

Determination of the Problems Experienced by Patients with Chronic Diseases and Their Caregivers During Home Care Process From Nursing Students' Perspectives: A Phenomenological Study

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ABSTRACT

Aim: This qualitative study was conducted to determine the problems experienced by patients with chronic diseases and their caregivers during the home care process from nursing students' perspectives.

Methods: Phenomenological method of qualitative research was used in the study. Data was gathered via in-depth interviews with seven nursing students who had a family member with chronic disease. Students were asked about the problems they and their family members experienced during the home care process with a semi-structured questionnaire. Data obtained from the interviews were analyzed using content analysis.

Results: As a result of thematic analysis, problems experienced by the patients with chronic diseases and their caregivers during the home care process are grouped under five main themes. These problems were physical problems, social problems, financial problems, psychological problems, and treatment-related problems.

Conclusion: This research revealed that the home care process of patients with chronic diseases causes various problems for both patients and their caregivers. Therefore, it is necessary to be aware of these problems, increase the quality of home care services and ensure the continuity of home care. In this way, physiological, psychological, financial, social, and treatment-related problems can be prevented.

Keywords: caregivers, chronic disease, family health, home care, nursing students

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Introduction

Rapid developments in medicine and technology (1), development of societies, and success in the control of infectious diseases have led to the prolongation of human life and prolonged life expectancy (2). The prolongation of human life has also led to an increase in the incidence of chronic diseases such as cardiovascular diseases, cancer, diabetes, and chronic respiratory diseases. These are the world's leading causes of death which cause 41 million deaths each year and are responsible for 70% of worldwide deaths (3). The prevalence of these diseases continues to increase, especially in low- and middle-income countries (4).

Patients with chronic diseases require ongoing medical attention and care (5). Due to the long-term treatment and care, the demand for post-hospital care services has increased. In this context, the most accepted model is the home care model (2,6). In this model, the care needs of the majority of individuals with chronic diseases are met by family members (7). This responsibility is generally given to spouses or children and is perceived as a family responsibility (8). In this process, family members have many complicated roles such as observing the disease-related symptoms, meeting the patient's self-care needs, problem-solving, decision making, emotional support, patient safety, and providing appropriate equipment and materials for the patients (9). These bring social, physical, economic, and psychological problems for the patients and family members (10,11). Serçekuş et al. (10) indicated that caregivers those care for a family member with chronic diseases had physical problems such as headache, loss of appetite, weight loss, insomnia; emotional problems such as distress, sadness, shock, anxiety, irritability; social problems such as restriction of social life, not being able to allocate time to their children, and financial problems due to transportation costs and due to leaving work. In another study, Kapucu et al. (11) demonstrated the difficulties experienced by patients' relatives who care for bed-dependent stroke patients. Accordingly, it was determined that the most

frequently reported problems were inadequate family support, social isolation, restriction in social activities, reluctance inpatient care in general, reluctance to bowel management, anger, depression, anxiety, hopelessness, suicidal thoughts, and deterioration of professional life.

As can be seen, caregivers experience problems in different areas during the home care process of individuals with chronic diseases. If these problems are determined and solved, patients can receive better care. In addition, the home care process can be improved for both patients and caregivers by minimizing the problems experienced by caregivers and patients due to the care process. Although there are studies that reveal the problems experienced by caregivers and patients, studies that evaluate the problems of both caregivers and patients together are quite limited in Turkey. Therefore, there is a need for a study that determines the problems of both caregivers and patients together. Based on this, this study was carried out to determine the problems experienced by patients with chronic diseases and their caregivers during the home care process from the perspectives of the nursing students.

Methods

This is a descriptive qualitative study conducted with a phenomenological approach in which nursing students' experiences during the home care process are revealed.

