Research Article

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Coping Strategies With Self-Management Barriers In Kidney Transplant Recipients: A Qualitative Study.

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ABSTRACT

Background: Self-management in kidney transplant recipients plays a pivotal role in their long-term survival. Transplant patients face numerous barriers and problems in the course of self-management. This study explained strategies for coping with self-management barriers in kidney transplant recipients.
Materials and methods: This research was a qualitative study interviewing 18 participants selected by purposeful sampling. The data were collected by deep and semi-structured interviews and analyzed by conventional content analysis.
Results: The findings encompassed one theme, i.e., acceptance of living with a chronic disease, and four main categories involving increased resilience (flexibility, high hopefulness, and the maintenance of the spiritual self), social support (continuous interaction with the treatment team and seeking supportive sources), self-empowerment (relationships with peers, health literacy promotion, and attainment of problem-solving skills), and adjustment to changed roles (adaptability to role changes and physical constraints).
Conclusion: The results revealed that kidney transplant recipients in Iran employed their special coping strategies tailored to Iranian and Islamic culture in the face of problems and barriers to self-management

Keywords : Self-management, Kidney, Transplant, Coping.

INTRODUCTION

Kidney transplantation is one of the best selective treatments for patients with end-stage chronic kidney failure and leads to low mortality and high quality of life in these patients (1). The post-transplant life is a fully stressed period for patients. These patients are released from an intolerable period of dialysis, fatigue, and liquid limitations, on the one hand, and encounter a life forcing them to use many daily medications, have repeated blood tests, and coexist with constant prior and new illnesses on the other hand (2). Transplant receivers are exposed to various psychological disorders like depression and anxiety due to the impact of physical and socio-psychological factors after the transplantation (3). Compared to other patients with chronic diseases, these patients experience high degrees of stress, anxiety, depression, and other negative emotional states, all influencing their medication adherence,

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self-care, and quality of life (4). To minimize the risk of long-term transplantation complications, e.g., transplanted tissue rejection, transplant patients are encouraged to be involved in their self-care and condition management extensively and bear further responsibility for their health (5).

Today, self-management is recognized as one of the chief aspects of successful healthcare. It enhances the health level, decreases the number of re-hospitalizations, and promotes quality of life in patients (6). Self-management is defined as one's capacity to manage the symptoms of a chronic disease, the treatment, and the side somatic and mental effects and change lifestyle to adjust to a chronic condition (7). The self-management of a chronic condition requires patients' active participation in disease management and the ability to make decisions about different alternatives (8). In the post-transplantation period, kidney transplant patients face problems and barriers that prevent their successful self-management (9). According to the results of studies, patients' involvement in adherence to post-transplantation self-management behaviors is poor regarding physical activities, diet adherence, and medication use (1, 10-12). On the other hand, other transplant patients have extensive self-management experiences followed by self-managing behaviors and report a >5-year kidney transplant lifetime without post-transplantation complications (1). Patients have perceived that successful kidney transplantation is a gateway for raising independence and restoring life control despite causing new problems that influence treatment adherence (13). Successful self-management and treatment adherence are impacted by numerous factors, such as lifestyle, social-demographic and social-psychological factors, and treatment regimen (18). Contrary to the significance of self-management in achieving desirable outcomes in kidney transplant patients, these individuals have not completely adapted to these behaviors yet and fail to implement self-management behaviors (1). Many studies have endeavored to describe and explicate the mental processes why some individuals reveal better self-management behaviors than others when suffering from acute diseases. These processes are often called adaptation or adjustment in texts (14). Kidney transplant patients often experience significant clinical mental symptoms and various stressors and health risks that influence their adherence to treatment and self-management behaviors (15). Kidney transplant recipients also employ various coping strategies to adjust to the barriers to successful self-management.

Since the coping strategies adopted by every kidney transplant patient and the process of adjustment to constraints to self-management success shape personal and multidimensional experiences influenced by different social and cultural factors, only a qualitative study can delve into the lived experiences of kidney transplant recipients who continuously touch the varying challenges of the condition. Hence, this research sought to explain the strategies for coping with self-management barriers in kidney transplant recipients.

