



Stigma experience in patients with kidney transplant rejection

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General Note

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ABSTRACT

Introduction: Chronic Kidney Disease (CKD) is currently a global health issue. Psycho- social aspect of physical disorders might cause more problems for an individual than the deficiency itself. Understanding the psycho- social experiences of patients with kidney

transplant rejection could help them to find a proper way to deal with it. *Objectives:* To illuminate psycho-social experiences of patients with kidney transplant rejection. *Methods:* In this qualitative phenomenological study was carried out in 2018 in north-west cities of Iran in 10 patients (4 females and 6 males) with kidney transplant rejection experience. Data were collected by semi-structured interviews. The interviews included main and exploratory questions and analyzed using Van Manen's phenomenology approach. *Results:* overarching theme of stigma which included three primary themes were emerged from the data analysis; 'self-blaming for causing a deficiency in another individual's body', 'hiding the disease', and 'seclusion'. *Conclusion:* The study has demonstrated that patients submitted to a kidney transplant rejection had an experience stigma. Considering the high rate of stigma in these patients, it is necessary to attend to it and it is suggested that social education about dealing with these patients appropriately be provided in various levels via media and by healthcare centers.

Keywords: Kidney transplant rejection, stigma, phenomenology

1. INTRODUCTION

Chronic kidney disorder (CKD) is one of the chronic diseases that might affect various aspects of individuals' lives (Bihl et al., 1988). Once 95% of kidney tissue is destroyed due to various reasons, body poisons are assembled so much that the patient becomes dependent on one of the alternative therapeutic ways in order to prevent uremia and its constant life-threatening side effects (Sayin et al., 2007). The different treatments available for CKD hemodialysis, peritoneal dialysis and kidney transplant are not a cure but they are an alternative. Compared to others, kidney transplant is described as the best treatment for patients with terminal CKD because it promotes a better quality of life and lower mortality as well as being associated with various benefits, including reduction of health care costs (Brito et al., 2015). The prevalence and outbreak of the final stage of kidney disorder that requires alternative therapeutic ways such as dialysis or kidney transplant is increasing (Schold and Meier-Kriesche, 2006). However, all kidney transplants do not succeed and the rate of kidney transplant rejection reaches to 12 % in the first year (Behrouzi and Mousavi, 2010). This rate increases as the time passes by and reaches to 20 % in the fifth year, 40 % in the tenth year and 50% in the fifteenth year (Salehi and Emamzadeh Ghasemi, 2014). Most of the people having kidney transplant encounter transplant rejection in different ways. Such unforeseen and undesired event causes hopelessness and desperation in patients and later results in depression (Christensen and Ehlers, 2002). Patients following kidney transplant rejection may suffer from severe depression due to the necessity of returning to dialysis, since most of the patients are unwilling to return to dialysis again and would not predict these stages beforehand (Gill and Lowes, 2009). Additionally, patients suffer from other problems such as Anemia, lethargy and family-related problems such as increased dependency to the family and negative body-image of self that might cause depression in these patients. Furthermore, they feel guilty about themselves and the living donor because of unsuccessful surgery; consequently, patients, and in few cases their family, often experience feelings such as rage and depression and even they attempt to commit suicide, which needs clinical intervention (Carosella, 1984). Understanding the effect of transplant rejection on patients and their families is of great importance for health care providers, since it affects the kidney receivers' whole life (Morse and Field, 1995). Various studies in China, Nigeria, Australia, etc have emphasized the importance of the social dimensions and stigma resulted from the disease (Ahsan Ullah, 2011). As a result, researchers emphasized the social and individual interventions concerning this issue. For instance, in a study by Varni et al. the importance of the patients' adaptation to the stigma caused by the disease and its relationship with the mental well being had been emphasized (Varni et al., 2012).

