

Renal Transplantation in Developing Countries: A Review of Psychosocial Issues Transplant Efficacy and Health Outcomes in Pakistan

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This review addresses the psychosocial issues based on the research evidence from Pakistan. The scarcity of research investigating psychosocial aspects of transplantation in Pakistan reflects the need to cater for recipients' psychological well-being besides physical health. The psychosocial issues include; availability / access and affordability of treatment, doctor-patient relationship, medication adherence, family systems and caregiver burden. The health outcomes and efficacy of renal transplantation in Pakistan is significantly influenced not only by clinical but psychosocial factors. The review will facilitate an in-depth understanding of the Pakistani scenario and the dire need for psychological assessment, screening and interventions. Incorporating psychological aspects in follow-up care can pave the way towards a better understanding of the dynamics involved in health behaviors, leading to increased treatment satisfaction and improved health outcomes and transplant efficacy.

Keywords: Renal Transplantation, Pakistan, Psychosocial, medication adherence, Doctor-patient relationship, Treatment satisfaction.⁷

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Background

Health Care after Renal Transplantation: Some Issues in Pakistan. Health care system in Pakistan is progressing with new reforms and improved policies. However, these programs are very limited in scope. There are inequalities in the rural and urban health care. Research has identified the major reasons for inefficient health care system in Pakistan including; poor governance, lack of access and unequal resources, poor quality of Health Information Management System, corruption in health system, lack of monitoring in health policy and health planning and lack of trained staff (Kurji, Premani, & Mithani, 2016).

Pakistan has an alarming rate of renal patients. It is estimated that every year, 25,000 persons suffer from renal failure. Out of which only 10 percent succeed in receiving dialysis and only 2.3 percent are lucky to receive transplantation. Sindh Institute of Urology is the only institution that provides 'free of cost' treatment to renal and liver patients (<http://www.siut.org/Transplantation.html>).

Life after transplantation is mainly dependent on clinical care which is not available to most renal transplant recipients (RTRs) in Pakistan. The main role is played by the family, caregivers, and doctors. Therefore, family systems and doctor-patient relationship are the main determinants of improved health outcomes after transplant (Adhikari, Taraphder, Hazra, & Das, 2017).

The governing forces of medical decision making in Pakistan are strong family systems and the authoritative position of the doctor (Moazam, 2000). The country suffers from serious issues of Illiteracy, poverty, poor awareness of patient's rights, and a lack of accountability for physicians, thus limiting the role of the patient. Since the family usually bears the cost of health care so the significant role in decision making is played by the family or the doctor (Aslam, Aftab & Janjua 2005).

Successful transplantation undoubtedly improves recipients' quality of life; however, the post-surgery management is a complex and life-long process (Kaballo & Hardinger 2017) for both the clinician and recipient. Renal transplantation is the most commonly performed solid organ transplant, however, it implicates serious clinical and psychosocial challenges post-transplant (Schulz & Kroencke, 2015). Studies in

Pakistan have identified factors associated with health-related quality of life (HRQoL) through a comprehensive analysis of demographic, psychosocial, and clinical characteristics among representative cohorts (Kamran, Rafique, Anjum & Raza 2017).

Despite a high rate of renal transplants being carried out every year, there is a scarcity of literature focusing on the psychological aspects of health care in Pakistan (Kamran 2014). The health care system in Pakistan has only limited its focus to clinical factors in physical health and treatment protocols, undermining the crucial importance of psychological screening, counseling, or interventions. RTRs belonging to diverse Sociodemographic backgrounds differ in their health beliefs, attitudes, and coping styles (Malik & Mazahir 2015).

The diverse sociocultural health care issues faced by the recipients after organ transplantation need to be addressed (Garcia, Harden, & Chapman, 2012). Some of the main challenges in life post-transplant particularly in the developing countries include economic issues, availability, and accessibility of quality health care. The paucity and high costs of renal replacement therapy allow only 10% to get dialysis and 4–5% transplants in Pakistan (Rizvi, Naqvi & Zafar 2011).

This is an overview of the literature regarding psychosocial aspects in renal transplant recipients (RTRs) in Pakistan.

Objectives

To discuss the literature with a focus on the psychosocial factors influencing the efficacy of renal transplantation and health outcomes in Pakistan. The studies were included in the present review based on the following criteria.