MATERIALS AND METHODS

This research was a conventional content analysis following Graneheim and Landman's (16) five-step approach, i.e., transcribing (implementing the interview texts and reading them to gain a general conception, dividing the text into meaning units, abstracting meaning units and extracting codes, classifying the codes into categories and subcategories based on their similarities and differences, and organizing and extracting themes from the hidden content of the transcripts. The inclusion criteria were kidney transplant recipients aged 18 years and above, a post-transplantation period of >6 months, and the capacity to recall and explain experiences. A total of 18 patients participated in this study.

Data collection

Since the coping strategies patients employ to adjust to self-management barriers are unknown in Iranian society, the researchers ran an initial field survey to identify samples with broad and rich knowledge of their condition. Thus, the sampling commenced with a purpose-based approach and continued until data saturation. The data were collected by deep and semi-structured individual interviews with open and complementary questions aiming to explain kidney transplant patients' attitudes and experiences in implementing coping strategies. For the purpose of the study and considering the generality of the self-management concept, the interviews started with the following questions: What self-management problems have you faced after receiving the transplant? What strategies have you employed to encounter and adapt to these problems? How did you adjust to post-transplantation changes, and how did you get along with care intricacies? Then, complementary questions were asked according to the participants' responses. Every interview lasted 30 to 60 minutes, and the data were analyzed simultaneously with their collection. Every new interview was conducted after the analysis of the previous one. The researchers compared the resulting data of every interview with all preceding data to elicit their interrelationships. The data were minutely decomposed into the smallest possible components, and the differences, similarities, and relationships between data and their inter-concept relational model were explained.

Data analysis

The data were analyzed as they were collected. Every new interview was conducted after the analysis of the previous one. The researchers compared the resulting data of every interview with all preceding data to elicit their

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interrelationships. The researchers meticulously decomposed the data into the smallest possible components and explained their differences, similarities, and interrelationships, as well as their inter-concept relational model. The four criteria of creditability, transferability, dependability, and confirmability were applied for data validity and reliability (17). The participant review method was employed to confirm the validity of the data and codes, i.e., the transcripts were turned back to the interviewees after coding, and contradicting codes were modified according to their views.

Ethical considerations

This paper has been extracted from a doctoral nursing dissertation in the Baqiyatallah University of Medical Sciences in Tehran, Iran, with the IR.BMSU.REC.1395.304 ethics code. After being explained about the purpose of the study, the samples completed the informed consent form. Data confidentiality and voluntary participation were sought, and the participants were allowed to leave the study at any stage.

RESULTS

Eighteen kidney transplant patients participated in this study (**Table 1**). The data analysis led to the extraction of a theme (acceptance of living with a chronic disease), four categories (increased resilience, social support, self-empowerment, and adjustment to changed roles), and eleven subcategories (**Table 2**).

Table 1. Demographics of the participants

Participant number	Gender	Age (Years)	Duration after transplantation/ Duration of working with a transplanted recipient	Marital status
1	female	49	4 years	married
2	female	45	27 years	married
3	male	38	6 months	married
4	female	41	4 years	married
5	male	29	2 years	single
6	male	55	20 years	married
7	male	35	5 years	single
8	male	36	4 years	single
9	female	57	17 years	married
10	female	38	15 years	single
11	female	24	8 months	single
12	female	-	20 years spouse of transplanted recipient	-
13	female	-	10 years working with a transplanted recipient	-
14	male	-	18 years working with a transplanted recipient	-
15	female	40	12 years	single
16	male	34	34 years	single
17	female	31	6 years	married
18	male	50	15 years	married

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Table 2. Explained categories and subcategories of the research.

Theme	Main categories	Subcategories
Acceptance of living with a chronic disease	Increased resilience	Flexibility High hopefulness Maintenance of the spiritual self
	Social support	Continuous interaction with the treatment team Seeking supportive sources
	Self-empowerment	Relationships with peers Health literacy promotion Attainment of problem-solving skills
	Adjustment to changed roles	Adjustment to role changes Adjustment to physical constraints

Acceptance of living with a chronic disease

Kidney transplant recipients had accepted the sense of being treated as a chronic patient and planned all life stages according to their somatic conditions. The participants integrated their chronic diseases into their daily lives by accepting unchangeable situations, developing realistic expectations, receiving counseling and psychotherapy, and accepting death. They believed that their somatic and health conditions caused a chronic circumstance and that they should tolerate their disease conditions until the end of their lives, similar to other chronic illnesses.