Label or stigma is a negative mark that people often attribute it to the individuals who differ from them in some aspects. Race, appearance, and physical and mental health are some examples (Corrigan and Watson, 2002). Since our study question was 'what is the experience of stigma in patients with kidney disorder? therefore, the qualitative approach was conducted. It was because the findings could enable us to thoroughly understand the truth of the experience (Morse and Field, 1995). Regarding the lack of enough studies and since almost no study has been carried out in Iran on this issue as well as the importance of identifying kidney patients' experiences and nurses' understanding of those experiences in client-based care programs and responding the study question (what is the experience of stigma in patients with kidney transplant rejection?), this study was conducted qualitatively.

2. MATERIAL AND METHODS

This interpretative phenomenological study was carried out with the participation of 10 patients having experienced the kidney transplant rejection in hospitals of Tabriz and Ardebil (north-west of Iran) using purposive sampling. The data were collected

through interviews. The interviews were implemented individually and their type was in-depth open following semi-structured interviews. Their sequence was not identical for all patients since the questions depended on the process of the interview and the patient's responses (Holloway and Wheeler, 2002).

The interviews included main and exploratory questions and each interview lasted for 20 to 45 minutes. After the first interview was implemented and transcribed verbatim, the statements were reviewed for vagueness. In some cases, the secondary interviews were arranged in order to present the data to the participants and clarify the ambiguous points. The interviews were recorded and transcribed verbatim shortly and coded. They were also continued until data saturation, which means repetition of the data. To analyze the data, six steps of Van Manen's interpretative phenomenology were used. This approach consisted of the followings: 1. considering the nature of the experience 2. Investigating the experience 3. pondering about intrinsic themes of the phenomenon 4. Writing and rewriting interpretatively 6. Conforming the study context considering its elements and whole (Van Manen, 2001).

Constant review of the question 'what is the experience of stigma in patients with kidney transplant rejection?' made it possible for the researcher through using interpretative analysis to reveal the perception of this experience as the participants experienced and lived it. Theme analysis was also done through separating intrinsic and secondary meanings using selective approach; as the transcriptions were read or heard several times and the meaningful sentences and units that based on the researcher described the desired phenomenon, were separated. This way, 140 thematic phrases, sentences or paragraphs were extracted from the interviews that were categorized into themes and subthemes based on the similarities. Lastly, by reading each interview for several times and the researcher's immersion in the interviews or by pondering about intrinsic themes, the main themes were identified. The distinctions in the main themes let the researcher provide lived meaning of the stigma. To this end, written interpretations and descriptions of the participants' statements as well as some examples from their speech were used.

Following these and in order to confirm the validity and accuracy of the study, credibility, dependability and confirmability of the data were investigated. To guarantee the validity, the findings were presented to the participants and they expressed their opinions on the adaptability of the findings and their own experiences to the researcher. Furthermore, the research team was deepened into emerged themes. Researchers guaranteed the confirmability of the study during all stages by maintaining the documents. Researchers' interest in the study phenomenon, long-term accessibility to the data and an attempt to obtain others' opinions on this issue are among other factors to guarantee the confirmability. In addition, the present study was carried out as a team work and under the theoreticians' supervision that enabled credibility and confirmability of the data.

In order to observe the ethical considerations, the license of the ethics committee was obtained from Tabriz University of Medical Sciences. Later, the participants were informed about the purpose and importance of the study and participated in it with informed consent. The permission to use a voice recorder for recording the interviews was obtained from the participants and they were assured that the data would merely used for the study purpose and they would not be revealed to the people except the research team. It was also emphasized that the participants were free to withdraw from the study at any stage and their information would be kept confidential during and after the study.

Ethical consideration

This research was approved on ethical committee on Tabriz University of Medical Sciences, Tabriz, Iran with code 21546/D/5.

3. RESULTS

Findings of this study resulted in the emergence of 140 thematic paragraphs from the interviews, from which 3 main themes were come out by pondering about intrinsic themes of the phenomenon. The distinctions between the main themes enabled the researcher to provide the description for the lived meaning of the stigma (Table 1).

