have to make some research for someone you love. You can't just make a quick decision (daughter in-law, participant 3)

Are they gonna take care of her as good as we do? How is she gonna be taken care of? These were among some of my thoughts (daughter, participant 12)

Discussion

In this study, three main themes were identified: having difficulty providing care, seeking solutions to maintaining care at home, and difficulty in decision-making to place their family members in a long-term care facility. Other studies have reported that family members taking care of people with dementia experience similar negative emotions as demonstrated in this study (Coehlo, Hooker and Bowman 2007; Chang & Schneider 2010; Stephan et al., 2014).

In interviews in this study, the caregivers stated that as the illness progressed, the home care needs gradually increased and they experienced an increased burden and difficulty in care. Similarly, Coehlo et al., (2007) reported that as the illness progressed so did the cognitive function of patients, which was among important reasons for seeking institutionalization. Patients with a gradually worsening cognitive function have higher needs and more compelling home care, which accelerated the decision for institutionalization. Behavioral problems were also among important factors for caregivers to consider for institutionalization. Stephan et al. (2014) also reported that the institutionalization of patients increased in parallel with an increase

in their behavioral problems. In addition, the researchers stated that gradually decreased functional capacity was also related to the institutionalization of patients. The caregivers who were interviewed within the scope of this study reported that behavioral problems of their patients was a component for considering institutionalization because they were unable to manage these problems.

Family members reported that they had disruption in family life, received insufficient support from other family members, and the emergence of their own health problems making home care impossible. Caregivers experiencing burden and difficulty had a higher tendency to place their patients in a nursing home which is similar with other research (Gilley et al., 2005; Stephan et al., 2014). Family members also stated that they had tried to take care of their patients, provided care with their siblings in turn, and employed caregivers at home before the decision for institutionalization. When they could not find any other options, they decided to institutional care. Other researchers also stated that the lack of support from family members affected the decision for institutionalization (Buhr, Kuchibhatla & Clipp 2006; Andel, Hyer & Slack, 2007).

During the decision-making process, family members mentioned despair, ambivalent emotions, social pressures, and anxieties. The decision for institutionalization is a sociocultural process (Verbeek et al., 2012) and is not readily accepted in Turkish culture. In the Turkish culture, people pay great attention to the thoughts of other people. For instance, they frequently ask the question, "what will others think" (Cüceloğlu, 2004). Thus, while making a decision about institutional care, individuals experience great difficulty and ambivalent feelings because of society's negative views towards institutionalization.

In this study, once family members made a decision for institutionalization, great efforts were made to find a good place. Many of them had negative views about the quality of nursing homes. Almost all the family members stated that they had made great effort and conducted good research to find a clean, professional, and convenient nursing home before making the decision for institutionalization. These results are consistent with the results of study conducted by Chang & Schneider 2010.

If family members believed that the selected nursing home was good for their patients, they felt comfortable and peaceful. This alleviates their feelings of guilt. While other studies examined the experiences of caregivers' decision for institutionalizing their patients with dementia in a nursing home from diverse cultures, this study was conducted with sample from Turkish culture. Because the majority of families in this study experienced social pressure against institutionalization, they delayed their decision as long as possible. One example of differing intra-cultural views is demonstrated by two siblings, one living in Turkey and the other in another country. While the sibling living in Turkey wanted to delay the decision for institutional care, the sibling living abroad wanted the decision made quickly.

Professionals providing health and social services should consider the cultural differences and subjective values of individuals. In Turkey, institutional care is not culturally and socially approved yet. Thus, it is very important to know the caregivers experiences while making that decision.

Limitations and Conclusion

This study enabled us to understand the experiences of Turkish family caregivers in the process of institutionalizing their family members. The results cannot be generalized to Turkish culture as a whole because of the diversity in Turkish and the small sample. These results make a small contribution to the healthcare professions, providing data on how some families decide to support and institutionalize their family members. The experiences of each family member are very precious for the health care professions. More qualitative research with larger samples is needed to understand the experiences of Turkish families requiring institutionalization of their loved ones.

Additional, limitation of the study were the different duration of nursing home stay of the demented elders. Duration of stay varied from one month to six years. Further study, clearly reveal the experiences, for instance within six months post nursing home admission, might be valuable to enhance deeper understanding into the nursing home placement decision making experiences of family members of demented patients.

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