Increased resilience

When negative thoughts flash in patients' minds, they fight against them by not reflecting on current conditions, adopting a sense of humor, and conversing with relatives. "When negative thoughts occur in your mind and make you angry and hopeless, you should be able to divert your thoughts and think about positive things. I draw pictures. Sometimes, I read books, watch films, and do whatever can bring me out of that negative mood" (P10). According to the participants' expressions, hope is one of the chief sources of increased resilience in kidney transplant patients and influences their attitudes, health conditions, and quality of life. "...every day, a new medication is produced, a new treatment is invented. I'm sure the produced medications will no longer have all these risky complications. Well! Humans live in hope..." (P16). The participants selected religious and spiritual approaches when they faced fear experiences and were concerned about losing the kidney again and returning to the hard dialysis period. Participants' spirituality was strengthened by faith in divine miracles, praying, Quran reading, and surrendering to divine fate. "With faith and trust in God! We are Muslims and believe that everything is at God's will. We believe that God opens another door if He closes one. I overcome my stress by trusting in God and being thankful to Him" (P6).

Social support

Visiting doctors regularly and interacting with the treatment team were among the participants' strategies for coping with self-management barriers. The participants expressed that they needed numerous medical services and constantly faced challenging situations that they could not handle by themselves. They also stated that they felt less stressed when they talked with a physician or other treatment member. "Anytime I visit a doctor, I save his office's number in my phone to call and ask for help in the case of a problem. I highly believe in my doctor's words..." (P5). Many of the participants attempted to identify available supportive sources. These supportive sources that largely met the emotional and financial needs of the patients were the family, relatives, social workers, and supportive associations. Based on the experiences of both single and married patients, the couple's emotional support had a significant contribution to their lives. In this respect, one of the participants said: "It is your family that always stays with you in difficult conditions. Now, whenever I go to the doctor, my husband accompanies me. The husband's support is very important and boosts one's morale in getting along with problems" (P4).

Self-empowerment

The participants recognized building relationships with peers to gain knowledge about disease management and solve existing problems and using their experiences as approaches to overcoming complications. "One receiving a kidney transplant before me is more experienced. In the clinic, I saw a transplant female who had received a kidney 20 years ago. She informed and guided me a lot. Anytime I notice an abnormality in my test results, I quickly call and consult with her" (P11). Transplant patients acquire the necessary skills by attending educational classes specific to kidney transplant patients. The participants had changed into specialist patients as due to repeating self-management behaviors and

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techniques. Considering the necessity for promoting health literacy to overcome self-management barriers, one of the participants explained: "You should acquire some skills to take care of yourself in the best way and make the new kidney function properly. I mean the skills for caring for yourself. It may be a little difficult at first, and you may not know the skills well. But you soon learn all over time" (P10). A skill the kidney transplant patients had learned and employed in the face of problems was the problem-solving skill. Concerning the need for learning this skill, one of the participants asserted: "Kidney patients should know how to solve their problems if they face any" (P8).

Adjustment to changed roles

The participants usually divided activities into several steps and accomplished them sequentially to increase their body energy and prevent fatigue. "Although one releases from previous conditions and difficult dialysis days after transplantation, the surgery brings new changes to the life. You have to adjust to these new changes and accept that you no longer have and cannot regain the pre-disease body strength" (P9). The participants expressed that after the kidney transplantation, they experienced changes in their occupational conditions and previous roles due to the nature and chronicity of the disease, external changes, and compulsory post-transplant care. "My job is full of stress. To reduce my work stress in these conditions, I have requested a transfer to a looser unit" (P7).

DISCUSSION

The reflected main theme in all categories and subcategories in this study indicates the participants' attempts to accept the chronicity of the condition and life with a chronic disease. After kidney transplantation, patients usually experience anger, fear, depression, and anxiety feelings that prevent proper self-management (18). Accepting and adjusting to these feelings causes transplant patients to tolerate their chronic and lifelong conditions (19). Transplant patients should accept the sense of being treated as chronic patients and plan all their life according to their somatic circumstances. They integrate their chronic diseases into their daily lives by going along with unchangeable situations, developing realistic expectations, receiving counseling and psychotherapy, and accepting death (20).

