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Orijinal Araştırma

Evaluation of Quality of Life of Patients, Transferred From Hospital Hemodialysis To Home Hemodialysis, In Terms Of Their Own Perceptions

Evde Hemodiyaliz Tedavisi Alan Hastaların Yaşam Kalitelerinin Kendi Algıları Açısından Değerlendirilmesi

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ÖZET

Amaç: Bu çalışma, evde hemodiyaliz tedavisi uygulayan hastaların deneyimlerinin belirlenmesi amacıyla yapılmıştır.

Yöntem: Çalışma, kalitatif bir çalışma olup, fenomenolojik araştırma biçiminde desenlendirilmiş; Şubat-Mayıs 2018 tarihleri arasında yapılmıştır. Veri toplama yöntemi olarak derinlemesine görüşme tekniği kullanılmıştır. Araştırmada, katılımcıların belirlenmesinde amaçlı örnekleme yöntemlerinden ölçüt örneklemeden yararlanılmıştır. Araştırma örneklemini altısı kadın, üçü erkek toplam dokuz hasta oluşturmuştur. Verilerin analizi sonucu altı alt tema, üç ana tema oluşturulmuştur.

Bulgular: Yapılan görüşmeler sonucunda araştırmacılar tarafından "ev hemodiyalizine ilişkin ilk deneyimler", "ev hemodiyalizine ilişkin olumlu deneyimler" ve "ev hemodiyalizine ilişkin olumsuz deneyimler" olmak üzere üç ana tema belirlenmiştir.

Sonuç: Bu çalışmada, son dönem böbrek hastalarının evde hemodiyaliz tedavisine geçiş sürecinde korku ve kaygı yaşadıkları, ancak tedavi sürecinde kendilerini fiziksel ve emosyonel olarak daha iyi hissettikleri, daha fazla sosyal ve çalışma hayatına katıldıkları sonuçları elde edilmiştir. Yine bu çalışmada, hastaların evde diyaliz makinesini görmeyi "*hastalıkla yüzleşmek*" olarak algılamalarına rağmen, "*özgürlük ve umut*" kavramlarını ön plana çıkardıkları görülmüştür.

Anahtar Kelimeler: Deneyimler, ev hemodiyalizi, kalitatif araştırma

ABSTRACT

Background: This study was conducted to determine the experience of patients who are undergoing home hemodialysis treatment.

Methods: The study was a qualitative study and was patterned in the phenomenological research. It was conducted between February and May 2018. In-depth interview technique was used as data collection method. For the determination of the participants in the study, criterion sampling is used as one of the purposive sampling methods. The study sample consisted of nine patients (six female, three male). Data analysis was performed manually using the content analysis method. As a result of data analysis, six sub-themes and three main themes were formed.

Results: As a result of the interviews, three main themes were identified by the researchers as 'first experiences of home hemodialyses', 'positive experiences related to home hemodialyses' and 'negative experiences related to home hemodialyses'.

***Conclusion*:** In this study, it was concluded that patients with end-stage renal disease experience fear and anxiety during the transition to hemodialysis treatment, but they felt better physically and emotionally during the treatment process, and they participate more in social and working life. Moreover, in this study, it was observed that even though patients perceived seeing the dialysis machine in the home as "*facing the disease*", they also emphasized the concepts of *"freedom and hope"*

Keywords: University student, Violence, Violence experience.

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INTRODUCTION

End-stage renal disease (ESRD) is an important public health problem. According to United States National Renal Database (USRD) 2015 report, there were 2,217,350 ESRD patients by the end of 2013. Prevalence of ESRD in Turkey is ranked 31st worldwide (Saran et al., 2017). Not only prevalence of ESRD is increasing by time but also individuals with ESRD have ower life expectancy and impaired quality of life (Atasoy, Çolak, Akdeniz, Tanrısev and Özyurt, 2013; Kalantar-Zadeh, Kopple, Block and Humphreys, 2001; Mcfarlane, Bayoumi, Pierratos and Redelmeier, 2003; Vestman, Hasselroth and Berglund, 2014). For this reason, the selection of renal replacement therapy methods in ESRD is becoming increasingly important to enable patients to continue their lives at optimal levels (Atasoy et al., 2013). Center hemodialysis (HD) is one of the most frequently used treatment methods in about ¾ of the countries (Saran et al., 2017). Center hemodialysis reduces the severity of the symptoms and prolongs survival of patients, on the other hand causes physical, emotional, psychological and socio-economic problems. These patients have to face many difficulties and also haand to make many compromises in their daily lives at work, school and home due to lost in health, strength, sexual functions, income, independence, life expectancy and opportunities (Duran and Güngör, 2015; Vestman et al., 2014). It is necessary to refer these patients to renal replacement therapies (RRTs) that will increase their quality of life (Atasoy et al., 2013). One of these alternative treatments is home hemodialysis which has been in use since the 1960s and has gained popularity in the last 5 years.