Study Selection

Cross-sectional and Prospective cohort studies assessing medication adherence, perceived quality of life, general health indicators, doctor-patient relationship, and perceptions of the health care system were included. Abstracts of relevant studies were studied to determine the eligibility of the study to be included.

Studies were eligible for inclusion if: (1) involved adult RTRs (2) published between 2010 and 2018; and (3) focused on objective and

subjective factors for recipients' non-adherence and health care services experience.

Search strategies for the identification of studies Searching for relevant researches was done using databases including Medline (2010-2017), Science Direct, Cochrane Library database, PsycInfo (2012-2017) followed by hand searching. The search included the terms: medication compliance, adherence, doctor-patient relationships, health beliefs, personal and psychosocial & demographic factors, renal/ kidney transplant recipients/ patients, transplantation, adherence and non-adherence, and treatment satisfaction with combinations using AND & OR.

Method

The articles were identified from the search against the inclusion criteria. Full-text versions of studies were analyzed thoroughly for detailed information. The abstracts found were screened; all research dealing with "psychosocial factors, medication adherence, doctor-patient relationship, treatment satisfaction, and transplant efficacy" other than the targeted contents was omitted. All articles were studied thoroughly and all the statements of the authors were judged based on the following factors: confirmed by data, plausibility, proven by references. The single articles covering most of the significant psychosocial aspects were summarized, however, due to the inconsistencies in the methods of measuring, confirming, and proving efficacy of renal transplantation based on psychosocial factors, only evidence-based literature could not be extracted. Additional reports were identified from the reference lists of key manuscripts and review articles. For the analysis of data, articles involving adult recipients of kidney transplants were included.

Description of studies

After screening from 52 papers assessing the efficacy of renal transplant in the psychosocial and sociocultural context, around 30 studies meeting these criteria were considered suitable for inclusion in the review. To analyze the psychosocial aspects influencing renal transplant efficacy, the manuscript by Frazier et al 1994(1) was used as a template against which other studies were analyzed. These factors involved medication adherence, recipients' attitudes and beliefs about medication, perceived quality of life, and orientation towards self, others,

and future prospects. The clinical factors included; general health indicators, doctor-patient relationship, and health care systems.

Other variables analyzed were type of transplant (cadaver or living donor), time since transplant, education, a dose of immunosuppressant, clinic attendance. These factors were categorized as patient-centered factors (demographics), social & economic factors (psychosocial), healthcare system factors, therapy-related factors, and disease (transplant & immunosuppressant) factors.

The challenges in health care, the role of family and physician in understanding, accepting, coping, and adjustment post-transplant are focused. Patients' individual life circumstances, beliefs, attitudes, and priorities need to be considered when customizing treatment protocols. Interventions can be planned to pave the way towards a better understanding of the dynamics involved in health behaviors, leading to increased treatment satisfaction and improved health outcomes

Transplantation efficacy & post-transplant challenges in developing countries

Renal transplant recipients require intensive specialized medical care pre and post-transplant. The recipients must be aware of their pre-transplant health status, surgical procedure and its implications, post-transplant complications, the significance of medication adherence, and stress management to ensure transplant efficacy (Gill, Wright, Delmonico & Newell, 2017). Unfortunately, a lack of empirical data makes it difficult to report perceived QoL and efficacy of transplantation in Pakistan (Malik & Mazahir 2015)

However, a longitudinal study for the first time investigated the psychosocial and clinical factors in influencing satisfaction with QoL after renal transplantation in Pakistan. The psychosocial variables included depression, perceived health status, life orientation (optimism), and conscientiousness. Clinical data comprised of their renal functioning, blood sugar, cholesterol, and blood pressure as health indicators. Compliance was assessed by recording their blood immunosuppressant levels. They found psychosocial factors as the strongest predictors of QoL as compared to clinical factors. (Kamran, Fife-Schaw & Ogden 2012)

Studies have found RTRs with good coping resources tend to manage stress in a more adaptive way after transplant (Pérez-San-Gregorio et al., 2017). Emphasis is made on the active role of health care services in providing regular reminders about the lifestyle benefits of kidney transplantation, providing support group opportunities to recipients to share their experiences, and usage of a reminder to take medications. These recommendations have relevance to clinical practice as these are assumed to reduce stress after transplant and improve health outcomes (Low, Crawford, Manias, & Williams, 2017). The lack of a supportive role of health care in Pakistan makes ‘aftercare’ a challenge for the recipient.