One of the categories explained in this study was increased resilience. Studies show that resilient individuals tend to employ coping strategies that call for positive emotions in regulating their negative emotional experiences. Accordingly, resilience inversely correlates with psychological stress and not only reflects one's ability to tolerate and adjust to problems but also protects and promotes mental health (21). Resilience enables individuals to respond to variable conditions and environments, as well as life intricacies and adversities, flexibly and resiliently without being traumatized and consider these situations as opportunities for personality development and excellence (22). One of the sources the participants applied to develop resilience and overcome barriers was flexibility. A study examining the impact of flexibility on patients' chronic pain management revealed that flexibility was one of the main factors of resilience in these patients and helped them to control and tolerate pain (23). One of the sources the participants employed to enhance their resilience was the maintenance of the spiritual self. Spirituality motivates individuals to take care of themselves (6). A qualitative study displayed that resorting to religion and spirituality, e.g., religious deeds like worshipping and trusting in God, was a factor in adjusting to chronic obstructive pulmonary disease and its symptoms. Likewise, religious beliefs facilitate using problem-solving strategies and adhering to medications and create peace, power, protection, safety, and self-confidence in individuals (24).

Social support was another explained category in this study. Individuals benefiting from high social support are able to adjust to life events, while those receiving low social support are more vulnerable (25). Studies on dialysis patients reveal that the degree of perceived social support can be introduced as a crucial factor in predicting the survival rate of these patients, such that a sense of higher social support improves patients' clinical conditions. Accordingly, the escalation of the perceived social support enhances self-care behaviors, medication adherence, and quality of life in hemodialysis patients and decreases their mortality (26). One of the primary pillars of social support in the participants was constant interaction with the members of the treatment team. The process of building relationships with the treatment cadre in chronic patients is different from the one employed by acute patients. The continuity principle was one of the main pillars of relationships in transplant patients. The hospital personnel and members of the treatment cadre should receive the necessary training to pave the way for trusted relationships with patients. Rao et al. asserted that dissatisfied patients less frequently followed medical prescriptions and their treatment process and tended to replace their physician or treatment team more likely (27).

Another coping strategy addressed in this research was self-empowerment. Self-empowerment in these patients is a process that allows them to obtain the necessary skills and knowledge of their disease and make informed self-care decisions (6). The research on self-care in kidney transplant recipients reflects that teaching self-empowerment skills promotes the patients' self-care behaviors (28). According to findings, relationships with peers are one of the approaches to raising awareness in patients and one of the strategies for

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overcoming treatment-associated stress and anxiety (29). A study examining the effect of the peer training support model on the quality of life and self-care behaviors of patients with myocardial infarction recommended peer training with healthcare specialists to promote life quality and self-care in these patients (30). Enhancing health literacy was the other strategy employed by the participants. According to the results of studies, health literacy strengthens self-care behaviors in patients with chronic kidney diseases (31). Kidney transplant patients analyzed their current situations based on the health literacy and information they had already gained. In the case of an abnormality, they sought to identify the problem and choose the most effective alternative from the present solutions. In this regard, problem-solving is an essential skill to solve the barriers to patients' successful self-management (32).

The last significant finding of this study was adjusting to changed roles after kidney transplantation. Due to the nature and chronicity of the disease, the participants experienced changes in their work conditions and prior roles that prevented successful self-management in their new lives (33). Individuals should accept the emerging constraints and alter their activities and behaviors significantly to adjust to new roles in life.

To the best of our knowledge, this was the first study in Iran into the Strategies for coping with self-management barriers among kidney transplant recipients. One limitation of the study was sampling among kidney transplant recipients who were older than eighteen. Therefore, the study provides little information, if any, coping strategies with self-management barriers among children and adolescents.

CONCLUSION

The results of this study displayed that kidney transplant recipients in Iran employed specific coping strategies tailored to Iranian and Islamic culture in facing problems and barriers to self-management. Considering the significance of self-management in these patients' survival, the outcomes of this research can help design more extensive interventions in the future to improve coping strategies and enhance adjustment to self-management barriers in kidney transplant patients.

Contributions

H. Mahmoudi, Z. Vafadar and H. Sharif Nia designed the research. Z. vafadar, H. Sharif Nia and S. Khezerloo performed the experiments, analyzed data and wrote the paper. All authors contributed to interpretation, revised the manuscript and gave final approval for publication.

This study was part of a PhD dissertation in nursing in Baqiyatallah University of Medical Sciences, Tehran, Iran. The dissertation was approved by the Ethics Committee of the university with the code of IR.BMSU.REC.1395.304.

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Conflict of Interests

The authors declare that they have no Conflict of Interests.

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