This qualitative study was conducted between 25-29 March 2019 in the Nursing Department of Ankara Yıldırım Beyazıt University. In line with the research question and purpose, we aimed to reach all nursing students (n=550) by using the purposive sampling method and ask them if they had any individuals with a chronic disease that they care for at home. Inclusion criteria were; having a family member with chronic disease at home, taking an active role in the care of the patient, and agreeing to participate in the study voluntarily. We reached all the nursing students and identified seven students who met the inclusion criteria. Consequently, the study group consisted of seven nursing students.

Data of this qualitative research were obtained by using a semi-structured interview form via face-to-face in-depth interviews. Interviews were conducted by the first and second authors who are research assistants, each with a Ph.D. degree, and both are trained in the qualitative research process. Each interview started with three questions about demographic data and two open-ended questions about the problems experienced during the home care process. These were followed by probing questions to examine these problems in more depth and to enable the participants to state the problems in more detail. The interviews were made in a single session and each interview lasted between 10-30 minutes. An audio recording was not taken because some of the participants were hesitant about recording. Instead, the answers were recorded in writing by the researchers after obtaining permission from the participants.

Data were analyzed using content analysis, which is an inductive analysis type. Accordingly, first of all, the data were read in detail by the first and second authors. Words, phrases, and sentences that could be meaningful were marked and coded. Second, codes with similar characteristics and linked with each other were categorized and organized into themes. Third, these themes were named according to the characteristics of the codes in each category. Determined themes were shared with the third author to ensure validity and strengthen the accuracy. Finally, after there was a consensus among the authors on all themes, the data were presented and reported.

This study was performed in line with the principles of the Declaration of Helsinki. Written approvals for the study was obtained from the Ethical Committee of Ankara Yıldırım Beyazıt University (Date: 15.03.2019, Decision Number: 89) to apply the study. Participants were informed about the purpose of the study, how the interview would be conducted and how long it would take. Written consent was obtained from the participants that they voluntarily agreed to participate in the study.

Results

All seven participants in the study were women

and the mean age was 22 ± 1.5 (minimum: 20, maximum: 24). Their relatives with chronic diseases whom they care for at home were their mother (n=1), father (n=1), aunt (n=1), grandmother (n=3), and great aunt (n=1). Participants were asked about the chronic diseases of these individuals who were given home care. Accordingly, it was determined that these individuals had chronic diseases such as dementia, diabetes mellitus, chronic renal failure, hypertension, hyperthyroidism, breast cancer, Chronic Obstructive Pulmonary Disease (COPD), heart failure, laryngeal cancer, and retinopathy.

Data analysis revealed that problems experienced by nursing students, their families, and patients during the home care process are grouped under five main themes; physical problems, social problems, economic problems, psychological problems, and treatment-related problems.

Physical problems

The physical problems experienced by nursing students, their families, and patients during the home care process were divided into two groups; physical problems experienced by family members as caregivers and physical problems experienced by the patients. As a result of the basic and in-depth analysis, physical problems experienced by nursing students and family members were difficult in meeting the needs of bedridden patients such as in-bed movements, shower, and toilet. In addition, they had health problems such as low back pain, headache, scoliosis, flattening of the neck, insomnia, and fatigue (Figure 1). Some of the opinions expressed by the students are as follows;

In-bed movements, bathroom and toilet requirements were serious problems for both sides since he was bedridden. Physical problems such as low back pain began to emerge in my elders and me. (Participant 1).

Many of the responsibilities that I run with the belief that I do the best and I can't leave it to anyone triggered my neck headaches. It caused my thinking process to deteriorate, and I learned that my neck was flattening. (Participant 4).

The physical problems we experienced were

insomnia, low back pain, and fatigue. (Participant 7).

The physical problems experienced by the patients were lack of meeting their needs such as movement, hygiene, and excretion; bedsores, infection, sores in the mouth, loss of strength, nausea, muscle loss, fatigue, and weight loss. In addition, inability to distinguish the drugs, balance problems, need for support while walking, and fear of falling because of diabetic visual impairment were the other problems in this category (Figure 2). Some of the opinions expressed by the students were as follows;

Bed wounds and infection occurred at other children's homes (uncle and aunt) who care for our patient. (Participant 1).