This application can be done 3 times a week in the patient's own home for 8 hours in a day or night (Karkar, Hegbrant and Strippoli, 2015; Trinh and Chan, 2017; Walker, Howard and Morton, 2017; Vestman et al., 2014). USRD reports that home hemodialysis treatment is used in 21 out of 50 countries. The rate of home hemodialysis is 18.3% in New Zealand, 9.4% in Australia, 3.0% in Canada and 6.0% in Western European countries (Saran et al., 2017). In our country, the rate of 0.71% (n = 414/77.311 patients) is relatively low compared to other countries (Süleymanlar, Ateş and Seyahi, 2018)

Home hemodialysis treatment offers advantages to improve patients' autonomy, comfort and quality of life (Karkar et al., 2015; Trinh and Chan, 2017). It is reported that patients who have at least 8 hours of dialysis treatment at home, apply less to the hospital, follow a free diet, have an active working life and and better quality of life in comparison with center hemodialysis (Watanabe et al., 2014).

When the literature is reviewed, there are quantitative studies showing that patients who undergoing centre hemodialysis experience more difficulties in social, physical and economic terms than those who perform hemodialysis at home (Nesrallah et al., 2012; Ok et al., 2011; Watanabe et al., 2014; Xi, Singh, Harwood et al., 2013).

All this information shows that; the social, physical and economic difficulties of patients undergoing central hemodialysis are higher than those performing hemodialysis at home. In the literature; the majority of the studies that demonstrate this comparison are quantitative research. The lack of descriptive qualitative research, in which patients who undergo hemodialysis treatment at home as expressed in their own words is remarkable, especially when the domestic literature is reviewed.

Based on these shortcomings; this qualitative research of home hemodialysis patients in Turkey aims to present the perceptions and experiences of the patients in a way that reflects our culture.

It is an important issue in terms of revealing the details of patients' lives, defining how they manage the process and which area they need support, maintaining the functionality of both the patient and the family, trying to reduce the effects of the negativities they experience and increasing their quality of life.

Therefore, this study is important in terms of guiding dialysis nurses who manage the education processes of patients admitted to hemodialysis treatment at home.

Purpose of the Study

The aim of this study was to determine the experiences of patients undergoing home hemodialysis treatment.

Study Questions

Study questions; (1) What are the experiences of the patients in the beginning of the home hemodialysis treatment? (2) What are the experiences of the patients during home hemodialysis treatment?

METHODS

Study Model

This study was carried out with a phenomenological research design. Phenomenology is a qualitative research method in which individuals describe their experiences about a case. The essence of the experiences of individuals with various experiences similar to the cases examined with these descriptions is reached (Van Manen, 1990). In this study, The COREQ-Consolidated Criteria for Reporting Qualitative Research, a guide to reporting qualitative research, was used.

Place of the Research Study

This study was carried out with patients who were undergoing home hemodialysis treatment in Aydın Adnan Menderes University Hospital Nephrology Clinic between February-May 2018 at Aydın.

The Universe and Sample of the Study

In the study, criterion-sampling method is used as one of the purposive sampling methods for the determination of participants (Yıldırım and Şimşek, 2008). Patients who undergoing hemodialysis treatment at home 3 times a week for 8 hours long for at least 3 months were included in this study.

