Difficulties and Coping Strategies of Kidney-transplant Recipients During Their Dark Postoperative Recovery Stage After Returning Home

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ABSTRACT

Introduction. Kidney Transplantation (KT) is the best treatment for end-stage renal disease to prolong patients' lives. To improve patients' postoperative survival rate and quality of life, postoperative care at home is vital. We explored the difficulties faced and coping strategies used by KT recipients during their dark postoperative recovery stage at home.

Methods. This qualitative, exploratory study used a purposive sample, which was obtained from a leading medical center in Taiwan. We used a semi-structured interview guide to collect data through in-depth, face-to-face interviews. Data were content analyzed.

Results. Fifty individuals were approached and agreed to participate (30 men, 20 women). Participants' post-KT timeframe ranged from 2 to 28 years. Seven difficulties were reported: 1. physical discomfort and treatment side-effects; 2. concern about the impact of transplant failure; 3. uncertainty about the future; 4. unbearable economic pressure; 5. concerns about becoming a family burden; 6. feeling that life lacks a purpose; and 7. feeling isolated. Coping strategies included 1. seeking assistance from health care professionals, 2. thinking positively, 3. changing one's lifestyle, 4. setting goals to divert attention, 5. seeking psychological, and 6. seeking spiritual support.

Conclusions. By elucidating KT recipients' adaptability and coping strategies, we hope to improve their quality of life at home. Health care professionals should be aware of the difficulties faced by patients during their dark postoperative recovery stage and promote effective coping strategies. This study informs future research and has implications concerning the effective coordination of transplant medical teams.

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KIDNEY Transplantation (KT) is an aggressive surgical intervention for end-stage kidney disease. Rapid improvements in surgical techniques, immunosuppressive drugs, and transplant immunology have enabled many patients to return to life as normal after surgery. Currently, the survival rate of KT in Taiwan is the highest among all organ transplantations with 1, 3, and 5 year survival rates at 96%, 93%, and 89%, respectively [1]. Improvements in immunosuppressants in the last 10 years have increased patients' expected mean survival rate from 15 to 20 years. Successful KTs are currently the best treatment method for patients with end-stage kidney failure [2].

Although KT has enabled patients to live longer, they must also face surgical risks and worry about infection and rejection; long-term immunosuppressive drugs; periodic follow-up visits postoperation; side effects or complications caused by drugs; and physiological, psychological, social, economic, and spiritual difficulties after returning home. These painful experiences can create a dark postoperative recovery stage for KT recipients. The coping strategies during this dark postoperative recovery stage may affect patients' quality of life after returning home. Therefore, the care process at home is an important topic that is worth examining to improve patients' postoperative survival rate and quality of life.

MATERIALS AND METHODS

This exploratory study was conducted at a medical center in central Taiwan. Purposive sampling was employed to recruit patients as study participants. Inclusion criteria were 1. aged $\geq$ 18 years; 2. having received KT; 3. returned home for self-care after surgery; 4. Is able to communicate in Mandarin, Taiwanese, or Hokkien; and 5. is willing to be interviewed for the study. The exclusion criteria were 1. patients who had a spoken language defect or were illiterate, 2. patients who were bedridden or not lucid, and 3. patients who resided outside of Taiwan during the study period.

A semi-structured interview guide was used for in-depth interviews with patients. A qualitative content analysis was performed with the collected data.

ETHICAL CONSIDERATIONS

The research obtained approval by the institutional review board (No.CE19189B) and informed consent from the participants required by the authority.

RESULTS

Demographic Data

Fifty individuals were approached and agreed to participate (30 men and 20 women; age range 18 to 69 years). Their postoperative duration ranged from 2 to 28 years, and they were divided into groups based on years since operation: group 1, 5 years or less (n = 4); group 2, between 6 and 10 years (n = 16); group 3, between 11 and 20 years (n = 27); and group 4, above 20 years (n = 3) after transplantation.

Thirty-two participants had a high school education or less, 17 had a college education, and 1 had obtained postgraduate degrees. Regarding religious beliefs, 6 participants were atheists, 9 were Buddhists, 29 were Taoists, 2 believed in folk religion, 3 were Christians, and 1 believed in another religion. Regarding occupation, 11 participants worked administrative jobs, 15 were in the working class, 3 were shop owners, 2 were teachers, 1 was a farmer, 1 was a student, 2 were freelancers, 5 housewives, 4 were unemployed, and 6 were retired.

The postoperative duration was related to the difficulties faced by patients. The interview data showed that, within 5 years after returning home, patients needed to adapt to physical, psychological, spiritual, and social changes; as such, patients in group 1 encountered more challenges than their counterparts, patients in group 2 learned to live with their graft organs after a period of time, and patients in groups 3 and 4 were mostly worried about organ failure, which gave them more stress and insecurity.