He could not take a bath alone due to old age, balance disorder, visual impairment, and panic attacks... Because he had diabetes-related vision disorder, he could not balance himself alone and

needed support while walking. He couldn't tell his medicine, he needed help. He also needed help in adjusting his insulin dose and measuring his sugar. (Participant 2).

She has persistent muscle pain. A special bed was made but the pain continues. (Participant 3).

Due to cancer, muscle pain, loss of strength, nausea, loss of muscle, and loss of power due to surgical intervention and organ dysfunction, she had problems in returning to her daily activities and maintaining her self-care adequately. As she could not use her arm, she had insufficiency in dressing and inadequate body care and individual hygiene. (Participant 4).

After the intensive care period, my father had difficulty moving, and he could not move at all. Then he started to move with the physical therapy we applied. (Participant 7).

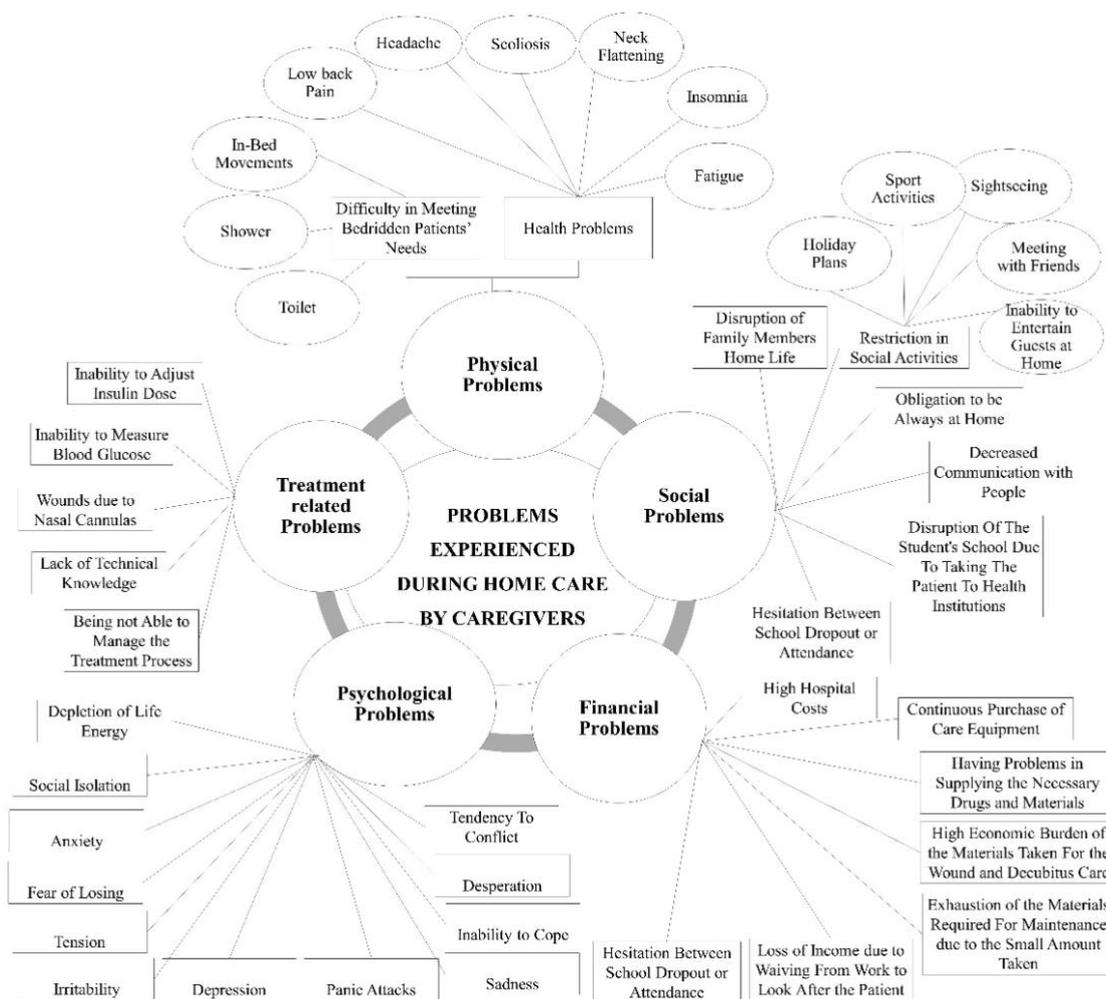


Figure 1. Problems experienced during home care process by caregivers

Social problems

The social problems experienced by nursing students, their families, and their patients during the home care process are divided into two groups; social problems experienced by family members and the social problems experienced by the patients. As a result of the basic and in-depth analysis, the social problems of caregivers and students were restricting family activities and holiday plans; deterioration of family members' home life due to the separation of a room in the house to the patient; inability to carry out social activities such as sports, sightseeing, meeting with friends; the limited circle of friends due to continuous care of the patient; the obligation to be permanently at home; decreased communication with people; negative reactions by the patient to the family members when they go out; inability to entertain guests at home, disruption of the student's school due to taking the patient to health institutions; and hesitation between school dropout or attendance due to financial difficulties in patient care (Figure 1). Some of the opinions expressed by the students were as follows;

Outside activities and holiday plan that we do as a family are restricted. One room was reserved for our patient. So the personal belongings in that room were moved to another room, our house layout has changed. (Participant 1).

Our patient is constantly sitting at home during the winter and wants his family members to stay with him all the time. When the family members go out, he reacts negatively to them because of the fear that his care will be reduced. That is why we cannot participate in all family special days and social activities. Somebody has to be always at home. (Participant 3).

