

## Experiences of Informal Caregivers in Turkey: A Qualitative Study

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**ABSTRACT** This research is designed with a qualitative approach and an aim to understand the experiences, emotions and problems of the family members, who give informal care to the bed ridden patients. Basic concerns of the present research are the perceptions of caregiving, the effects on the caregiver's emotions regarding the homecare process, the obstacles for the caregivers and the role of domestic support and gender in the homecare process. Most family members stated that they have incurability and burnout in the homecare process. In addition, they indicated that being a formal caregiver is the task of the women at home. Informal caregivers also noted that the biggest obstacles in the caring process are the economic and the social problems. Both the bedridden patients and the informal caregivers can experience physical and psycho-social problems because of immobility or the lack of capacity to move. It was concluded that families should be provided with psycho-social support and that the care should be planned professionally.

### INTRODUCTION

Due to the human nature, nursing neediness has always had prominent issues in every era of history. Although there are differences among the methods and the provisions of the nursing services, human beings have preferred to look after their relatives and immediate friends at home because of their love and a feeling of loyalty towards them (Karatas 2011). Social values, traditions, customs and religion in Turkey present a supportive approach regarding nursing the patients at home. Therefore, people prefer giving care to their sick abed intimates in their homes instead of settling them in a professional caring center. Caring at home can be classified under two groups as professional and voluntary. Whereas people giving voluntary care do not expect any return on their services, the ones giving professional care expect a material return for their services. Professional homecare is providing services and equipment to the patients in order to maintain their health, functionality and comfort at a maximum level or reassuring these (Journal American Medical Association 1990). Homecare is the service provided by the health professionals for health care and supportive care. In all life-cycles, homecare is an

extensive and an integrative part of the health care provision system to patients in their individual environments. Homecare process is a service aiming to allow families and individuals in the long-term caring needs to reach maximum treatment and to minimize adverse impacts of the sickness and handicap by affecting their daily life at a minimum possible level (Fadiloglu 2013). Since human beings are biological, psychological, social and cultural creatures, they need a number of things. Beside physiological needs such as cooking, drinking, breathing and cleaning; there are psychological and social needs such as loving, being loved, being respected, and recognized by others. Under regular circumstances, it is expected that self-caring activities can be implemented independently. However, this is not always possible. An individual who experiences inadequacy due to his/her handicap, elderliness or disease might need others' support. Necessity of this support service results in putting the caring services into action (Karatas 2011; Atagün et al. 2011).

In the U.S. and in Canada, homecare services are essential in terms of efficiency of the patients with chronic disease and elderliness care. In the U.S., establishments more than 18,000 are providing homecare services to 7 million people from all the age groups with a permanent hand-

icap or acute diseases in their terminal period, and need a long-term care (National Association for Home Care and Hospice 2004). Forty-four percent of these people were the patients who had been just discharged from the hospital and needing medical or nursing care and required a post-hospital care at home, which cannot be provided by their intimates (American Medical Association 1991). In Denmark, the results of a 6-year pilot research introduced in the four territories in 1937 revealed that the home visits during the postpartum period reduced the death rate of the babies and their sickness rate played a significant role in increasing the importance of the home visits and homecare. In the homecare health system of China, homecare services are adopted as a method to provide service to the elders. In Turkey, homecare is a service that has gained prominence in the last decade. Homecare activities in Turkey were taken into legislative scope based on the legal regulation called "Legislation on Provision of Homecare Services" published on the Official Gazette with 2575 serial number on 10.03.2005; and it was necessitated that all the institutions which provide the service in this framework are required to obtain the certificate of conformity from the Ministry of Health. According to the directive issued by the Ministry of Health, with 01.02.2010 date and 3895 serial number, a program for giving the health services at home was introduced in Turkey. Then, a new directive took effect with an official endorsement with 8751 serial number on 24.02.2011. According to the data published by the Ministry of Health in 2011, 85,358 patients received a homecare service (Ministry of Health 2011). The relevant statistics indicate that professionalism and institutionalization of the homecare services have developed in parallel to the technology and the science. Based on the data published by the Turkish Statistical Institute (TUIK) in 2015, while the population of citizens 65 and over was 6,495,239 (8.2%) in 2015, it is envisaged that this population would be 19,484,834 people (20.8%) by 2050. Again, based on the 2002 data of the TUIK, percentage of the handicapped population in Turkey was twelve percent. 1,228,355 people receive a monthly allowance from the fund for encouragement of social cooperation and solidarity under the Ministry of Family and Social Policies according to the law regarding allocation of monthly allowance to the Turkish citizens over 65 years old