Difficulties

Based on an in-depth analysis of interview data, the difficulties patients faced in the dark postoperative recovery stage after returning home can be divided into seven major themes, which are described in Table 1. The most common difficulty faced by recipients was physical discomfort and side effects of medication, which troubled patients (n = 39, 78%) the most. Patients mentioned that they felt uneasy after returning home postoperation and were unable to work normally. Patients were also troubled as a result of frequent hospitalizations for infections, which caused inconveniences in their lives. Some patients also mentioned that transplantation caused premature aging and that the side effects of long-term medication and insomnia affected their lifestyles. Secondly, patients were worried about the impact of transplant failure (n = 38, 76%), including readmission and undergoing dialysis again. Psychologically, participants were uncertain about their futures (n = 36, 72%) and felt that there was no hope for the future, worrying that they were unable to work as a "normal" person could and fearing that they had no one to care for them in the future. In addition, patients often felt fatigued and physically weak post-transplantation, and many were unable to work and feared that they will not have financial support (n = 35, 70%). This also caused a family burden (n = 33, 66%) and hindered familial relationships. Some patients (n = 21, 42%) mentioned that they were unable to accept the fact that they are sick and wondered why it had happened to them. Some lacked purpose in life, did not envision a future, and even thought about committing suicide. Moreover, some patients expressed that they feared infection after transplantation and that they had reduced social activities and contact. They also feared people were "staring" at them as they wore masks to reduce the risk of infection. This promoted self-isolation and demonstrated the social difficulties faced post-transplantation (n = 19, 38%).

Table 1. Difficulties and Coping Strategies Perceived by Kidney-transplant Recipients (n = 50)

Difficulties	Coping Strategies
(1) Physical discomfort and treatment side-effects (n = 39, 78%)	(1) Seeking assistance from health care professionals (n = 38, 76%)
1.1 Side effects of anti-rejection drugs affects quality of life	1.1 Consulting medical staff
1.2 Premature aging of the body	1.2 Complete trust in the medical team
(2) Concern about the impact of transplant failure (n = 38, 76%)	(2) Thinking positively (n = 29, 58%)
2.1 Fear of undergoing dialysis again	2.1 Taking it easy
2.2 Threat of kidney disease occurring again	2.2 Living in the moment
(3) Uncertainty about the future (n = 36, 72%)	(3) Changing one's lifestyle (n = 28, 56%)
3.1 Feeling hopeless about the future	3.1 Adjusting diet and lifestyle
3.2 Worry that nobody will care	3.2 Employing good preventive measures
(4) Unbearable economic pressure (n = 35, 70%)	(4) Setting goals to divert attention (n = 26, 52%)
4.1 Unable to continue working and earning money	4.1 Listening to music
4.2 Unable to make ends meet	4.2 Regular exercise
(5) Concerns about becoming a family burden (n = 33, 66%)	(5) Seeking psychological support (n = 25, 50%)
5.1 Worry about disharmony in the family	5.1 Seeking psychological counseling from medical staff
5.2 Worry about not being able to see children grow up	5.2 Positive interactions with friends and family
(6) Feeling that life lacks a purpose (n = 21, 42%)	(6) Seeking spiritual support (n = 19, 38%)
6.1 Unable to accept the fact that they are sick	6.1 Thanking God for giving them a new life
6.2 Inability to predict the future	6.2 Seeking religious assistance
(7) Feeling isolated (n = 19, 38%)	
7.1 Lacking social interactions	
7.2 Worry about others staring at them	

Concerning the difficulties encountered relative to postoperative duration, patients in group 1 were still in the adaptation stage and hence faced many of the above-mentioned difficulties. Although patients in group 2, who had progressed 6 to 10 years after transplantation, had adapted to their new life circumstances, they were still mostly worried that they could not continue to work, or that they might become a burden to their families. Patients in groups 3 and 4, having used their new organs for more than 10 years, were most fearful about kidney failure and returning to dialysis for life, thus creating a sense of uncertainty towards the future. The physical and psychological discomforts caused by long-term use of anti-rejection medication troubled all the groups for a long period of time, making these the most common difficulties.

Coping Strategies

Post-transplantation, patients required treatment and lifestyle adjustments to adapt to the new organ. Most patients felt that they had obtained a new "lease on life," and they had a better mental state than during dialysis. However, patients experienced varying degrees of dark period difficulties after returning home and adopted different coping strategies. The most common coping strategies employed by patients included 1. seeking assistance from health care professionals (n = 38, 76%); 2. thinking positively (n = 29, 58%); 3. changing one's lifestyle (n = 28, 56%); 4. setting goals to divert attention (n = 26, 52%); 5. seeking psychological support (n = 25, 50%); and 6. seeking spiritual support (n = 19, 38%).

Patients used both problem-focused and emotion-focused coping strategies. Regarding the former, patients mentioned that they actively sought advice from health care professionals on precautions and drug information post-transplantation, and some patients complied with the instructions of health care professionals and fully trusted the treatment provided by the medical team. To maintain new graft function, patients had to adjust their lifestyles; specifically, patients who did not exercise before began to exercise continually and pay attention to their diet, rested more, and took preventive measures when going out (ie, such as wearing masks).