The study sample consisted of 9 patients who undergoing hemodialysis treatment at home for at least one year after central hemodialysis treatment. In the literature, it is reported that the sample volume of qualitative researches can be determined according to the data saturation of the samples that can provide detailed data that meet the objectives of the research rather than large groups (Aksayan and Emiroğlu, 2002; Coyne, 1997). Participants, aged 24 to 69, 3 were female and 6 were male, have been undergoing hemodialysis treatment at home for 3 years. The features of the participants of the research are given in Table 1.

Table 1. Features of the Participants (n:9)

Age 48.88±13.74 age (min:24-max:69)	
Sex	
Female	3
Male	6
Marital status	
Single	2
Married	6
Divorced	1
Education	
Primary school	4
High school	2
University	3
Profession	
Student	1
Engineer	1
Freelancer	1
Housewife	2
Retired	2
Farmer	1
Officer	1
Hemodialysis duration 4.44±3.08 age (min:1-max:8)	
Home hemodialysis duration 3 year	

Data Collection Form

In this study, semi-structured interview form which is developed by the researchers was used to collect data. The interview form consists of two parts. First part of the form included 7 questions about socio-demographic characteristics, disease and treatment data; and second part of the form had 9 open-ended questions about the experiences of patients in the treatment of home hemodialysis. During the interview, additional/explanatory questions were needed in addition to existing questions. In order to ensure the internal validity of the interview form, expert opinion was obtained from a faculty member who is teaching a qualitative research course at master's and doctorate level and the interview form was finalized. After that, the comprehensibility and applicability of the form has been improved and the interview has been standardized by piloting with two people. Pilot study was excluded from the research.

Data Collection Method

For the interviews, prior permission and appointments were made with the patients. Data were collected by "in-depth individual interview" method. Interviews were conducted by researchers who were trained in qualitative research during the Ph.D (second and fifth researcher). The second researcher, who was familiar with the patients and involved in the care of the patients, conducted the interviews; the fifth researcher completed the missing data by making the registration. The interviews were conducted at home to make the individuals feel more comfortable. Interview questions were directed by the researcher to the participants and recorded with a voice recorder with their permission. The duration of the interview and the order of the topics were different according to the patient. The average duration of the interview was 40-60 minutes.

Validity and Reliability of This Study

The validity and reliability of research are the most important criterias for the credibility or quality of the results obtained (Daymon and Holloway, 2003). The following measures were taken for internal and external validity and reliability of this study;

- In order to ensure the internal validity of the research, semi-structured interview questions were examined with expert opinions. The fact that the researchers and participants have known each other for a while strengthened the internal validity of the research.
- In order to ensure the external validity of the study, the research environment, the characteristics of the participants and the data collection processes were presented in detail to the other researchers for designing a different research pattern by following these paths.
- For the internal reliability of the study, the answers of the patients to open-ended questions were examined separately by both a researcher conducting the study and another unbiased researcher.
- In the light of the data obtained, main themes and sub-themes were discussed in terms of ‘agreement and disagreement’ and the decisions regarding the first and second questions were gathered and necessary arrangements were made under common themes and sub-themes.
- For the reliability calculation of the study, the reliability formula proposed by Miles and Huberman (1994) was used. The reliability of the study was calculated to be 80% as a result of Reliability = Number of aggrements / Total number of agreement and disagreement. Miles and Huberman (1994) report that over 70% of the reliability calculations are sufficient for the reliability of the study. The results obtained based on this information show that the results of the study are reliable.
- In order to ensure the internal reliability of the research, direct quotation from the participants were used in the data findings.
- In order to ensure the external reliability of the research, the interviews were recorded with the voice recording device, transferred and stored digitally. In addition, the data collection and analysis processes were carefully reported in detail.

Evaluation of Data

The voice recordings obtained in the research were transferred to text by the research team and a 64-page raw data document was created in Microsoft Word. Before starting the coding of the data, each interview text was read and a holistic view of patients' opinions was tried to be revealed. Data analysis was done manually by inductive content analysis method. The inductive analysis approach involves categorizing the data by coding, revealing the relationships between categories and reaching an integrated picture from categories and subcategories accordingly (Yıldırım and Şimşek, 2008). In order to create the basic idea, similar codes from the data are combined and reported as certain number of categories. At first, 50 codes were created; later 26 codes were obtained by combining these codes. 6 sub-themes and 3 main themes were created with these codes (Table 2).