Table1 Themes related to the experiences of stigma in patients with kidney transplant rejection

	Self-blaming to cause a deficiency in someone else's	Worry about causing a problem for the donor in the future	Thinking about the case in which the donor might lose her/his other kidney too and need to get dialysis- hoping that no problem would affect the donor's other kidney
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Sigma	body	Feeling guilty conscience toward the donor	Feeling of causing a flaw in someone else's body - malversation - sadness toward the kidney donor- destroying another one's kidney - fear and embarrassment to meet the donor- inability in taking care of the donor's kidney- soothing self for unintentional rejection of the kidney rejection
		Feeling of indebtedness towards the donor	Feeling of being beholden to the donor- indebtedness -asking about the donor from time to time
	Hiding the disease	Being accused of negligence resulting in transplant rejection	The patient being accused of inability in taking care of the transplanted kidney against temperature change, not using corticosteroid tablets, not receiving required educations of care
		Dialysis and transplant rejection taboo	people mistaking dialysis for having sexual problems- obloquy of committing a sin- improper jests about the disease such as not being male- unpleasant feeling for others to be friend with an ill person
		Pretence of being healthy	Pretending to be healthy- it is not required for others to be aware of the disease- the problem cannot be solved by others' awareness- hiding the disease from the youngest child not to lose his/her pride and spirits- hiding transplant rejection from in-laws recommended by the suppose because of family's temptation to divorce
	seclusion	Feeling lonely	Getting alone- being isolated from others- feeling of imprisonment- feeling lonely- feeling isolated
		Withdrawal from the people	Not participating in ceremonies because of fearing of people questionings and revelation of the transplant rejection- no relationship with people due to lethargy and not being in the mood

Self-blaming to cause a deficiency in someone else's body

One of the important themes in participants' experiences of the stigma was blaming their self for causing a deficiency in someone else's body. In this study, 3 sub-themes of 'worry about causing a problem for the donor in the future', 'feeling guilty conscience about the donor', and 'feeling of indebtedness toward the donor' emerged from the participants' experiences.

A: worry about causing a problem for the donor in the future

In this theme, participants continuously thought about the donor who might encounter kidney failure and need dialysis. A patient said: "from the moment of the transplantation, I thought that well I'm now ok and at ease, but the donor may face any problem with his/her kidney, like me and has to get dialysis' (participant 1).

B: feeling guilty conscience toward the donor

Participants felt that they had flawed another person's body and had the feeling of malversation and sadness. They also felt that they fell short of taking care of the donor kidney. "After transplantation, I feared to meet the donor and she/he'd ask me why I

couldn't keep his/her kidney safe. I thought with myself that a young person gave his/her kidney to me, but I couldn't take care of it. But actually, I didn't do anything deliberately to cause the transplant rejection. I didn't have facilities, so it happened. For example, our lavatory is in the yard. I had to go there in cold and snow. Or my house doesn't have gas and I had to buy petrol in that cold. It wasn't my fault". (Participant 2)

C: feeling of indebtedness toward the donor

In this theme, participants felt indebted toward the donor and stated that they owed the donor a lot. "I always thought about the kidney donor and visited him once a month. I always wished him to be ok". (Participant 3)

Hiding the disease

One of the most important themes emerged from the participants' experiences was hiding the disease. Each of the participants mentioned this theme in different way based on their experience. This theme consisted of 3 sub-themes: 'being accused of failing to take care of the kidney resulting in the transplant rejection', 'dialysis and transplant rejection taboo', and 'pretence of being healthy'.

A: patients being accused of failing to take care of the kidney resulting in the transplant rejection'

Participants stated that to prevent being accused of not taking care of the kidney properly, they hid the transplant rejection. Therefore, they refused to reveal it in order to keep safe from people's and relative's condemn. "it isn't necessary for people to know about it, because they don't have enough knowledge and they don't know that transplant may not even work. A person, who lacks enough knowledge, believes that it's your fault and you didn't take care of the kidney. For example, they think that we didn't take cortone tablets on time, or we didn't take care of the kidney in cold weather, so the body rejected the transplant. They also think we didn't observe doctor's recommendations". (Participant 2)