A qualitative study identified how the renal transplant recipients (RTRs) perceived the major benefits and stressors, one year after their transplant. It was found that recipients experienced a mixed picture of life after transplant. The significant positive change included a return to routine life. On the other hand, their stressors included; fear of losing their transplanted kidney and queries relating to the immunosuppressive medication perceived as the main challenges after transplant (De Brito, de Paula, Grincenkova, Lucchetti, & Sanders-Pinheiro, 2015). Such serious concerns are not addressed in any follow-up protocols in Pakistan.

Transplantation in developing countries like Pakistan involves many sociocultural issues (Kamran & Ghazal 2017). The nature of barriers in life post-transplantation differs across the globe (Edinur, Manaf & Che Mat, 2016). In the developing countries, the economic limitations make transplantation, a lower priority than public health fundamentals and basic life necessities such as food, clean water, sanitation, and basic health. On the other hand, the technical challenges implicated in transplantation, involving the availability of a donor, candidacy, and the consequences of immunosuppressant medications restrict the number of suitable recipients care (Jalil, Zakar, Zakar, & Fischer, 2017). There is a dire need to address these issues at societal, professional, and governmental levels (Kamran, Rafique, Anjum & Raza 2016).

In Pakistan, the journey from illness to wellness involves sociocultural health care issues after transplantation needs to be addressed. Some of the main challenges in life post-transplant particularly in the developing countries include a range of

Sociodemographic factors influencing health outcomes, such as; economic issues, availability, and accessibility of quality health care (Kamran & Ghazal 2017).

Transplant recipients are dependent on Immunosuppressive medications on a lifelong basis to prevent graft loss (National Kidney Foundation, 2015). Studies have shown that medication non-adherence is the major cause of rejection in transplant recipients. To ensure graft survival and longevity, solutions for medication non-adherence must be found and implemented (Kamran 2015).

Qualitative literature has explored the causes of medication non-adherence in renal transplant recipients. The analytical themes identified included; affordability issues, the need for medication; and the nature of the doctor-patient relationship. Medication adherence can be improved by facilitating patients to understand the significance of making medicines as an integral part of their routine life. There is a need to address patient beliefs about medications. Patients must be involved as active participants in treatment decision making. Medication cost, a lack of awareness, and knowledge of medication efficacy and side effects were found to be the main barriers in medication non-adherence (Zaidi, 2010).

Qualitative evidence identified six themes in medication non-adherence in RTRs. These include; (i) recipients' attitudes towards medicine taking, its impact on lifestyle, self-image, relationships, and life orientation; (ii) forgetfulness and preoccupation with life commitments; (iii) medication effects; (iv) quality of healthcare services, issues of availability and affordability (v) lack of skills to comply with prescribed regimen; and (vi) social support. This consequently leads to either not taking medicines, skipping or changing doses, and varying the timing of doses reflecting patterns of non-adherence (Tong et al., 2011).). Similar studies are needed to identify issues as reported by recipients in Pakistan.

Adaptive problem-focused Coping strategies are required to follow a lifelong medication adherence and lifestyle alterations. In Pakistan, recipients are faced with unavoidable adverse medication side effects due to limited medication options that have a direct influence on medication non-adherence (Kamran, Fife-Schaw & Ogden 2012). Besides the negative medication consequences, the developing countries like Pakistan are also faced with issues regarding access, availability, and affordability of quality health care and psychological support makes things more challenging (Jalil, Zakar, Zakar, & Fische, 2017). However,

in all cases, they do need to share a long term therapeutic relationship with their physician/s (nephrologist, urologist, G.P). This becomes a tough task for them to balance out due to some main issues. These issues can be categorized mainly as ‘Medication-Related’ and ‘Doctor-Patient Relationship Related’ (Hamedan & Aliha, 2014). The main goal after a successful transplant is the maintenance of health status and improved QoL, which requires medication adherence and regular follow-up visits involving long-term doctor-patient interactions. (Zhu, Zhou, Zhang, et al., 2017). Therefore, medication adherence has a direct association with psychosocial factors and, doctor-patient interaction, in particular, plays a significant role (Kamran 2014).