Social problems experienced by patients were; being disturbed by the sound and the crowd, undesirability to have guests at home; requesting a family member near him all the time; social isolation (when no visitors are allowed to the house visits due to infection risk), being able to feed only at home and unwillingness to go out for eating (due to nausea and vomiting due to tumor and chemotherapy), being not

able to benefit from the state-provided home care service since there is no organ loss; and finally, inability to be included in social activities due to transportation difficulties (Figure 2). Some of the opinions expressed by the students were as follows;

We cannot provide transportation to include our patients in our activities. Although we provide transportation, sometimes he does not want to participate in the activities. He is often disturbed by the arrival of guests. (Participant 3).

We try not to accept guests because of the infection risk. But when the guests did not come, we observed that he was constantly sleeping. (Participant 6).

Since the tumor is in his throat, he has difficulty swallowing. That's why he doesn't want to eat out. Chemotherapy causes nausea, so he doesn't want to eat out. He also doesn't want to go out because of tiredness and psychological depression. He always wants to be at home. (Participant 7).

Financial problems

Financial problems faced by caregivers and patients were; high hospital costs, continuous purchase of equipment for the care, having problems in supplying the necessary drugs and materials for the maintenance of health, the high economic burden of the materials taken for the wound and decubitus care, exhaustion of the materials required for maintenance due to the small amount taken, loss of income due to waiving from work to look after the patient and insufficient budget to cover transportation costs for the socialization of the patient. In addition, since there is no health insurance due to foreign nationality, some had to pay fees for all health services, medicines, and care materials. This creates an extra financial burden when caring for these patients of foreign nationals at home (Figure 1 and Figure 2). Some of the opinions expressed by the students were as follows;

Since my father worked in construction, he was making as much money as he does daily and couldn't work when he needed to be with my grandmother. (Participant 2).

As with all diseases, cancer is related to nutrition, and cancer patients need natural, organic nutrition,

which is very burdensome. (Participant 4).

Treatment is very expensive. Because her medicines come from abroad. (Participant 5).