*who are in need, helpless and solitary with 2022 serial number; which entails 145 TL (52 •) allowance for the elder citizens in need 65 and over, 291 TL (104 •) for the citizens between forty percent and sixty nine percent handicap rate, and 437 TL (155 •) for the citizens with a seventy percent handicap rate. Moreover, the cash allowance allocated to the citizens receiving the homecare service is 793 TL (281 •), (Ministry of Family and Social Policies 2013).*

Giving care is an experience perceived from multiple dimensions by the care givers. Through the care giving process individuals might experience several difficulties beside a number of positive sides such as arising sincerity and love, self-realization, self-development, receiving social support from others, self-respect, and self-satisfaction (Yaci 2011; Özdemir et al. 2009).

The present research aims to reveal the physical, psychological, and the social issues experienced by the family members who give care to a bedded patient, and what they feel about, what they experience in this process; and to provide psycho-training and suggestions on the social service intervention to bring a solution to the issues they face. Although there are a numbers of quantitative studies in Turkey concerning the caregiver burden, there are only a few qualitative studies on this subject. In these qualitative studies, while caregiver burden scales are applied, qualitative studies are oriented on problems, psychological and moral values of the care givers (Karatas 2011). Researches have usually been conducted on mental patients, individuals with neurological diseases, cancer, elders and dialyses patients. In this research, qualitative research patterns in which the care givers can express their feelings and thoughts clearly and freely were used.

## MATERIAL AND METHODS

### Sample

The present research which aims to comprehend the issues experienced by the family members who provide nursing to a sick abed patient is structured through a qualitative approach. The purpose, mutually shared by all the disciplines serving the human being, is trying to understand the human action in connection with its relative environment and from multiple perspectives. Human behavior can only be investigated

through a flexible and holistic approach; and opinions and experiences of the participants in this research are significantly important. From such a point of view, a qualitative research can be a major tool to comprehend the opinions and the feelings of the participants from multiple dimensions. Therefore, phenomenological approach pattern was used in the research. From the Social Assistance and Solidarity Foundation database, contact information was collected about the persons; and semi-structured deep interview sessions were held with the caregivers of 8 elderly patients who were confined to a bed. Interviews were conducted at their home in privacy. Majority of the patients' houses are private and they are located in the neighborhoods with disadvantage in terms of an infrastructure. Majority of these families also survive a life of economic difficulties. Physical structure of their homes is not appropriate to provide a comfortable life to a person confined to a bed. In some of these houses, restrooms were built outside. Interview commenced with filling in the personal information form and then, this was followed by an interview form. While the semi-structured interview was in process, both the relevant forms were filled in; and then, the interview was recorded with the help of a voice recorder. Before the process started, purpose and confidentiality policy on the information were explained to the participants. During the process, the interviewer was not always satisfied with a "yes and no" answers; and sometimes respondents were excused for a while in silence. In end of the interview, relevant contact information was given in case they would like to reach the interviewer. They were asked if they had any further questions and their questions were answered; the interviewer abstained from being judgmental. Until a certain saturation level was acquired, appointments were maintained and they were kept at about 20-30 minutes.

### **Instruments**

The data collection tool consisted of two sections: while section one included a Questionary form which consisted of 15 questions to determine the socio-demographical characteristics of the participants, the second section included an application of a semi-structured form which consisted of investigator questions with alternatives prepared by taking the literature

(Kulkarni et al. 2014; Simmons et al. 2014; Stajduhar 2013; Pope 2012; Karatas 2011; Yilmaz et al. 2010; Huang 2004; Babaoglu and Öz 2003; Flanagan and Holmes 2000) and the nursing process into consideration. Before the data collection process, three patients were interviewed by the means of a semi-structured form; and various amendments were applied based on these interviews.

### **Data Collection and Analysis**

Detailed interviews with the patients and the care givers were held in their own residences by using an interview form. As the whole interview process was recorded through a voice recorder, obtained records were deciphered into written documents by means of a 4-hour study within a 30-day period. Documents were analyzed for their content through uploading them onto the NVIVO 8 statistical software program.

### **Measures Taken for Validity and Reliability**

Purposive sampling method was used to increase the liability and validity of the research. Interviews were also supported by the observations. In this research, the evaluation was done by six specialist persons –three academicians, two family practitioners and a homecare nurse with the researcher. To get a confirmation of the participants, it is asked to the persons whether to add or to remove any topics and answers were reviewed again. Detailed description was made and often direct quotations were given.

