

# Coping strategies in patients with kidney transplant rejection: A phenomenological study

*Estrategias de afrontamiento en pacientes con rechazo de trasplante renal: un estudio fenomenológico*

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## Abstract

**M**ost of the patients with kidney transplantation are exposed to its rejection in different ways. The undesired phenomenon of transplant rejection causes various physical and mental problems in patients and it is inevitable for them to utilize coping strategies in order to deal with the new condition. The aim of this study was to obtain a deeper insight into coping strategies that kidney transplant recipients utilize in order to deal with the challenges.

**Methods:** Deep semi-structured interviews were implemented with 10 participants using phenomenological approach. Data analysis was done using Van Manen's method and sampling was based on purposeful method.

**Findings:** three themes and seven subthemes describing the coping strategies of patients with transplant rejection were emerged from data analysis. The themes included 'seeking support', 'spirituality', and 'accepting the reality'.

**Conclusion:** it seems that one specific adaptation strategy is used in every stage of coping with transplant rejection. During first days, the strategy of family and friends' support plays an important role. Afterwards, patients perceive that through spirituality, they can manage their disease and after a while, they admit the inevitability of accepting transplant rejection; thus, setting new goals for themselves and trying to achieve adaptation despite their restrictions.

**Key words:** Transplant rejection, Kidney transplanr, Coping strategies.

## Resumen

**L**a mayoría de los pacientes con trasplante de riñón están expuestos a su rechazo de diferentes maneras. El fenómeno no deseado del rechazo de trasplantes causa diversos problemas físicos y mentales en los pacientes y es inevitable que utilicen estrategias de afrontamiento para hacer frente a la nueva afección. El objetivo de este estudio fue obtener una visión más profunda de las estrategias de afrontamiento que utilizan los receptores de trasplante de riñón para hacer frente a los desafíos.

**Métodos:** Se implementaron entrevistas semiestructuradas profundas con 10 participantes utilizando un enfoque fenomenológico. El análisis de los datos se realizó utilizando el método de Van Manen y el muestreo se basó en un método específico.

**Resultados:** del análisis de datos surgieron tres temas y siete subtemas que describen las estrategias de afrontamiento de pacientes con rechazo de trasplante. Los temas incluyeron 'buscar apoyo', 'espiritualidad' y 'aceptar la realidad'.

**Conclusión:** parece que se usa una estrategia de adaptación específica en cada etapa del manejo del rechazo de trasplantes. Durante los primeros días, la estrategia de apoyo de familiares y amigos juega un papel importante. Luego, los pacientes perciben que, a través de la espiritualidad, pueden manejar su enfermedad y después de un tiempo, admiten la inevitabilidad de aceptar el rechazo de trasplante; así, estableciendo nuevas metas para sí mismos y tratando de lograr la adaptación a pesar de sus restricciones.

**Palabras clave:** rechazo de trasplantes, trasplante de riñón, estrategias de afrontamiento

If kidneys cannot function more than 10-15% of their normal capacity, it is considered as End-stage renal disease (ESRD). At this stage, kidney transplantation, hemodialysis, or peritoneal dialysis is necessary<sup>1</sup>. Although more costly, kidney transplantation is often a common and more effective treatment than dialysis that additionally promotes the patient's life<sup>2</sup>.

The number of patients needing kidney transplantation is increasing day by day worldwide; as in the US, this number increases 7 to 8% annually<sup>3</sup>. In addition, patients confront some problems such as anemia, lethargy, and family-related problems such as increased dependency on the family and negative mental image of their body, all of which might cause depression<sup>4</sup>. Depression in patients with transplant rejection might be intensified due to the necessity for getting redialysed, since most patients dislike getting dialysis again and they do not anticipate these stages<sup>5</sup>. Furthermore, they feel guilty about the living donor because of the failure of operation on themselves; therefore, patients and, for lesser degree, their families, experience feelings such as rage or depression and in some cases patients attempt to commit suicide that requires clinical interventions<sup>4</sup>. For returning these patients to their common life, they need help to adapt themselves to new condition and meet their disturbed needs<sup>6</sup>.

Many studies have tried to explain the mental processes of why some individuals can cope with a severe disease better than others can. In literature, these mental processes are often titled as 'adaptation'. Adaptation is associated with individuals' ability to adjust themselves when confronting stressful incidents<sup>7</sup>.

Adaptation refers to cognitive and behavioral efforts to overcome, tolerate, and/or decrease conflicts and internal/external needs. These efforts constantly involve evaluation, re-evaluation, and individual- environment relationship<sup>8</sup>.

