

Obstacles in the Way of Self-Care Programs for Renal Transplantation Recipients

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Received: January 31, 2016

Accepted: May 26, 2016

ABSTRACT

Background: Renal transplantation as a treatment to chronic renal failure requires constant self-care to improve health and quality of life as well as to prevent side effects, transplant rejection in particular. Evidence, however, shows insufficiency of self-care in renal transplantation recipients. Obstacles in the way of self-care behaviors are probably rooted in cultural background and lifestyles. There is limited relevant data in Iran. The current qualitative study, therefore, aims to describe the obstacles renal transplantation recipients face in their self-care programs.

Methodology: The current study was carried out using qualitative content analysis method. Participants were renal transplantation recipients who were selected on the basis of the aim of the study. Data was collected using semi-structured questionnaires to the point of data saturation. Data analysis was carried out using conventional content analysis method.

Findings: Five themes in 19 classifications were extracted from analyzing the data: limitation in resources and their availability thereof, cultural and educational weakness, environmental factors, intrapersonal factors, and self—care complications.

Conclusion: Our results provide wide insights into obstacles renal transplantation recipients face in their self-care programs in the context of Iranian culture. The resulted themes can be useful in planning more precise and better educational programs by providing new insights of policymakers, health care officials, society, and families.

KEYWORDS: Renal Transplantation, self-care, obstacles, data analysis research method

INTRODUCTION

Renal Transplantation is the treatment of choice for a minority of patients with end-stage renal disease which is considered an opportunity to improve the patients' quality of life (1, 2). It is effective in reducing treatment costs and increasing the chance of survival of the patients (3). Since the first kidney transplant between identical twins in Boston in 1954, the method has been given incremental attention (4). In 2014, more than 17,000 renal transplants were performed in the U.S (5). In Iran, more than 49% of patients with chronic renal failure undergo renal transplantation procedure (6). 2000 cases was reported in year 2012 (7).

Patients who have undergone renal transplantation experience a chronic state (8). The most important factor in controlling chronic diseases is self-care (9). Renal transplantation recipients are definitely in more need of self-care than other patients with chronic diseases (10). Due to the fear of rejection of the transplant in recipients, as well as complicated medical diets with various side effects and changes in lifestyle, special self-care behaviors throughout life is of crucial importance for renal transplantation recipients (11, 12).

Self-care activities are often troublesome and require changes in lifestyle. Many renal transplantation recipients do not follow their doctors' recommendations, in spite of being aware of transplant side effects (13, 14). Several quantitative studies show that renal transplantation recipients lack required self-care programs to manage the side effects and to prevent the rejection of transplant (15, 17). Lack of self-care may result in such problems as increase in treatment costs, decrease in the level of quality of life, and the rejection of transplant. Therefore, identifying the obstacles and inhibiting factors in self-care is of great importance (18).

Gordon et al. show that there is a big difference between the recommended self-care activities by doctors and actual self-care activities performed by renal transplantation recipients. Most recipients face various obstacles in implementing their self-care programs including inappropriate contact with service providers, lack of awareness,

information controversies, and financial problems (19). Perceived obstacles are predictive. Too many obstacles may decrease self-care behaviors. Accordingly, describing perceived obstacles in self-care programs may help in improving the quality of care services (20, 22). In addition, awareness of common obstacles in self-care programs avail required information for interventions. It also results in identifying appropriate approaches to overcome the obstacles (19).

While official centers of renal transplantation emphasize on constant self-care and understanding inhibiting factors (19), there is a small body of knowledge in this regard. Searching through the databases revealed that no studies has been carried out in Iran on the same subject. Self-care behaviors may be rooted in cultural background, beliefs, and the environment where a patient lives in (23). Accordingly, enjoying experiences of those who are always involve in self-care related issues can be beneficial in gaining more precise information. Qualitative research is the best method to describe events and phenomena in depth. It provides delicate details of events which are difficult to be described using quantitative methods (24). Therefore, qualitative research method seems to be able to shed a light on more dimensions of inhibiting factors in self-care programs and behavior. Inhibiting factors can be identified using qualitative research method. Consequently, appropriate approaches can be planned to overcome the inhibiting factors (19). The current qualitative study aims to describe the inhibiting factors in self-care behaviors in renal transplantation recipients.