Table 2. Experiences of Patients Receiving Home Hemodialysis Treatment (n:9)

Themes	Sub-Themes	Start Codes
First Experiences	Adaptation Period	Fear (n= 7), Easy learning (n= 6),
Positiand Experiences	Physical Changes	Decrease in fatigue (n= 5), decrease in lassitude (n= 3), decrease in cramps (n= 2) and decrease in drug usage (n= 2), increase energy (n= 3), more effectiand dialysis (n= 2), quality of sleep (n= 4), increase sexual desire (n= 4), increase in appetite (n= 3) more productivity at work (n= 4),
	Emotional Changes	Self-confidence (n= 5), treatment management (n= 4), home comfort (n= 2), freedom (n= 9), long life expectancy (n= 3), make plans for the future (hope) (n= 9), happiness with the lack of service cart (n= 1), escape from social pressure (n= 2)

The Ethical Dimension of the Study

This study was carried out in accordance with the principles of the 2013 Helsinki Declaration. Required ethical approval was obtained from Aydın Adnan Menderes University Faculty of Medicine Non-Interventional Clinical Research Ethics Committee (date 18.01.2018 and protocol number 2018/1301). In addition, written and verbal consent was obtained from the patients.

RESULTS

The data obtained from the study were collected under three main themes: first experiences with home hemodialysis, positive experiences with home hemodialysis, and negative experiences with home hemodialysis. Due to ethical sensitivities, the quotations of the participants are presented together with their code numbers. (Patient 1, Patient 2, …, Patient 9).

The patients who participated in the study evaluated the first experiences of home hemodialysis in terms of adaptation to treatment. Some of the statements of the participants on this subject are as follows;

"Before I started I was afraid how I could do it, if I could achieve it .....but I think I adapted very quickly" (Patient 2)

"I have learns in two-three weeks" (Patient 1)

"I have learned everything in for weeks because I wanted it so much" (Patient 5)

It was determined that the participants experienced positive physical, emotional, social and economic changes after they started home hemodialysis.

In the period after starting home hemodialysis, patients stated that they experienced positiand physical changes such as decrease in fatigue, lassitude, cramping and drug use and increase in energetic, sleep quality, sexual desire, appetite as well as more effective dialysis and productivity in business life. Below are examples of patients' explanations.

"There is a lot of difference between home dialysis and hospital dialysis. If the cleaning of the blood in the body is 30-40% in the hospital hemodialysis, it can reach up to 80% at home hemodialysis. I am more focused on sexuality because I do not feel tiredness in home hemodialysis." (Patient 5)

"I am the same before and after the machine. There are no more fatique, tiredness and low blood pressure. I feel more energetic…..... Our sexual life has been in incredible order" (Patient 1)

"My fatigue, my weakness has decreased very much after I changed into home hemodialysis. ……. Sexuality is also increased." (Patient 2)

"Since I am in dialysis for 8 hours at home hemodialysis, my blood is cleaning better so I use less medication." (Patient 3)

"The advantages of home hemodialysis cannot be compared with dialysis in the hospital. After starting home hemodialysis, I have no complaints about fatigue, tiredness and cramps anymore " (Patient 9)

"Since I started hemodialysis treatment at home, I can eat everything. Protein restriction is no longer needed…. "(Patient 6)

Some of the codes experienced by patients after the onset of home hemodialysis in the sub-category of emotional changes were self-esteem, managing treatment, home comfort, freedom, long life expectancy, making plans for the future, happiness about the lack of arrival of the service cart, and getting rid of social pressure. Some of the statements of the patients about these experiences are as follows;

"...Because, life is getting a little more normal with home hemodialysis. You don't haand to go to the hospital for 3 days a week. Yay! Freedom!..."(Patient 7)

"……Even my medications have fallen. Do you know what this means? It means freedom…… I don't have to be drug dependent to be better..." (Patient 1)

"Working, getting married and having kids were dream for me but now they are my purpose.." (Patient 2)

"If I wasn't doing home hemodialysis today, I couldn't work and trust myself." (Patient 5)

"I think of my own health. I'm the doctor now." (Patient 1)

"It has more advantages than dialysis in hospital. I decide when to go into dialysis. Whether day or night....."(Patient 8)

"It's hard to explain with words. It was hard that everybody knows I am sick, I couldn't bear when people were looking at me. Now my treatment is at home. I don't have to go to the hospital. Nobody knows I am sick." (Patient 4)

"I used to couldn't work in the days of dialysis because of tiredness. It seemed to me that I was getting an unfair profit, but now I work full-time, I'm more peaceful, I'm happier; my workplace efficiency has increased" (Patient 3)

After the beginning of home hemodialysis, patients stated that there were changes in their social situations such as social activities, daily life activities, family and households. Below are examples of patients' explanations.