Adaptation to the disease is to maintain positive attitude toward oneself and the world despite physical problems. Weak adaptation to the disease is associated with more service usage and weak health outcomes<sup>9</sup>.

Coping strategies are specific techniques that individuals utilize facing stressful condition. These strategies encompass individuals' cognitive and behavioral efforts in interpreting and overcoming the problems. Consequently, an individual's ability to cope with such problems might be investigated from three aspects. Coping strategies include the efficient and useful actions that an individual takes meeting stressful condition and they cover the strategies of active coping, planning, preventing hasty actions, and seeking instrumental support. Positive-emotion-oriented coping strategies consist of the efforts that are done in

order to manage emotional responses to a stressful event and they include the tactics for seeking emotion-, acceptance-, and humor-based social support. Negative-emotion-oriented or ineffective strategies include lack of mental involvement in the problem, denying, lack of behavioral involvement in solving the problem, focusing on the emotion and taking medicines or drinking alcohol<sup>10</sup>. The aim of this study was to investigate those coping strategies implemented by the patients with kidney transplant rejection.

Considering the severe effects of this phenomenon on the patients and their families and for providing the support for them, it is necessary to make efforts to become aware of the experiences of the people involved in this phenomenon, since successful management of the patients and their family and caregivers requires a comprehensive perception of their experiences<sup>11</sup>.

This interpretative phenomenological study was conducted with the participation of 10 patients who had experienced kidney transplant rejection in Adrabil and Tabriz (north-west Iran) hospitals using purposeful sampling method. Inclusion criteria were kidney transplant rejection during the last 10 years, age above 18, ability to make communication, no history of mental disorder, and consent to participate in the study.

After selecting the participants, communicating with them, and explaining the study aim, informed consent for participating in the study and having their voice recorded was obtained from them. Mean of participants' age was 45years and their education level ranged between illiteracy and BA degree. There were 4 female and 6 male participants. Data were collected through open deep semi-structured individual interviews; however, the sequence of interviews was not similar for all participants, since it was associated with the interviewing process and each participant's responses<sup>12</sup>. Interviews consisted of main and discovery questions. Each interview lasted for 20-45 minutes. At least one interview was implemented with every participant. The second interview was done to remove the vague points of the previous interviews and to prove the researcher's understandings of the participants' statements. An interview guide was used to lead the interview. The interview guide consisted of main and follow-up questions. After implementing the interviews and transcribing them verbatim, texts were investigated for ambiguity. In some cases, second interviews were managed in order to refer the interviews to the participants to clarify the previous confusing points. Interviews were implemented and shortly they were transcribed verbatim and coded. In addition, interviews were continued until data saturation, i.e. data repetition. To analyze the data, steps of Van Manen's hermeneutic phenomenology were used. This approach consists of following steps: 1)

Turning to the nature of lived experience, 2) Investigating experience, 3) Reflecting on the instinct themes of the phenomenon, 4) Hermeneutic writing and rewriting, and 5) Balancing the research context by regarding parts and the whole<sup>13</sup>.

Constant existence of the question (experience of coping strategies in the patients with kidney transplant rejection) in the researcher's mind made it possible for her, through using hermeneutic analysis, to reveal the understanding of that experience as it was lived by the participants. Implicit analysis was additionally done by separating the instinct concept from secondary meaning. The selective approach was used in which the texts were read or heard several times and meaningful units and sentences that, according to the researcher, were describing the related phenomenon were separated. This was resulted in deriving 180 implicit phrases, sentences, or paragraphs from the interviews as organized themes and subthemes by considering the similarities. At last, through reading each interview for several times and the researcher's immersion in or reflection on the instinct themes of the phenomenon, main themes were emerged. Distinction between the main themes provided the researcher with the possibility of collecting the narrative description of lived strategies to cope with the kidney transplant rejection.

Following that, the data were investigated in terms of their validity, credibility, reliability and confirmability as well as the accuracy of the study. To guarantee the credibility of the data, findings of this study were presented to the participants and they stated their opinions about the consistency between findings and their experiences. In addition, cooperative deep thinking about emerged themes was done in different stages of the study.

Researchers guaranteed the confirmability of the study through recording the documents. Researchers' interest in the study, long contact with the data, and an effort to receive others' opinions on this field were among other factors to guarantee the data confirmability. Furthermore, the present study was conducted as teamwork whose credibility and confirmability was provided with the theoreticians' help and guide.