We had difficulty in supplying medication, hospital expenses, supplies necessary for sustaining health. Because my grandfather had no income other than a pension. So we were getting the supplies we

needed, little by little. Of course, this was a problem in emergencies. (Participant 6).

We made significant economic expenses for the decubitus wound after intensive care before cancer treatment. There were special dressing materials I bought for daily dressings. (Participant 7).

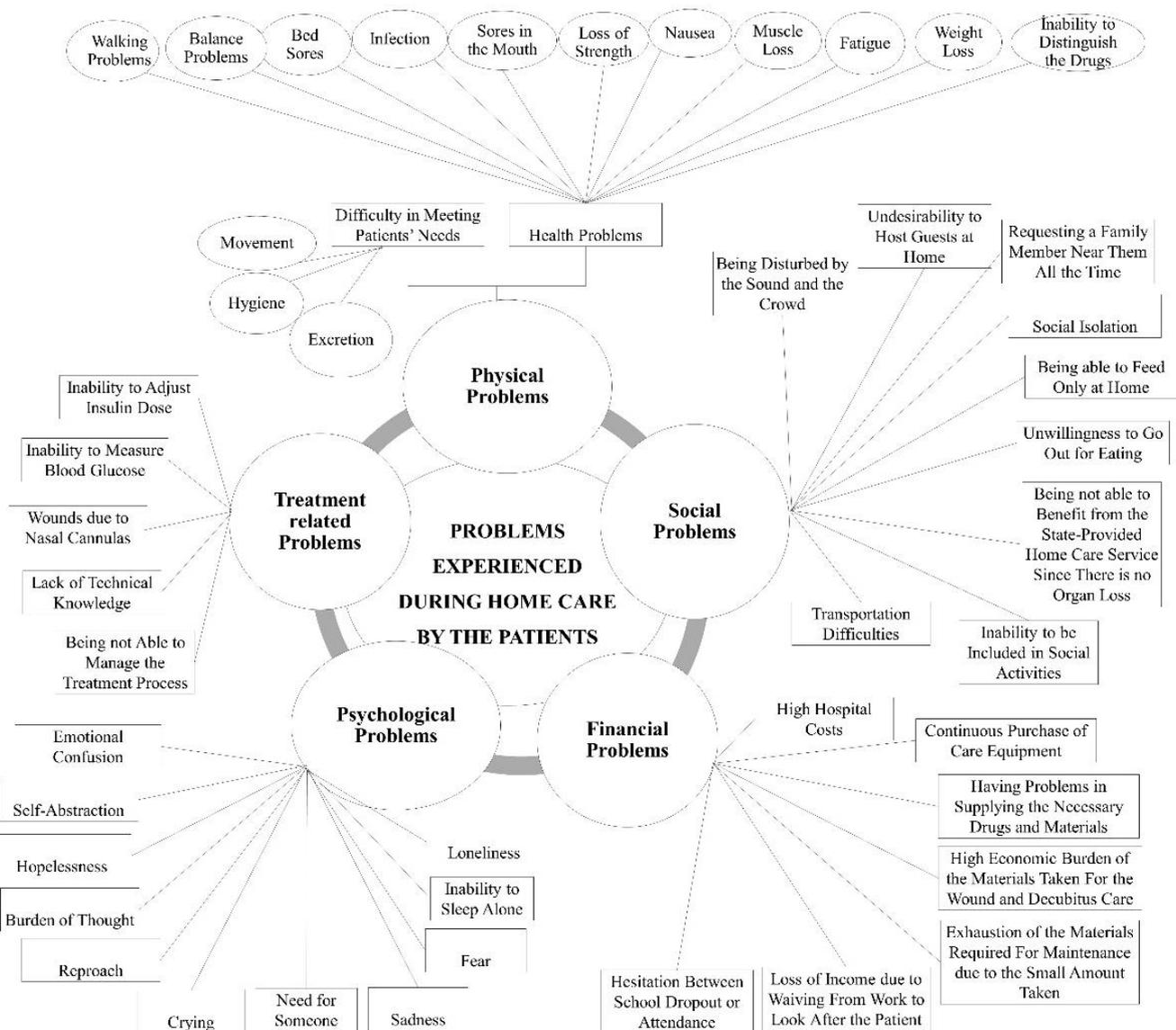


Figure 2. Problems experienced during home care process by the patients

Psychological problems

The psychological problems experienced by nursing students, their families, and patients during the home care process are divided into two as psychological problems experienced by family members and psychological problems experienced by patients. As a result of the basic and in-depth analysis,

it was determined that caregivers and students had psychological problems such as depletion of life energies, social isolation, anxiety, fear of losing, tension, irritability, depression, panic attacks, sadness, inability to cope, desperation and tendency to conflict (Figure 1). Some of the opinions expressed by the students are as follows;

My mother was constantly tired and tense because she had difficulty going to the hospital with my grandmother and doing housework. My grandmother's stress and my mom's tension and anger sometimes caused controversy. (Participant 2).

The failure to carry out our social activities and to host guests at home could cause conflicts between us and our patients. (Participant 3).

She became more sensitive to environmental stress due to the medications she took. Her restlessness and anxiety were inevitably reflected in me. She turned me into a worried and tired person who was too scared to entrust her to anyone. I had a panic disorder. I've had a much more anxious personality. Because of fear of loss, workload, and environmental stress, I became prone to depression. (Participant 4).

On the other hand, the patients had psychological problems such as loneliness, inability to sleep alone, the tendency to sleep, sadness, fear, need for someone, crying, reproach, the burden of thought, hopelessness, self-abstraction, and emotional confusion (Figure 2). Some of the opinions expressed by the students were as follows;

My grandmother was upset that she could not meet his needs. She didn't like to live addictively all the time. She would think about it and cry herself. (Participant 2).

Looking at him with pity eyes was hurting my dad so much. That's why he isolated himself. Occasionally, he had a feeling of confusion, sometimes laughing and sometimes crying. (Participant 7).

Treatment-related problems