Regarding the latter, most patients sought spiritual support through religion, such as thanking God for giving them a new lease on life, praying at the temple, donating, and participating in volunteer work. Many patients employed positive thinking, such as taking it easy, living in the moment, and learning how to let go. When encountering physical and psychological difficulties, many patients reminded themselves that they were luckier than those who must continually undergo dialysis or those who did not get a kidney transplant. This helped them cope with stress. Further, patients also employed passive methods, such as diverting attention by listening to music, exercising regularly, and using work to avoid thinking too much. Many patients sought support from health care professionals, friends, and family or encouraged fellow patients to remain positive during the dark postoperative recovery stage at home.

DISCUSSION

The results showed that patients experienced difficulties during the dark postoperative recovery stage at home owing to physiological difficulties caused by the kidney transplantation that resulted in psychological stress. Post-transplantation, patients' emotions often fluctuated along with their condition owing to uncertainty about their prognosis and their future and anxieties about rejection. This is because rejection represents failure of the new organ and a return to dialysis; therefore, hopes are dimmed and the threat of death looms. This comprises the dark post-operative recovery stage after patients have returned home.

Emotional problems cause discomfort to patients and simultaneously affect their physiological development [3–5]. Studies have shown that patients who are more depressed are more likely to develop chronic transplant nephropathy, re-undergo dialysis, and die as compared to those who are less depressed; further, depression is associated with patients failing to comply with treatment, which affects the survival of the new organ [3,4]. Another study showed that depression post-transplantation is associated with complications and cardiovascular diseases [5].

In addition to the threat of organ rejection, psychological rejections may also cause negative effects [4]. The long-term interactions between physiological and psychological difficulties causes a vicious cycle, which further affects patients' social lives or even causes spiritual difficulties. Our findings concerning patients' drive to seek spiritual support are consistent with the findings of previous studies [6]. Furthermore, although some studies examined the physiological and psychological difficulties of KT recipients, scant research has examined the difficulties faced during the dark postoperative recovery stage at home and the coping strategies that patients utilized. Therefore, our findings can be used as a reference for future studies.

We sought to first understand patients' difficulties before identifying effective coping strategies. Many patients employed problem-focused coping strategies, such as seeking assistance from health care professionals (including information about medication, lifestyle, and diet consultation) to better adapt to post-transplantation life. Studies have shown that health education and consultation by health care professionals can increase patients' medical compliance [7]. Many patients employed positive thinking to change their moods, such as thinking that KT is better than dialysis, which is consistent with prior findings [8]. Lazarus and Folkman [9] noted that problem-based coping strategies are mostly used when faced with moderate or low stress levels, while emotion-focused coping strategies are used when facing severe stress, which is consistent with the strategies employed in this study: that emotion-focused coping strategies were mostly used when the difficulties during the dark period were serious; however, patients with less severe difficulties employed both types of coping strategies. Moreover, prior studies have shown that social support from family members, health care professionals, and fellow patients helps patients face stress related to KT and foster healthy adjustment [8].

Transplantation surgery involves a series of physiological and psychological adjustment processes for patients. During these processes, the roles played by health care professionals are important. Psychological adjustment difficulties may be caused by differences between transplantation outcomes and expectations: some patients believe that they can lead a normal life post-transplantation and do not need to take medication or see their physician, while other patients believe that they can lead an uninhibited life post-transplantation, possibly resulting in damage to their new kidneys. These patients do not know that long-term medication and self-care post-transplantation requires physical and mental discipline. Therefore, education provided by health care professionals is essential and requires further examination in relevant studies.

Prior studies have shown that health care professionals often overlook the social and emotional support needs of transplant recipients [10]. In our study, some patients mentioned that post-transplantation care by health care professionals is significantly lacking compared with the care they received during the dialysis stage, particularly when patients return home after surgery and worry about transplantation failure and do not know how to cope with lifestyle adjustment. These concerns highlight the dark postoperative recovery stage at home. Attentive follow-ups should be frequent during the initial stage when patients are discharged from hospital to home to help them through the dark postoperative recovery stage. Specifically, health care professionals should proactively contact patients after they have returned home to assess how they are coping.

Based on the results of this qualitative study, the authors will conduct quantitative research using a questionnaire whose validity and reliability have been established. We will utilize data analysis and scoring to further explore the severity of the difficulties faced by KT recipients and the effectiveness of the coping strategies they adopt in the dark recovery period. Further investigations of the difficulties and coping strategies of KT recipients during their dark postoperative recovery stage after returning home can improve patients' quality of life and provide a reference for their medical teams.

CONCLUSIONS

The difficulties encountered by KT recipients during the dark postoperative recovery stage at home and their utilized coping strategies may greatly affect their quality of life and survival rate; therefore, the support of the transplantation team is critical. Health care professionals should carefully observe patients for their responses toward physical and psychological difficulties to timely evaluate whether the utilized coping strategies are helping patients adjust effectively. This will foster kidney-transplant recipients to have fewer negative experiences during the dark postoperative recovery stage, improve their postoperative quality of life at home, and enable patients to remain optimistic and have a well-being life.

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