Medication adherence is associated with the characteristics of a health care provider. Mutual trust, respect, good communication skills, and unconditional acceptance are essential components of a healthy doctor-patient relationship (Fredericks & Dore-Stites, 2010). The efficacy of ‘Adherence-enhancing interventions’ depends on the nature of the doctor-patient relationship. These interventions need to be a part of a treatment protocol for reducing the risk of rejection (Iuga & McGuire, 2014). The treatment failure due to non-adherence is high in Pakistan. It is argued in the socio-cultural scenario, the decision making depends on the doctor-patient relationship. Physicians must take time to develop this functional relationship, not for monitory reasons but for improving adherence to medical treatment (Kamran & Ghazal 2017).

Psychosocial factors in medication non-adherence may include; psychiatric co-morbidities (depression and anxiety), inadequate awareness and knowledge of treatment, low social support, substance abuse, life stress, barriers to medication access, and poor physician-patient relationship (Fredericks et.al, 2008; Dobbels et. al, 2010). Fortunately, most of these factors are modifiable and can be dealt with intervention, however, a lack of research investigating the impact of an intervention on medication adherence in Pakistan needs attention (Kamran, Fife-Schaw & Ogden 2012).

A healthy doctor-patient relationship is based on good communication, mutual respect, and trust with a person-centered approach. Unfortunately, the practice in Pakistan lacks these key features (Ahmad et al 2015). It was found that the philosophical, cultural, societal, and communicative approaches to the traditional doctor-patient communication styles used in Asian countries like Japan and Pakistan are

quite different from U.S (Matusitz, & Spear, 2015). Researchers recommend improving the communication skills of doctors that have a direct influence on patients' satisfaction and physicians' self-efficacy (Ghaffarifar, Ghofranipour, Ahmadi, & Khoshbaten, 2015).

There is a lack of authentic data on doctor-patient relationship and treatment satisfaction in Pakistan. Improvement in the doctor-patient relationship depends on the development of effective interpersonal and clinical skills in doctors serving in public sector healthcare in Pakistan. Furthermore, there is a need to study context-specific factors influencing patient satisfaction (Jalil, Zakar, Zakar & Fische, 2017).

In Pakistan, there are two types of patient beliefs about doctors; the first category involves the perception of doctors as a 'god-sent' with ultimate power and authority and the patient religiously following the doctor's advice. On the contrary, the second group of patients lacks trust and faith in medical doctors and prefers 'faith healers' which is a commonly followed 'cultural norm' (Hashmi, 2003).

Most patients belonging to lower socioeconomic class and seeking treatment in public sector government hospitals do not share an open and comfortable doctor-patient relationship. They do not 'question their physician' and accept whatever the physician decides the best for them (Rocque, & Leanza, 2015) due to lack of education and lower socioeconomic status. Unfortunately, the majority of the population in Pakistan cannot afford private health care due to a lack of financial resources. This socioeconomic gap and psychosocial barriers limit access to quality health care and have a negative impact on the doctor-patient relationship. Religious beliefs and orientation', 'cultural norms' and ethnic backgrounds are some of the Sociodemographics factors hindering an open doctor-patient relationship (Chipidza, Wallwork & Stern, 2015). Literature confirms that the most frequently reported barriers were: socioeconomic status and physician characteristics. Ethnic minorities may have specific psychosocial barriers to healthcare use (Paduch et al., 2017).

In Pakistan, one of the reasons for treatment dissatisfaction involves issues in doctor-patient relationship. Studies suggest that medical students need training and exposure to patients from the beginning of their medical education in clinical settings, more sympathetic to patient-centered care (Ahmad et al., 2015). The contextual factors that need to be studied and to be resolved include; language

barriers, discrimination, differing values, and acculturation. There is a scarcity of studies exploring the cultural aspects of doctor-patient relationship and treatment satisfaction. Future research should address these cultural challenges. This suggests the need for tailored interventions to patients' preferences, to ensure treatment satisfaction (Rocque & Leanza, 2015). The religious beliefs and cultural norms have a significant impact on patients' satisfaction and trust, gender issues, informed consent, ethical and cultural issues in medical decision-making (Chamsi-Pasha & Albar, 2016).