"Doing hemodialysis at home is like recovering the time you lost in the hospital …. " I do not lost time in home hemodialysis, I am able to travel, do my work myself." (Patient 3)

"I'm not hospital dependent ……. I'm in dialysis at night; but during the day I travel and go shopping with my friends." (Patient 5)

"I can spend quality time with my child and my wife/husband. Because of that we are very happy." (Patient 1)

After the beginning of home hemodialysis, the patients stated their economical relaxation as earning money and paying their debts. Below are examples of patients' explanations.

"I've been working since I started home hemodialysis. I earn my money, and I can stand on my own feet If I have depts., I pay it." (Patient 2)

"I was worried about whether the workers at the workplace were doing the work right while I was at hospital for dialysis. Ever since I started home hemodialysis, I have never fell behind at work. I take care of everything. Company earns so much more." (Patient 6)

In the study, it was found that the participants perceived emotional negativity in the home hemodialysis treatment.

Emotionally negative aspects of home hemodialysis treatment perceived and expressed by patients as anxiety from continuous seeing the macine at home facing, the disease, living dependent on the machine. Some of the participants expressed these disadvantages as follows:

"Dialysis machine is always at home, Of course it's a concern to see the dialysis machine constantly .... A little bit like a facing the disease." (Patient 4)

"You're depented to the machine. It is our destiny to live dependent on the machine." (Patient 9)

DISCUSSION

In the study, firstly, it was revealed that patients experienced fear and anxiety about home hemodialysis treatment as fear against the unknown in the decision and learning phase, but they were able to adapt in a short time after starting the treatment. In the literature, patients' descriptions about home hemodialysis are generally reported as difficult to learn and beyond their abilities (Walker et al., 2017). It is also stated that patients experience anxiety in many subjects, especially the placement of needles to themselves, and that their anxiety decreases after about five weeks (Hanson and ark 2017; Trinh and Chan 2017; Vestman and ark 2014; Walker and ark 2015). These results indicate that patients experience more anxiety during the period of trasition to home hemodialysis. Initiatives such as providing comprehensive and appropriate training for home hemodialysis, providing easy-to-use machinery, supporting independence and self-care can reduce the fears of patients by increasing self-efficacy/competence.

In the study, it was detected that the participants experienced positive physical changes in adaptation period shortly after they started home hemodialysis. As the participants emphasized, in the related literature, the incidence of intradialitic hypotension in the eight-hour home hemodialysis is reported to decrease by 60-70% compared to the four-hour central hemodialysis (Nesrallah et al., 2012; Ok et al., 2011). In another study, it is reported that more than 50% of patients with four-hour hemodialysis treatment experience fatigue and in order to cope with fatigue symptoms patients needed about five hours of sleep or rest after dialysis (Sklar, Riesenberg, Silber, Ahmed and Ali, 1996; Zengin and Yıldırım, 2017). In a qualitative study, a hemodialysis patient defined this situation as 'I do nothing on the days I take dialysis, I spend all day resting at home, I have no strenght left to do anything' in the interview (Krespi, Bone, Ahmad, Worthington and Salmon, 2008). Consistent with our study, the literature also reports lesser rates of muscle cramps, weakness, and hypotension in patients due to slower blood flow rate and long-term administration (Vestman et al., 2014; Xi et al., 2013). With the eight-hour hemodialysis treatment, the effective removal of the toxins in the deeper parts of the body and the lack of aggressive fluid and solute changes provide a number of advantages for the patients. This situation causes an increase in the physical performance of the patients.