### **Ethical Considerations**

Participants were taken into the study on voluntary basis. Participants were informed about the privacy policy concerning the interview process and that interview records will not be used for other purposes. Special verbal permissions of the care gives were asked for the voice records. Required written consent was received from the Tosya County Governorship Social Solidarity and Cooperation Foundation concerning the usage of their data.

## **RESULTS**

Eight respondents participated in the study. All the individuals giving homecare service were

females; and their age varied in the range of 46 and 82. While single mean age of the participants was about 66, 7 of them were married and 1 was single. 2 of the participants were illiterate, 4 of them were literate, 1 was a primary school graduate, and 1 was a secondary school graduate. All of the respondents had social security. 5 of them were housewife and 3 of them were farmers. When the respondents were considered in terms of their relativity with the patient, 4 of them were the spouses of the patient; 2 of them were the daughters of the patient; 1 of them was the mother of the patient; and 1 of them was the grandchild of the patient. Whereas the shortest care giving period was 20 days, the longest period was 6 years. Concerning the number of residents at the patient's house, the number of member ranged between 2 and 6. Average household income per house was usually between 501 TL (178 •) and 1000 TL (355 •). While 6 of respondents had their own house, 2 of them resided at a rental place. While the age of the patients ranged between 42 and 87, mean age was 75. While 7 patients were males, one of them was a female. 4 of them were illiterate, 3 were literate, and 1 was a university graduate. Concerning the special room availability to the patients, while 7 of them had special rooms where they can stay alone, one did not.

### Perception of Giving Homecare

4 of the participant care givers viewed this process as an "obligation"; 4 of them viewed the process as a "responsibility". They described these feelings with expressions of "we have to look after him anyway", "he is our ancestor, we have to take care of him", "I need to take care of him until I die", "I am obliged to take care of him, I have to" and "this is of course a responsibility". "We will look after him in any case! He is our grandfather; even we take allowance (homecare allowance paid by government) or not, we have to take care of him. Even we have nothing, we are compelled to give care to him, and we have to." (G4, Woman, 46), "I think, this is more like responsibility. There is no something like obligation. You can't get anybody done something forcibly. I view this as responsibility. Not only in elderliness, you would not know, won't you? I can happen to all of us. Right outside of this door, I would stumble and fall, hit my head, and I would need

homecare during the rest of my life. I am doing this for the sake of my God. I am doing this because I wanted to." (G6, Woman, 57), "Because she is my mother, I have to take care of her until I die. She is my mother. She is my parent. I am obliged to take care of her. Whatever her faith is, I would ensure she receives proper service either in church or in mosque. This is my duty. This is my daughterhood duty (in a determined way)." (G8, Woman, 67).

### Hedges of Homecare Giving Process from the Point of Care Giver

All of the respondent care givers emphasized that the most significant hedge in the caring process is "economic and social issues". "You would not make a phone call to anybody to talk about your problems. We are experiencing economic difficulties." (G1, Woman, 63), "When you can't make money, and when your expenses increase, of course difficulties increase necessarily. Over the time, we have learnt how to manage in terms of economic way; we are trying to survive on a single retirement salary." (G2, Woman, 80), "I cannot get out of the house, we need money, but I not able to work; I cannot even visit my neighbors or shopping" (G5, Woman, 82).

### Importance of Gender and Family Support in Homecare Process

All of the participants who gave care emphasized the significance of the gender of the "woman"; and they indicated children as support factors in the homecare process. "My son says "mom, I feel sorry about you, I still have off days, let me come there and help you", but this is not something to with children. This can only be done by women, male children cannot handle this." (G8, Woman, 67), "My children also help me while I am taking care of my father. For instance, when he asks for water, they give him. When I am busy with something, they give his food and medication." (G6, Woman, 57), "My parents have already too much burden on them; they always support me by saying that my burden was also too heavy." (G1, Woman, 63), "Even we need our children's help to draw our allowances. Thank to our son, he is drawing it; and he goes shopping for us" (G7, Woman, 72).