METHODOLOGY

This study is a qualitative content analysis. Qualitative method is capable of providing the researchers a deep insight into people perception and experiences (25). It uses systematic classification, codification, themes, and designing patterns to interpret the content of data subjectively (26). Our sample population was selected on the basis of the aim of the study. Participants were 14 renal transplantation recipients aged 16-70, with a transplantation history of +6 months in Kohkiluyeh Boyer-Ahmad Province, Iran. In depth semi-structured interviews were used to collect data. Interviews started by asking general questions and were guided according to the answers from the interviewees. Interviews duration were 40 to 80 minutes. Data collecting process continued until the data saturation. Data was analyzed using conventional content analysis method where classes are extracted from the text data directly (26). Therefore, interviews were recorded, transcribed, and read over several times. Next, themes were conceptualized and codified according to the aim of the study and questions (27). Extracted codes were compared and classified according to their similarities and differences. At the end, main themes obtained from comparison and precise examination of the classes (28). To transcribe, codify, compare, and retrieve the data and comments MAXQDA10 was used. In order to observe the ethical considerations, having received the official permit from authorities (ethic Code from Yazd Medical University: K/90/491), eligible recipients were selected. Recipients were informed about the aim of the study, the research method, and the confidentiality of information. Participants were asked to fill and sign the written content form for participation in the research. Participants' rights were observed during the whole process of research.

In order to conform the reliability and validity of the research four criteria were used: validity, conformity, reliability, and transferability. Interviewees were asked to review and confirm the data and codes (31, 32). In selecting the participants, researcher tried to find participants from different age groups with different disease history, occupation, gender, and education. The context of interviews were revised by professors. In case of disagreement, discussion and clarification were perused until reaching to an agreement.

Findings

Table 1 shows the demographic features of the sample population. Five themes in 19 classifications were extracted from analyzing the data: limitation in resources and their availability thereof, cultural and educational weakness, environmental factors, intrapersonal factors, and self—care complications.

Table 1: Demographic features of the participants

Number		14
Age range (year)		16-70
Sex	Male	8
	Female	6
Married		9
Single		5
Time of transplantation (year)		1-14
Kind of organ transplantation	Deceased	10
	Living	4

Limitation in resources and their availability

Limitation in resources and their availability is one of the important and effective inhibiting factors in self-care process in renal transplantation recipients. It was classified into five groups: insufficient support, shortage in facilities, costly care services, time shortage, limited availability of medications and health services. Insufficient support from family and friends is an inhibiting factor in self-care behaviors. As it was stated by a participant: "Family often gives lip-service. They do not help me in my self-care program. For example, when I ask my brother to come with me for a walk, he refused by giving excuses like "I am tired", or "Let's go tomorrow". He is not obliged to exercise every day".

In addition, participants perceive insufficient support from government and society as well as health insurance limited coverage as inhibiting factors in their self-care programs. Limited public and personal facilities, such as lack of sports facilities and locales, no diet foods in hotels and restaurants, lack of availability to devices and appliances to watch weight and vital symptoms (Blood Pressure Meter, glucometer, weighing machine, etc.) are other obstacle in the way of keeping self-care program. As a female participant stated: "there is no appropriate locale for ladies to work out". Another male participant stated that: "I am told to weigh myself every day. But I do not have a weighing machine at home and I am rarely able to weigh myself".

The majority of the participants perceive costly health care services as an inhibiting factor. Expensive diet dishes, expensive visit fees, tests, and medicines, and expensive home sports appliances were stated by participants. As a participant stated that: "I have to use olive oil and sesame oil. But they are expensive and I cannot always afford to buy them."

Another participants stated that: "Health insurance does not cover foreign medicines. We are told only domestically produced medications are covered by insurance companies. While a pack of CellCept or Ciclosporin cost me more than 2000,000 Rials. This is a huge amount for a person like me who is retired and have to support his family."

Some participants states that they are not able to follow their self-care program due to shortage of time, as they have lots of responsibilities at home and work. A participants stated that: "I do not make time to work out. I live in a village. I have go to the city few times a week to do shopping. I am at work every day until 4. P.M. and most of the time I have no time to exercise".