Regarding ethical considerations, the permission was obtained from ethics committee of Tabriz University of Medical Sciences before the study started. Afterwards, participants were informed about the purpose and importance of the study and they participated with their informed consent. The permission for recording their voice using a voice recorder was also obtained from them and they were made sure of using the data only for the study purposes and not revealing them to any outsider. In addition, they were assured that they could leave the study at any stage and their information would be kept confidential during and after the study.

Findings: The data analysis resulted in the emergence of various coping strategies that participants used for man-

aging the stressful events of kidney transplant rejection. Three themes were as follows:

'seeking support', 'spirituality', and 'accepting the reality'. Seven subthemes are shown in Table 1.

**Table 1. Themes and Subthemes**

| Theme                          | subtheme                                     |
|--------------------------------|--|
| Seeking support                | a. Family and friends' support               |
|                                | b. treatment team's support                  |
| spirituality                   | a. Surrender to destiny written by God       |
|                                | b. God's examination                         |
| accepting the kidney rejection | a. obligatory acceptance                     |
|                                | b. Acceptance by passing the time            |
|                                | c. Previous preparation for kidney rejection |

1. Seeking support: one of the important themes in coping with the kidney transplant rejection was a support provided by the family, friends and the treatment team that made the patients hopeful about life and the future.

a. Family and friends' support: family support was experienced as one of the most important sources of peace and coping with the disease. It helped patients ventilate their mental pressure to some extent.

Participant 1: "I'm completely satisfied with my family. Along with God's help, they made me hopeful about life. They even helped me in doing my personal chore such as taking bath or putting on my clothes. My friends and acquaintances also were very kind to me and provided us with financial help. My teen boy also worked to help remove our financial problems. All of them also supported me spiritually and sympathized with me."

b. Treatment team's support: participants stated that doctor's and nurses' communication and guide made them hopeful about the future. Participant 2: "doctors and nurses worked very hard. They made me hopeful about re-transplantation and listened to my problems. For example, any time I called my doctor, she/he answered me. Nurses also were very kind to me and taught me necessary diet and liquid restrictions."

2. Spirituality: one of the important themes of coping strategies of the patients with kidney transplant rejection was spirituality that included 2 subthemes of 'Surrender to the destiny written by God' and 'God's examination'.

a. Surrender to the destiny written by God: the attitude that individuals' destiny has been written by God specifically and in advance, and there is no escape from it, was a dominant opinion among almost all of the patients. Most of the patients stated that when God wills to do something, they must surrender to it, since this is the real meaning of devotion. This attitude was prevalent in the interviews. Participant: "I believe that,

for example, no leaf falls without God's permission. Nothing is beyond God's knowledge. If God wants it for me, I'm satisfied with it."

- b. God's examination: one of the participants' strong beliefs was that God examines the human being in different ways during their life and the one who is patient and can pass the examination successfully, will be rewarded in other world. Therefore, the opinion that they were being examined by God helped the patients deal with their disease. One of the patients (participant 3) told about it: "I'm sure that God is examining me to see whether or not I'll stay on my beliefs despite this much problem. God examines good people. He even examined his messengers such as Ayyoub prophet with too many problems and hardships, let alone me!"
3. Accepting the reality: one of the very important themes emerged from participants' experiences was accepting the reality. Every participant referred to this theme the way he/she had experienced it. Three subtheme of 'previous preparation for transplant rejection', 'accepting the rejection by passing the time', and 'compulsory acceptance' formed this theme.
  - a. Previous preparation for transplant rejection: patients, who had previous knowledge about kidney transplant rejection; for example, they had researched about it before implementing transplantation and they knew that not all of the transplantations would succeed, or they themselves had rejection experience, as well as the patients that adapted themselves to dialysis before transplantation and were not too sad about it, coped with the rejection better than others. Participant 5 said: "my spirits didn't droop too much after transplant rejection, because before that I had searched about its probability and I'd read something on the net. I knew that my transplantation wasn't going to succeed, so after the rejection, I accepted the reality."
  - b. Acceptance by passing the time: as the time passed, patients got accustomed to get redialysed and this way they considered transplant rejection as a normal event. Participant 4: "after some months passed from my transplant rejection, everything seemed normal to me and I got used to commuting for dialysis."
  - c. Obligatory acceptance: acceptance due to feeling helpless was another reason to make patients get along with the transplant rejection, since there was no other choice and they felt obliged to adapt themselves to this problem because of their families and children. Participant 7: "I had no other choice. Did I? I had to accept this problem because life goes on. I have a child, a family, so I must keep on living for them."