In Pakistan, the decision to re-visit the same consultant is mainly determined by the nature of the consultation experience (Rocque & Leanza, 2015). The continuation of seeking consultation depends on patients' satisfaction with their consultation experience (Maseko, Chirwa, & Muula, 2014). Dissatisfied patients tend to delay and sometimes discontinue seeking medical consultation and prefer self-medication (Abioye et al., 2010). However, in developing countries like Pakistan, the scarcity of resources in health care, and unavailability of alternatives, the patients from the lower socio-economic background, are forced to continue seeking the same consultation services irrespective of dissatisfaction. At the same time, physicians in the public sector are also faced with the challenge of dealing with these patients from lower-socioeconomic and rural settings, with diverse health beliefs, lacking health awareness, and poor hygiene (Jalil, Zakar, Zakar & Fische, 2017).

Physicians in the public health sector are faced with the challenge of understanding the patients and making them understand the causes of illness, efficacy, and course of treatment due to lack of education and individual health beliefs (Hashmi, 2003).

The doctor-Patient relationship in Pakistan needs a complete reform. According to the Gallop Survey (2011), Pakistan scored the lowest in the world on the Global Doctor-Patient Communication Assessment test with five points in contrast to Ireland that scored the highest score of 66 points (Worldwide Independent Network of Market Research, 2011).

A qualitative study exploring patients' perceptions and experiences after renal transplant revealed that most recipients feel hesitant to express their anxieties and fears about their treatment to the doctor due to a number of psychosocial issues that add to their stress. We

need to identify these challenges and bridge the doctor-patient gap (Kamran, 2014).

Absence of psychological care for recipients, family and caregivers

Psychological care can facilitate recipients in better stress management. A study found that renal transplant recipients needed psychological support and stress management (Naqvi, 2015). Therefore, cognitive-behavioral interventions involving relaxation techniques, educational and supportive work for stress management can alleviate stress after transplantation (Brito et al., 2016). Unfortunately, the treatment plan and follow-ups in Pakistan do not encompass psychological care and family counseling.

Besides the recipient, the family members and caregivers also experience increased distress before and after transplantation (, 2015). Family counseling, and supportive therapy, can facilitate stress reduction. The psychological well-being of the family and caregivers is equally important to maintain the social support provided to the transplant patient. Family counseling can address the issue of possible stress and conflicts due to changing family roles and new responsibilities Kamran 2014)).

Non-adherence after kidney transplantation mostly involves potentially modifiable factors, such as; social support, treatment experience, side effects, intentions and beliefs, forgetfulness, and mental health issues Besides patient-related factors, doctor characteristics, and health care issues are not well researched (Rebafka, 2016).

Recent studies in Pakistan are now attempting to investigate and resolve these psychosocial issues. It is suggested that prospective studies need to be carried out in the future, to develop a model to identify risk factors influencing QoL and determine interventions that facilitate psychological well-being. Research focus needs a shift of focus from deficit-oriented to resources and conditions for a better QoL (Masood, Kamran, Rashid & Mazahir 2017)

Suggestions & Recommendations

Considering the dismal scenario in Pakistan, it is recommended that health policies should focus on psychological care and improve doctor-patient communication. Risks and barriers to adherence are

The resolution of these psychological issues can improve recipients' treatment satisfaction and improve their psychological well-being and overall quality of life (Kamran, Fife-Schaw & Ogden 2012).

Conclusion

This review has identified some of the major psychosocial issues faced by renal transplant recipients in Pakistan. The socio-cultural aspects of 'medication adherence and the dynamics of the doctor-patient relationship are discussed. The aim is to highlight the significance and impact of these factors on recipients' physical health and psychological well-being.

Literature confirms that the most frequently reported barriers were; financial issues affecting medication & health care affordability, health beliefs, adverse side effects, and problems in developing an open and healthy doctor-patient relationship. All these psychosocial issues tend to, directly and indirectly, affect medication adherence.

The medical culture in Pakistan needs to introduce reforms in psychological care for transplant recipients, their family members, and caregivers. It is suggested that professional training and skill development programs should aim to improve doctor's knowledge about psychosocial aspects of health care, so they deal with patients from diverse social classes to ensure effective health outcomes.

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