According to the statements of the nursing students, we determined that both patients and their caregivers had treatment-related problems such as inability to adjust insulin, inability to measure blood glucose, and wounds due to nasal cannulas. It was also determined that there was a lack of technical knowledge in cases where the respiratory device has deteriorated and there were problems of not being able to manage the treatment process containing medicines and medical supplies at home (Figure 1 and Figure 2). Some of the opinions expressed by the students were as follows;

She could not distinguish her medications. She needed help adjusting her insulin dose and measuring her sugar level. (Participant 2).

As he was connected to the breathing apparatus, we had trouble when it broke down and we provided oxygen cylinders for emergencies. We carefully selected the nasal cannulae. Because the hard cannulae caused wounds and disturbed him. (Participant 6).

Discussion

This study aimed to determine the problems experienced during the home care process by nursing students, their families, and their patients with chronic diseases from the perspectives of nursing students. This study revealed important findings in terms of highlighting the main problems that need to be addressed in the home care process and guiding health professionals who provide home care services, especially nurses, for the necessary solutions.

We determined that those patients with chronic diseases and their caregivers had important physical problems during the home care such as low back pain, headache, scoliosis, flattening of the neck, insomnia, and fatigue. These findings corroborate the findings of previous studies which reported that caregivers of patients with chronic diseases experience physical problems such as headaches, muscle and joint pain, fatigue, insomnia, and loss of appetite (10,12-14). In a study conducted by Sercekus et al. (10), some caregivers of patients with cancer stated that their existing illnesses such as migraine or disc herniation worsened, while others stated that they had hypertension, eczema, and psoriasis. Similarly, caregivers of patients with cancer were found to have higher physical health risks such as high blood pressure, fatigue, stress, burnout, physical injury, and poor general physical health compared to the general population (15). On the other hand, patients receiving home care were found to have physical problems such as not meeting movement, hygiene, and discharge problems; bedsores, infection, mouth sores, loss of strength, nausea, muscle loss, fatigue, and weight loss. In similar studies, it was found that patients

experienced fatigue and pain (16,17). In addition, Adamakidou et al. (18) reported that they needed more help than outpatients while receiving home care, and their level of dependence on others was high. Results of the study are consistent with these previous studies which demonstrated that the home care process makes both caregivers and patients have physical health problems or may increase the severity of existing physical problems.