B: Dialysis and transplant rejection taboo

Based on the majority of the patients, most of the people have wrong understanding of the disease due to the lack of enough knowledge. "I don't tell others too much about my disease, because they misuse it. For example, my sister-in-law had an argument with my wife and she had told her that I'm not a male. I can see that many people misunderstand my illness; even my friends tell some jokes that I get offended. For example, they say: "because he is sick, so he's not a male" (Participant 10). "My brother condemned me and believed that because I had committed a sin, so God was punishing me this way". (Participant 3)

C: pretence of being healthy

In many cases, patients had experienced the pretence of being healthy and believed that it was not necessary for others to be aware of their transplant rejection. Some patients hid the rejection even from their own family in order not to upset them. "I believed that it wasn't necessary for people to know about my transplant rejection, because they don't have enough knowledge about dialysis and transplant" (Participant 4). "I really don't like it to tell others about my disease, because I don't want to lose my pride. I don't want anyone to know about my transplant rejection and feel pity for me. I dislike it" (Participant 7). "I hid transplant rejection from my in-laws, because I didn't want them to be upset or tempt their daughter to get divorced. My wife herself wanted me to hide it from her family". (Participant5)

Loneliness and seclusion

All of the participants had experienced loneliness and seclusion after transplant rejection differently.

A: Feeling of seclusion

Patients stated their experiences of being alone and being isolated from their friends because of staying at home and getting reserved. They said that they had no relationship with their friends and did not take part in ceremonies, since they feared of being questioned by people about transplant rejection or revealing it. Therefore, they felt as if they were imprisoned.

B: Feeling of loneliness

In this case, patients had lost connection with their friends unwillingly and due to the lethargy or frequent dialysis; therefore, they were isolated from the society and their friends and felt lonely. "Before transplant rejection, I had communication with all of my

friends, but now I just have my family with me because I'm not in the mood to go out or I don't have enough time to communicate with others. Dialysis takes most of my time and after that I'm usually inert, so I don't take part in ceremonies". (Participant 7)

C: withdrawal from the people

Considering this issue, patients stated that they themselves did not want to participate in ceremonies and gatherings, since they did not want their disease to be issued everywhere. "I don't take part in ceremonies because I don't want my disease to be talked in such places" (Participant 1). "You get secluded even in the society and your relationship with friends decreases, because no one wants to hear about other's illness. So, they limit their relationship with the sick person". (Participant 8)

4. DISCUSSION

Despite advances in immunosuppressive drugs and clinical treatment techniques, fear of graft loss has been reported as one of the major stressors following kidney transplant. This same result was found by other researchers (Chen et al., 2010 and Rosenberger et al., 2005 and White et al., 1990) in which the fear of rejection or uncertainty about the future, related to health, is of the greatest concern for renal transplant recipients.

The experiences of stigma in patients with kidney transplant rejection affect their mental /physical health badly, thus impairing the process of their improvement and healing. It seems that bearing a stigma of transplant rejection would not be without cost and it would be accompanied by several cognitive, emotional and behavioural side effects. Stigmatized people internalize society's negative attitudes toward themselves. During this internalization, individuals create negative self-evaluation, experience extreme negative feelings such as rage and despair, become secluded and conceal their disease from others (Major, 2006).

According to the findings of this study, one of the themes was the patients being accused of failing to take care of the kidney that resulted in transplant rejection. The patients expressed this theme by hiding their disease and dialysis taboo as well as transplant rejection. In addition, they pretended to be healthy. In some studies, on the experiences of stigma in patients with HIV, a significant relationship was reported to be between individuals' knowledge and stigma (Ghabili et al., 2008). Inadequate knowledge and improper perceptions about some chronic diseases result in inappropriate social behaviours toward patients. Hence, patients with transplant rejection emphasized constantly that the society should be notified about this disease. Smart and Wegner 1 state that hiding the stigmatized situation leads to agitation, which in turn may affect an individual's mental life according to its severity and nature (Smart and Wenger, 2000). Patients seek a strategy for hiding their disease because of the stigma of kidney transplant rejection. Followingly, they become more isolated, do not follow the treatment and withdraw from supportive networks (Hassall et al., 2005). Therefore, it seems that cognitive and psychological interventions have an effective role in patients with kidney transplant rejection in order to modify their self-beliefs, promote the level of their self-esteem, enable them to take the control of their life, and rehabilitate their abilities, all of which result in their return to the society. Studies unanimously indicated that the stigmatic individuals usually encounter specific problems that are restricted to their experiences. Stronger feeling of stigma has a positive significant relationship with more depression symptoms (Crocker and QD, 2000 and Yoo et al., 2014 and Reeve et al., 2017).