Some participants also stated that limited availability to specialists, dieticians, and non-domestic medicines, long distance from clinics, as well as domestic medicines with low quality are some of the obstacles they face in following their self-care programs. As a participant stated: "Where I live there is no specialist or dieticians, nor a good laboratory. I have to travel to go to visit my doctor".

Cultural and educational weaknesses

Cultural and educational weaknesses was another theme extracted from the data. Insufficient knowledge, inappropriate recommendations from doctors, lack of skill, inappropriate lifestyle, personal beliefs, family and friends negative attitudes are some of the examples rooted in cultural and educational weaknesses.

Participants knew their inappropriate knowledge on self-care program as an inhibiting factor. Inappropriate knowledge was extracted from two sub-class educational weakness and information controversies. A participant stated that: "Doctors do not explain things clearly. For example, my doctor recommend me I work out. But never explained how, how often, and how much. When I want to go for a run, family and others tell me not to because my kidney may dislocate. When I want to have something I may be told not to with the reasoning that it is bad for your kidney. Or the diet consultant whom I go to for my diet tells me to get one unit of protein, but never explain how I can get one unit of protein".

Some participants' comments suggest information controversies in the process of self-care. As a participant stated that: "Doctors recommend us one thing. Some recipients recommend different things. My dieticians says suggest me to do one thing and the doctor I currently go to for my regular visits recommend a different thing".

Some participants suggested insufficient recommendation or no recommendation from caregivers. In this regard a participant stated that: "my eyes are affected by cataract which is said to be a side effect of medicines I have to take. I was never told to wear sunglasses or look up at the sun. Now that my eyes are having cataract they say it is a side effect of the medicine and being exposed to the sunlight. I would have never gone out during the day, if I had been told not to".

Lack of skills such as making diet dishes, not knowing how to use Blood Pressure Meter, were other inhibiting factors. As a participant stated in this regard: "when I am alone at home, I have to have leftovers or some fast food. I cannot cook".

Renal transplantation recipients perceive inappropriate lifestyle as inhibiting factors that reduces the quality and quantity of their self-care behaviors. Obstacles like non-diet foods on parties and occasions, family interest in

having fast foods, inappropriate and wrong food habits, disorder in the time of main meals, lack of exercise, immobility, availability of personal transportation vehicles, and industrialized style of life were mentioned by the participants. A participant stated that: “when I have car I do not feel like going around on foot. I prefer to drive”. And another participant: “In parties there is a variety of foods. All contain lots of spices and oil”.

All participants’ experiences revealed that wrong beliefs of family and friends is another inhibiting factor. As a participant stated that: “The delicacy of a food is from oil. Low fat foods are not yummy”.

Interviews showed that some participants believe that ghee is healthier. A participant stated that: “Some relatives say ghee is healthier. They say the secret of long life and being healthy is to use ghee. I believe the same and use ghee”.

In addition some participants believed that having received the renal transplantation they need no care. The following comment from a participant shows the same: “People think that one needs to be ill to have healthy food. I have got the same belief. Now I do not go for a dialysis and I think I am fine and do not have any problem”.

Negative attitudes of society is another inhibiting factors that participants referred to. Some participants stated that due to others inappropriate behavior, sympathetic or pitiful attitudes, as well as problems in getting married, they have lost their ambitions after the renal transplantation surgery. A participant stated that: “I hate sympathy. When someone talks to me in a pitiful way I feel I am weak. I think people view me as a weak or unable person. It makes me lose my ambitions. I reminds me of my illness and problems”.

Some participants also complained that people find it annoying when they refuse to shake hands or kissing when greeting due to possibility of infection. A participant stated that: “In parties when I avoid to shake hands or kiss others, people may get upset and complain later. I explain that my immune system is weak as a result of taking drugs after renal transplantation. When I was in Abadan, I kissed a relative and I got sore throat the same day”.

A participant believed that wrong attitudes of people can be an inhibiting factor in following self-care program. As he stated that: “when people see you are wearing a mask and gloves, they think you have an infectious disease. They think you must not meet others... once on a plane I was wearing a mask and gloves. A lady in the back seat told me you should not take a plane in contact with others when you have a disease. That is why I do not wear a mask so people do not think I have a dangerous disease”.

Environmental factors

Participants’ experiences suggest that social environment, workplace, and atmosphere at home influence their self-care programs to a great extent. The following remarks of a participant confirms the same: “I like going cycling. But in my society it is not an acceptable thing to do for a girl (shaking head as a sign of regret)... where I live, cycling, even at times going to a walk by yourself is not easy for a lady... specially at nights”.