We determined that individuals with chronic diseases and their caregivers encounter various social problems during the home care process. Restriction of outdoor activities and holiday plans with family members, deterioration of the family members due to the separation of a room to the patient, the necessity of having someone next to the sick individual at home, reduced communication with people, inability to entertain guests at home and inability to go out for food and eating were the main social problems that both caregivers and patients experienced. Similarly, there are various studies that both caregivers' and patients' social life can be negatively affected during the home care process. It is stated that caregivers limit their social lives due to their concerns about the possibility of infection, cannot allocate sufficient time to their children, have to leave their job, and postpone solving their medical problems (10,14). Various studies have also reported that home care harms vacation, travel, social life, interpersonal relationships, hobbies, and self-time (15,19-21). Our study findings are compatible with the literature.

We have also demonstrated that caregivers experienced depletion of life energy, anxiety, fear of losing, tension, irritability, depression, inability to cope, helplessness, and conflict during home care. On the other hand, it was found that the patients had psychological problems such as loneliness, a tendency to sleep, sadness, fear, reproach, thought of being a burden, hopelessness, and self-abstraction. The existing health problems of the patients, changing family roles, dependence, financial losses, social isolation, disruption in working life, and changes in social life can trigger psychological problems in patients. In addition, many factors such as health

problems, burnout, financial losses, disruption of school life, decrease in social relations, and decrease in social support resources are thought to negatively affect the psychological well-being of caregivers.

Another notable finding of this study is that the home care process can create financial problems for both patients and caregivers. These financial problems are high hospital expenses, constant supply of equipment for the care of the patient, loss of income due to the waiver of work to take care of the patient, and payment of fees for all health services, medicines, and care materials. This finding corroborates the findings of previous studies which have been demonstrated that the home care process causes extra expenses and financial problems (12,15,17). Our study findings are compatible with the literature. Long duration of treatment processes, continuous medication use, expensive diets specific to chronic diseases, expensive drugs, and transportation costs caused by regular controls might cause financial problems in home care of the patients with chronic diseases. In addition, the treatment and care of complications due to chronic diseases are stated to create an extra financial burden. Lastly, the lack of health insurance and paying for health services, medicines, and care equipment with their own money might have also caused them to experience economic difficulties.

Our findings have also indicated that patients and caregivers had treatment-related problems such as inability to adjust insulin dose and measurement of blood sugar, and inability to intervene due to lack of technical knowledge in cases where the respiratory device was disrupted. These results conform to those studies which reported that caregivers experience a lack of knowledge about symptom management, care, and treatment during the home care process (12,17). Similarly, Adamakidou et al. (18) reported that patients and caregivers have a lack of knowledge about "insulin therapy", "wound, stoma and catheter care" and "lymphedema care". In addition, Meneguín et al. (20) determined that caregivers had difficulty in tracheostomy care and did not know how to reattach the discharged feeding tube. This result shows that

although patients and their caregivers were informed about disease information, treatment, and the use of treatment-related equipment during discharge, and although there are nursing students among the caregivers, they still experience a lack of knowledge and skills which need to be addressed.

Conclusion

The findings of this study concluded that

individuals with chronic diseases and caregivers experienced physical, social, financial, psychological, and treatment-related problems during the home care process which affects both patients and caregivers. From this point of view, it is necessary to improve and increase the necessary initiatives, assistance, planning, and policies towards the existing problems of the patients and their families in the home care process.

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