## Discussion

The meaning of the ability to cope with the disease could be of importance the way individuals evaluate their lives<sup>14</sup>. Kidney transplant rejection has numerous mental and emotional outcomes. Study findings indicate that patients with transplant rejection are subjected to various mental outcomes such as depression, anxiety, negative thoughts in conjunction with decreasing the quality of their life. The fact that some patients with transplant rejection might attempt to commit suicide adds to the importance of the issue<sup>4</sup>. Most of the patients adapt themselves through different ways and they use various mechanisms to cope with the imposed physical and mental challenges. To our knowledge, the present study is the first qualitative study conducted on describing coping mechanisms used by the patients with transplant rejection. Regarding physical and mental-social outcomes relating to this disease, it is of great importance to investigate the coping strategies to help such patients.

Findings of this study showed that patients received various support during their adaptation to the disease. Participants mentioned that they had received the major part of support from their families. Support and attention provided by the family would create hope for them and they would have the feeling of not being alone facing the disease. Patients referred to their life partner as the key figure in giving support. In fact, the support provided by the spouse could be the most important protective source for individuals spending this period<sup>15</sup>. Spouse's presence as a supporter was effective in decreasing the tension and increasing the satisfaction with life during the disease<sup>16</sup>. Additionally, participants referred to their friends and acquaintances' supportive role. The protective behavior along with paying attention to the patients created the feeling that despite the disease, their friends did not leave them alone. In the literature, it has been stated that the support provided by friends improves the patients' social communications and it results in decreasing their depression and anxiety and increasing the level of satisfaction with their health condition. Consequently, the provided support increases the patients' self-confidence<sup>17</sup>.

Another supportive aspect, which participants referred to, was receiving support from their doctor and nurses that had a great role in returning them to life and restarting the treatment through encouraging them to get another transplantation or redialysis.

In addition, based on the findings one of the patients' most important and pivotal coping strategies was religion and their spiritual approach. Spirituality indicated the patients' beliefs, opinions, and religious culture. Faith and trust in God and destiny, insight into hardships and invoking the messengers were among the known coping strategies<sup>18</sup>. These strategies that stem from religious be-



iefs are active strategies that help patients re-correct their thought and focus on the problem and making a right decision about it. Despite transplant rejection, patients were able to alleviate their mental and spiritual problems and achieve a relative repose in all steps of coping process through relying on their religious beliefs. The important power that helped them withstand transplant rejection was resorting to religious approaches. For most of the patients, religion was a routine and current issue in their everyday life and it was a strategy to cope with the disease and an important source for feeling relaxed and powerful. Associating the present events with God's will, God's examination and destiny were such good shelters for the patients to seek peace in. Participants considered their condition as God's will and believed that they were being examined by him. Believing in fate and the fact that every human being has their own destiny written by God and they must surrender themselves to God's will was another way that patients utilized to retrieve their lost peace, since after transplant rejection, a new chronic condition accompanied by hesitation could create a noticeable rate of anxiety and depression<sup>5</sup>. In present study, patients coped with their disease using multilateral religious approaches. One of those important approaches was the idea that patients considered their disease as a predetermined destiny written by God, his will, and his knowledge; consequently, they surrendered themselves to him. The result of the study by Taleghani et al, in which women with breast cancer believed that their disease was in God's hands, was relatively consistent with the present study<sup>19</sup>. Similarly, the study by Ebadi et al on Iranian chemically- injured people showed that they believed that their disease was God's will and considered the ache, disease, and pain as a gift from God<sup>20</sup>.

Another aspect of religious invocation was considering the disease as God's examination. As cited in holy Quran's verses and religious lessons, human being are always being examined by God in different ways and those examinations are the path for obtaining other-worldly prosperity after death. One of the ways that God examines the human beings is making them suffer from diseases.

After experiencing all challenges of transplantation and seeking help from coping strategies, most of the participants admitted that they had no choice but accepting the reality and the limitations, since denying the restrictions not only did not solve any problem, but also postponed coping with various issues relating to transplantation. Planning for better use of life and preventing its wastage creates an aim in life and retrieves the lost peace. It was something that participants were completely aware of and tried to utilize that. Acceptance included compatibility with an altered life condition, limited horizon, learning to be patient, dignity and not demanding beyond the ability<sup>21</sup>.

This way, interest in life would be recreated, energy would return, social communication would be presented again as a source of joy and activities related to intrapersonal qualifications would be redone<sup>22</sup>.

The study results indicated that comparing the condition of self with others that were experiencing worse condition, was one of the optimistic methods that had effective role in patients' adaption to some issues. Participants stated that since they found their condition better than before and they considered their problem unimportant compared to other chronic diseases, they could cope with that easier. In various studies such as the study by kaba et al, this strategy has been mentioned<sup>23</sup>.

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