Environmental limitations like inconvenient state of sidewalks, difficult job conditions, and at times bad weather are perceived as inhibiting factors by renal transplantation recipients participated in the study. “There are lots of puddles in main streets and alleys. Once I were going to the bakery I twisted my ankle and had to have it in a cast”, a participant said.

Another participant stated that: “when there is too much air pollution, like when farmers make fires on their farms to make it ready to seed I do not go out for a walk... neither do I when it is warm”.

Some participants view unhealthy meat, fruits, and vegetables (due to use of excess chemical fertilizer, no label on products, preparing foods by others as other obstacles in their self-care program. “Is the fruit we use healthy? Have you ever seen an organic watermelon? Fruits and vegetables are grown using chemical fertilizers. Are they really healthy and good for me? I do not know what to do? Tomato, cucumber, onion... almost all vegetables and fruits we get are produced in green houses and in artificial conditions.”

“I check production and Expiry dates when getting a thing. But my husband never does so, as he is always hasty and careless in shopping”.

Intrapersonal Factors

Intrapersonal factors is another theme from psychological and physiological factors in this study.

Participants’ remarks revealed that psychological factors- including stress, anger, embarrassment, forgetting doctor’s recommendations, being undetermined, laziness in following the self-care program, no appetite, mental tiredness, hiding the disease, difficult experience of dialysis, no belief in the effect of self-care- lead to unfollowing programs and recommendations. As a participant remark in this regard confirms the same: “they recommended I wear sunglasses. I do sometimes. When I am here I feel shy to wear sunglasses”.

“I am fed up with having diet foods all the time. I do not like the taste of diet foods and I give up my diet”.

“People are afraid of sick people. Their attitudes to you change when they realize that you are sick. That is why I do not like others to know I have a health problem. Many people in our relatives and friends know that I am

sick. However, when I am new somewhere I prefer not to tell others about my illness and behave normally. I have meals with them and I do not take my medicine in front of others so they do not learn that I have had a renal transplant”.

Participants also view fatigue and physiological problems as inhibiting factors. As a participant stated that: “we are told to work out. After exercise my legs are painful and it has caused difficulty in walking”.

Self-care complications

Participants’ remarks showed that self-care programs such as medical diet, nutrients diet, sanitary recommendations, preventive activities, etc. are arduous to follow. Accordingly, three classification were extracted: difficult medical diet, inevitability of contact with others, difficult nutrients diet.

A participant stated that different medicine with different dosages and timings is a factor that makes following the self-care program laborious and challenging: “I have to take different drugs with different timings and dosages. One needs to be taken at 6 A.M., the other at 9 A.M., and one at noon. At times I forget to take my medicine, at times I mix up which one I have to take during day and which one at night”.

Various side effects was another factor that participants find to be a nuisance in following their self-care program. A participant stated that: “I had a huge appetite for foods. I used to get hungry soon. I thought it was due to the transplant and that my body is getting back to normal state. But I was gaining weight in spite of going for a walk. Later I noticed that it was a side effect of the drugs I used to take after the renal transplant”.

Some participants believed that it was inevitable to have contact with others. They considered kissing and shaking hand which is a way of greeting in Iranian culture an inhibiting factor. As a participant’s remarks in this regard shows: “You cannot run away from people. You may come across a friend in the street. I am a teacher and I am always in contact with my students and colleagues. If one of them has a cold I may catch it easily too. It is not always possible not to greet people. You cannot refuse when someone wants to shake hand with you. In addition, at times it happens that you meet a friend after a while. The first thing they may do is to kiss you on the cheek. It is a part of our culture”.

Differing diet of the recipient and that of the rest of the family is another obstacle participants mentioned in their remarks: “sometimes I do not feel like making a different dish for myself. Others cannot follow my diet. They do not have to”. Alternatively, another participant who stated: “sometimes I feel bad about my family having to make a different dish for me. That is why I join them and have the same food as theirs”.

DISCUSSION

In this study some of the obstacles on the way of following self-care programs by renal transplantation recipients were identified on the basis of participants’ experiences.