In the study, the patients stated that beside positive physical changes they also had a significant decrease in their medication use with home hemodialysis and that they were able to get rid of addiction and as a result had more freedom. Similarly, in the studies conducted on this subject, it has been reported that the amount and frequency of use of erythropoietin, phosphate-binding and antihypertensive drugs decreased in patients undergoing home hemodialysis treatment (Ok et al., 2011; Xi et al., 2013). These results are important in terms of patients' decreased dependence on hospital, health care personelles and drugs as well as increased fellings of freedom with home hemodialysis treatment.

In the study, it was determined that patients spent more time on their social life and felt more satisfied with the home hemodialysis. Zengin and Yıldırım (2017) also emphasized that end-stage renal disease may cause significant problems in the relationship of individuals with their social environment. In some other studies, it is stated that due to the time spent in dialysis, physical complaints and mental problems caused reduced participation in work efficiency and social activities as well as social isolation is experienced (De Nour, 1982; Duran and Güngör, 2015). However, patients who perform hemodialysis at home have the freedom to make dialysis treatments whenever they want (day or night) and able to spend more time on family members and friends (Walker et al., 2015; Wise et al., 2010). Therefore, these results are valuable in terms of demonstrating that home hemodialysis is an effective method for improving the social lives of patients.

In this study, the patients stated that they did not have to take breaks or take the day-off from their work in dialysis day because they did not have symptoms such as hypotension, fatigue, etc. after hemodialysis treatment at home and they were working more efficiently in their business life. It is stated that working in any job benefits not only economicly but also psychologically, unemployed individuals can have decreasing self-esteem, increasing anxiety and depression (Hergenrather, Zeglin, McGuire-Kuletz and Rhodes, 2015). Many patients undergoing hemodialysis treatment cannot continue their work (Zengin and Yıldırım, 2017). Therefore, it can be said that the work life of individuals in working age at home hemodialysis is not affected too much and they do not have any concern about business life because they do not feel different from healthy population in terms of productivity.

It was determined that home hemodialysis patients were more hopeful about their life and future and therefore they did not postpone their future plans according to findings in this study. In contrast, it is reported that the patients experienced more symptoms such as anxiety, depression, pain, sexual dysfunction, fatigue, and change in the concept of self due to process and side effects of center hemodialysis (Sert et al., 2015). Based on these results, it can be said that home hemodialysis treatment allows patients to realize their hopes and future plans due to their long life expectancy.

In addition to positive results, the patients reported that they perceived emotional negativity related to home hemodialysis treatment. There are a number of drawbacks in implementation and maintenance of treatment such as patient safety, complex procedures, caregivers' and family members' complaints in addition to the numerous benefits of home hemodialysis (NICE 2002; Tong et al., 2013; Vestman et al., 2014; Walker et al., 2017; Wong et al., 2014). In fact, instead of complications, concerns perceived as negativity in the study. The

patients stated that they experienced anxiety due to the transformation of their home into a hospital environment, the dialysis machine's presence as constant reminder of the disease at home and and the disruption of the normalization of daily life due to the burden of treatment. Considering the study in its entirety, it is determined that patients feel more free with hemodialysis treatment at home in many areas from social and economic life to less drug use even with all their concerns about difficulty and reality of the treatment and disease. Managing patients' treatments (hour, time, blood flow rate, ultrafiltration rate etc.) by themselves removes them from patient role and helps them to gain autonomy (Vestman et al., 2014; Xi et al., 2013). Similarly, in a qualitative systemic review evaluating the perceptions of hemodialysis patients and caregivers done by Walker et al. (2015) found that home hemodialysis was an opportunity to strengthen freedom, flexibility, well-being and relationships (Walker et al., 2015). All these make it easier for patients to adapt more easily to daily life (NICE 2002). Based on these results, hemodialysis treatment at home allows the patients to adjust individual and physiological treatment according to their lifestyle, thus making patients independent physically, emotionally, socially and economicaly.

Based on these results, qualified training should be given to both health personnel and patients in order to spread the application of home hemodialysis which is new in Turkey and to direct appropriate patients to this treatment. In order to increase awareness about home hemodialysis treatment, trainings and application facilities should be provided to health personnel. Qualitative research is needed for comparison of home hemodialysis not only with the center hemodialysis treatment but also with all other renal replacement treatment methods.

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