According to the results of the present study, isolation is another side effect of the kidney transplant rejection, in which patients felt lonely, withdrawal and rejection. However, the rate of such feelings varied in different individuals. Wrath, Kim, Ritz and Carigan found that defensive strategies against stigma such as social isolation or hiding the disease increase the anxiety. Such an increase in the feeling of discrimination and unworthiness has, in turn, a negative effect on self- efficacy and empowerment (Venable et al., 2006). A decrease in empowerment, influences depression and leads to a low-quality life (Hassall et al., 2005).

General understanding of transplant rejection that has been introduced since early 20th century, endured great deal of wrong and superstitious perceptions. However, one of the aspects that make the transplant rejection more complicated is indication of various symptoms in different individuals (Lord, 2011). A better understanding of the perceived problems associated with different aspects of living with a chronic illness may illuminate possible interventions to improve disease outcomes. According to recent literature, patients receiving psychological support protocol before transplantation and during follow-up after transplantation lead to improved compliance with treatment and quality of life with physical, emotional, and psychological adjustments (De Pasquale et al., 2011 and De Pasquale et al., 2014). In fact, it seems that when individuals receive the same recognition of kidney transplant rejection, they express different characteristics and weak and strong points. This wide variety in individuals with kidney transplant rejection along with the lack of general knowledge on this disease creates social stigma in the community (Yoo et al., 2014 and Reeve et al., 2017 and Venable et al., 2006 and Lord, 2011 and De Pasquale et al., 2011 and De Pasquale et al., 2014 and Martin Danielle, 2012). Social stigma resulted from the lack of general knowledge, has been reported in different levels. Studies that have

been conducted during these 2 decades, indicates the feeling of stigma in patients and their family after transplant rejection (Gill and Lowes, 2009).

Ashkani et al. in a study investigated the psychological trauma in the patients having kidney transplant before and after the surgery. By and large, the study results stated that there was a probability of high rate of depression and anxiety prevalence in patients with kidney transplant especially those with dialysis. Although the final recognition of depression requires psychological examinations, this phenomenon might have some outcomes such as impairments in treatment, medicine use and diet and it might influence the patients' life quality (Ashkani et al., 2002). Findings of this study showed that considering people's negative attitude toward the patients with kidney transplant rejection, stigma is being introduced as an important factor in cure failure. Undoubtedly, following the treatment process in patients with transplant rejection is of great importance so as to obtain desired therapeutical results in these patients. Consequently, regarding the diverse ethnicity and lack of enough knowledge on the stigma and strategies to deal with it in Iran, it is recommended that more proper studies be conducted in order to obtain better understanding of the issue. Based on the mentioned subjects, studies show that stigma might cost a great deal of mental and social expenses for the society and the individuals with a particular label.

Therefore, various strategies for altering the stigmatic attitudes and empowering individuals to deal with it could be used in order to reduce stigma and its side effects in patients with kidney transplant rejection.

5. CONCLUSION

This study showed that patients referring to transplant rejection had some form of stigma. Given the high level of stigma in these patients, it is recommended that appropriate social education be provided on these patients through the media and health centers at different levels. The recipients were able to envision several benefits of the kidney transplantation, favoring a better family and social involvement, emotional aspects and suppression of stigma, representing an effective treatment for people with advanced kidney disease.

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