### Care Givers' Feelings Due to Giving Homecare Service

Five of the participant care givers considered what they felt during the caring process as "desperation", and 3 of them considered it as "exhaustion". *"Sometimes I feel that I am so exhausted because; while there is no such problem within the family, he cannot do some activities because of his disease; some of his words offend me, some of mine offend him. But, then, we can get over this, we recognize that this is an issue due to his disease, and we move on. I took anti-depressant medication for almost one and half year. But, now, I am ok, I do not use it."* (G1, Woman, 63), *"I am doing best as I could. There is nothing that I want to do for myself. I am so sorry about my mother's situation. IT is not possible to ignore this. My mother was so hard worker. Now she is confined to bed, and she is sorry too"* (G3, Woman, 60). *"This is elderliness. It can happen to all of us. We would not remain always in the same shape like this. I do not get angry or I do not feel stressed because I am a calm person. I have erratic blood pressure disease. When I get headache, I would not recognize anybody. Even my children. I would not stand on my feet to prepare food myself. Somehow we need to give care, this is end of all. Of course, we are having difficulty to raise him; when think that we will be in the same situation, I get sad."* (G6, Woman, 57). *"I do not have chance to go out, how would I? When I go to the kitchen, he shouts after me not to leave him behind. Even, I am not able to do my daily works"* (G7, Woman, 72).

## DISCUSSION

### Perception of Giving Homecare

Within the scope of the research, some family members, who were interviewed in detail, view care giving process as an obligation but they avoided facing their feelings. Some members of the families giving nursing care view the caring process as a responsibility. It is remarkable to observe the word "obligation" used frequently in the opinions stated by family members regarding the caring process because while the family members stated that they had to do this, they considered their relationship and ties within family. Moreover, it can be deducted from this

expression that all the family members were obliged to take care of another family member who was confined to a bed. This also suggests that elderliness and being confined to the bed are viewed as a circumstance that can be encountered by any person. In another research conducted in Canada (Legare et al. 2014), it was reported that the family members who gave caring experienced problems concerning their values and their preferences about giving care. It was observed that two family members who gave nursing caring were not able to continue the caring service for their own relatives because of their personal physical and psychological problems. Furthermore, these family members experienced a contradiction while conciliation of their personal needs and their relative values. In another research, the majority of participants indicated that they perceived caring service as their religious, moral, and spiritual values. Additionally, there were also the one who do this for mercy, compassion, and responsibility (Karatas 2011). According to Heo and Koeske (2011), care givers emphasize that they maintain these services for the sake of the religious and moral values. Besides, the present research reveals that religious practices have a significant influence on the depression and the work load that arises due to care giving.

### Hedges of Homecare Giving Process from the Point of Care Giver

In Karatas's (2011) research, it was revealed that the majority of the care givers emphasized that they experienced difficulties in this process. Families also experienced problems because of the socio-economic poverty. In regard to the families interviewed within the scope of the research, twenty six percent of them stated that they experienced economic problems although they received homecare allowances. Giving homecare has a direct and/or an indirect cost burden on the families giving care. For instance, patients with chronic lung disease in the U.S. cause annual indirect cost of 2,200 USD and the relevant cumulative cost for the whole country was more than two billions in 2001 (Langa et al. 2002). The present research also revealed that the most significant hedges of the care givers are the economic ones. In the current research, economic problems were seen as prominent limitation and difficulty problems by the relatives of the pa-

tients. According to their initial reactions, the researchers observed the word “material” was used. In his research, Stajduhar (2013) emphasized that physical, psychological, and economic obstacles can be experienced. According to Huang’s (2004) research, monthly income can have an influence on the health of the care givers. In the various researches conducted on the family members giving nursing care to the cancer patients, it was determined that the care givers experienced difficulties with their nursing role (Babaoglu and Öz 2003; Flanagan and Holmes 2000). Again, in another study, it was found that activities such as walking, shopping, house works, and playing game have an influence on the caring load. Care givers who cannot do these activities have comparably higher burden scores (Cohen et al. 2014).

### **Roles of Gender and Family Support in Homecare Process**

As a result of the conducted interviews, it was seen that based on the fact that women have difficulty in participating in the official work force, and based on the perception that caring process is a job of the women, female caregivers usually look after patients confined into bed. In some studies in literature, it was reported that family member care givers are usually female. According to the traditional structure, it is emphasized that care giving works are woman-specific jobs because all the housekeeping work and cleaning work are usually carried out by the women (Adak 2003; Sims-Gould et al. 2013). In another research, it was reported that about ninety percent of the care givers were woman (Dramali et al. 1998). According to the findings of the research reported by Altun (1998), it was observed that seventy eight percent of care givers were women. Karatas’s research revealed that ninety three percent of care givers were women (Karatas 2011). In Pope’s (2012) research, the importance of the female care givers in the homecare service process were stressed; and it was reported that either female relatives of a family or a daughter can take over the caring duty. Cohen et al. (2014) suggested that seventy three percent of care giver family members were women. In the American society, eighty percent of the individuals giving homecare service are the family relatives. Almost three forth of the elders who receive nursing care from the family mem-