These obstacles are limitation in resources and their availability thereof, cultural and educational weakness, environmental factors, intrapersonal factors, and self—care complications which shows the impact of different personal, cultural, social, familial, and environmental factors on the process of following self-care programs.

Limitation in resources and funds to afford diet foods, medications, and sports appliances, inadequate coverage of health insurance, shortage in time, etc. were among the inhibiting factors that participants mentioned. It is in consistency with findings of other studies (19, 32, 36). In controversy with our findings, Marcicano et al. found that recipients from families with higher income do not follow their self-care programs (37). While many studies showed that financial factors are inhibiting in following self-care programs, inadequate coverage of health insurance and government support seem to have a lower level of impact in other countries than in Iran. This reveals the importance of reviewing insurance coverage and supportive institutes in Iran.

Our findings revealed that participants do not receive adequate information about self-care program from caregivers. They were given no advice on avoiding sunlight without wearing sunglasses. Due to taking immunosuppressive medicines, the danger of skin cancer in renal transplantation recipients is 3-5 times as many as in healthy people (38). Therefore, education on avoiding sunlight shall be started before the first summer after the transplantation. (5). Participants in our study stated that there are controversies in information and recommendations given by caregivers. It is in consistency with the findings of 19, 39, and 40. Controversies in recommendation from doctors and consultants as well as other renal transplantation recipients lead to confusion and as a result failure in following self-care program (19). It suggests the importance of good communication with patients and post-surgery education. It is of vital importance that doctors and caregivers explain required information about self-care program to recipients in simple and easy to understand language.

Intrapersonal factors including psychological and physiological ones are another group of obstacles that renal transplantation recipients face in following their self-care programs. It is in consistency with Gordon *et al.* and Weng *et al.* (19, 41). This finding shows the impact of common human characteristics on findings in different cultures.

Participants also view the impact of environmental factors such as non-standard physical and structural environment, social places limitations, difficult job conditions, and bad weather as other inhibiting factors. They believe that it is difficult to follow self-care program when the requirements are absent. It is consistent with findings of 19, 42, and 43. Unhealthy food, using chemical fertilizers in farming, additives, and no label on ready foods were some additional obstacles. Robinson (44) reports the impact of environment on dietary habits in African Americans. He suggests that availability of fresh and healthy articles in nearby stores create more ambition in people to have healthy foods.

Complication of self-care programs is another obstacle. According to participants' experience, changes in medicines, their dosage and timing may lead to confusion and disorder in self-care program. It is consistent with findings of Gordon *et al.* (45). Participants stated that side effects from transplantation medicine is inhibiting in following their self-care program. Although two third of such side effects can be avoided, many recipients experience side effects due to lack of awareness (46, 47, 49). Findings of 37 show that 51% of renal transplantation recipients do not follow post-surgery medicine diet. This ratio is higher than in other transplantation recipients (50). It is estimated that 36.4% of losing the transplanted kidney is because the recipients do not follow the post-surgery medicine diet (51). Considering the vital role of medications to prevent the rejection of transplantation, it is of crucial importance that the medical team provide the recipients with the required education on post-surgery self-care programs.

Our findings shed a light on obstacles on the way of following self-care programs. Findings from recipients' experiences revealed that the aforementioned obstacles are rooted in complicated and multi-dimensional social, economic, educational, cultural, intrapersonal, and medical factors. Accordingly, it is suggested that those involved in renal transplantation help to resolve the problems and obstacles recipients face. As the renal transplantation is a highly costly surgery, it is of vital importance for recipients to be helped to control the chronic and acute side effects, improve the quality of life, and prolong the transplantation age.

Our findings increase the awareness in government officials, society, families and caregivers about the obstacles renal transplantation recipients face in their lives. They also can be used in planning educational programs to improve self-care behaviors in renal transplantation recipients.

The current study suffers from the common limitations in qualitative researches. Not being able to have participants from different provinces with different cultural background was the prominent limitation of the study. Researcher tried to minimize the effect of the aforementioned limitation by selecting participants from different age groups and transplantation history. It is suggested that future research be carried out on describing and providing solutions for the obstacles and problems renal transplantation recipients are facing.

Acknowledgement

The current study is extracted from researcher's Master thesis in the school of Nursery and Midwifery, Yazd University of Medical Sciences.

I would like to express my sincere gratitude to university authorities and participants.

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