bers live in the same house with these members. Majority of them are the spouse or the daughter of the patient (Aneshensel et al. 1995). In Holland, ninety four percent of the employees working in the homecare sector are females (Danis and Solak 2014). Female care givers are usually 65 or older; they are married, jobless and they give more intensive and complicated homecare service compared to the male care givers. Responsibilities left by giving the homecare on the care giver, difficulties experienced in sharing these responsibilities with the other family members, and difficulties experienced in the caring process cause emotional problems for the female care givers. Women tend to give up on religious activities and attending them, to take over the caring responsibility (Navaie-Waliser et al. 2002; Thomas et al. 2002; Legare et al. 2014). In the present research, support factors of the homecare process were specified as their children. Legare et al. (2014) stated that family members who gave homecare service usually received support from their neighbors, friends and relatives such as their children, brothers, sisters, and cousins.

In the present research, it was seen that family support is more important for the support systems instead of the professional health workers. Yaci (2011), in his research compared the homecare burden and depression of the family members who give homecare to Alzheimer patients, reported that as stages of the disease progress, it was found that caring load and depression rates increased accordingly. Moreover, it was understood that increasing dependency on the daily life activities, neuropsychiatric symptoms, difficulty in the caring process, and expanding caring hours were significant factors that elevated depression rates and the caring load among the care givers. It was observed that the female factor only exhibited influence on the incidence of depression as a risk factor. This suggests that care givers and especially the women are required to be supported in terms of the support systems.

### **Care Givers’ Feelings Due to Giving Homecare Service**

Almost half of the care givers exhibited symptoms of depression and stress; and they complained that their sensitivity regarding their own personal health problems have increased

(Schulz and Beacy 1999; Thomas et al. 2002). The present research reveals that the feeling about the home caring process is usually desperateness and exhaustion. Home caring takes place in the range of 4 and 8 hours per day; but, since the care giver is a family member and the sick patient live in the same house, it can be considered as a 24-hours care giving day process. This responsibility might take between 1 and 4 years according to the health level of the patient confined to the bed (Stone et al. 1987). Karatas (2011) emphasized in his research that the care givers usually experience confusion and shock; and reported that individuals usually described this process as devastating. It was observed that the family members who give the home caring service to their patients usually feel sadness, desperation and exhaustion. If the care giver is a family member, they usually think that this process is sort of a test from God and they are punished because of the sins that they have been committing. In research, Özdemir et al. indicated that there were changes observed on the care givers' perception regarding their own personal health after they started the home care activity (Özdemir et al. 2009).

### CONCLUSION

Patients confined to the bed might experience several physical, social and psychological problems because they have limited or no mobility. These problems have also been observed for many family members who give nursing care to these patients as well. Care giver family members experience emotional problems such as exhaustion, desperateness, and sadness. Especially, it was observed that there are problems seen in the mobility-related issues such as taking the patients outside of the house or even taking them to the restroom was not possible. Physical conditions of the patients and their families' house usually affect the caring process adversely. For instance, location of house in narrow streets or on a hill, and the existence of narrow and high stairs in the house are prominent physical difficulties experienced during moving the patient. It was determined that the family member who provided the primary nursing care to the patient cannot fulfill their own social, psychological and moral needs because they cannot leave the home, to participate in social activities, spare time for themselves, and maintain

their own relationship with the neighbors because of the health condition of their patient. It was observed that the care givers are usually women and the significance of women in the caring process was emphasized. Especially, women are required to have the psycho-social support in this field. It was observed that families experience social-economic problems because they incur high expenses in the treatment and accessing services. Since average monthly income of the families is in the range of 501 TL and 1000 TL (178 • - 355 •), their income does not cover the costs associated with home caring. Moreover, since the care giver does not have any insurance, their personal treatment and medication costs are not supplied for.

### RECOMMENDATIONS

It is necessary to provide an insurance for the individuals who give minimum 8 hours of their daily time to towards home caring for a patient. Additionally, it was observed that family member experience exhaustion because there is only a limited support to the family member from other members of the family. When all these negative results are taken into consideration, the necessity of a family member who would support another member who gives the house caring to the patient should be emphasized. There is a need for asking for help from the professional medical caring personnel in the medical treatment of a sick abed patient. These professionals can be homecare technicians or an elder house technician competent in their fields. It is necessary to reorganize the physical conditions in the interiors of the house, and more comfortable physical environment is required to be structured for the patients confined to the bed or a wheel-chair in which they can be mobilized more comfortably. Care giver families are required to be supported in terms of the medication and the house conditions for the patients; and to facilitate their access to medical equipment by the relevant government bodies.

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