

Living with a Kidney Transplant: Perceptions and Experiences

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Abstract The qualitative study was carried out as a part of a larger longitudinal study on renal transplant recipients (RTRs) following a successful transplant in Pakistan. The aim was to explore why recipients with similar physical health status and healthy kidney functioning, differ in perceptions of Quality of life. Using in depth interviews the study participants with the highest and lowest scores on a standardized QoL index were asked to describe their experiences and attributions regarding kidney failure and to describe their health status pre-and post-transplant. The themes emerging from the analysis related to individual differences in the ‘impact’ of transplant on ‘relationships’ with significant others, (family, work and social life) ‘self identity’, ‘social comparisons’, perceptions of ‘health care and medical professionals’, adjustment, acceptance and ‘coping’ with a transplant. The recipients with a positive perception in these aspects tend to report a more satisfied QoL.

Keywords: renal transplant recipients (RTRs), quality of life, psychosocial, life orientation, relationships, thematic analysis

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1. Introduction

Kidney transplantation has become the most desirable treatment option for patients with renal failure for its efficacy and health outcomes. Although transplantation is assumed to bring recipients’ life closer to normal there are new challenges and altered life styles after renal transplantation such as living with the fear of rejection and the need to comply with a complex regime of medication capable of producing pronounced side-effects (White et al., 1990; Hauser et al., 1991). Key concerns post transplant relates to a number of psychosocial and health-related stressors. However, it is not clear whether stress levels or coping methods change with the passage of time. Therefore, ongoing research, both qualitative and quantitative aims to explore the underlying environmental, personal, clinical and psychosocial factors influencing recipients’ perception and satisfaction with QoL. Fallon, Gould, & Wainwright, (1997) found that recipients live with a chronic physical condition after transplantation. However, with recent advances in health care survival rates have greatly increased and fear of rejection might not be the highest ranking stressor for renal transplant recipients to date. In the same study, they found that ‘prayer and an objective attitude towards problems’ were used in coping with stress and problem-oriented coping was significantly higher than affective-oriented coping. Most qualitative studies aimed to explore the experience of living with a kidney transplant with a focus on comparing life pre and post transplant. Despite consensus

on efficacy of transplantation, there are common stressors experienced by recipients. Veroux, Corona, Patel & Veroux (2010) reported that perceived physical appearance, issues related to sexuality, stress anxiety and even guilty may complicate the emotional and psychological well-being.

Research suggests that recipients need to be aware of the challenges of life post-transplantation. Urstad et al (2012) carried out a qualitative study to evaluate patient’ knowledge and awareness of life post transplant. Sixteen renal recipients were interviewed 4-6 weeks post-transplantation about content and methods in the patient education program.

They described kidney transplantation as a ‘turning point in life’, causing learning difficulties because of both physical and mental stress. The recipients expressed that a supportive learning atmosphere characterized by patience, respect, continuity and active participation was essential. This study revealed new knowledge about renal recipients’ need for individual application of the educational content, as well as cognitive difficulties, and other factors impacting on learning in the early post-operative phase. It contributed towards understanding the patients’ perspective. Such studies are useful in creating effective interventions for RTRs (Urstad, Wahl, Andersen, Øyen, and Fagermoen 2012).

Kidney transplantation requires life long compliance and regular follow ups. Recipients need family & social support, awareness and motivation. Unlike most of the developed countries, the situation in some of the developing countries such as Pakistan, India and Iran is quite different. The psychological assessment and

education of the transplant candidate is not considered to be an important part of the transplant process. Several studies showed existing challenges regarding education of these patients. A qualitative study using content analysis was conducted in Iran to define patients' experiences from their received education about the process of kidney transplant. The findings revealed that recipients did not receive adequate knowledge about kidney transplant process. This issue reveals an unstructured and uncoordinated education given to kidney transplant patients by health care and transplant teams before transplant. With regard to high motivation of the patients, designing such educational program based on self-management in the process of kidney transplant for these recipients is essential. The transplant team can include this in their educational role to develop problem solving methods and selection of the best solution to preserve their transplanted kidney and consider renal transplant recipient self-management as their first priority toward these patients (Ghadami, Memarian, Mohamadi, and Abdoli 2012).

Qualitative and longitudinal studies are needed to investigate the unique experiences and individual differences in the transplant process, so that these issues can be addressed when designing psychological care plans as a part of follow-up management. Organ transplantation is not merely a physical experience; rather, it influences the recipient and the family as a totality. The psychological consequences of transplantation and the

underlying mechanisms can be better understood by conducting qualitative studies.

1.1. Aim

The aim of this study was to explore how renal transplant recipients in Pakistan perceive their QoL life and why some recipients were more satisfied than others with their QoL after renal transplant.

2. Method

Design: Semi-Structured/ In depth qualitative interviews

Participants: Renal Transplant Recipients participating in the main study were requested to participate in the qualitative interview. The participants were requested for qualitative interview after completion of quantitative assessment, based on their scores on QoL Index. The extreme scores (highest & lowest 5 scores) were calculated and the recipients scoring highest and lowest scores were included in two groups as success and failure stories. Due to an over representation of male recipients as high scorers on QoL Index, it was then decided to interview both gender categories i.e. male and female high scorers at time1 and 2 of this longitudinal study to have an equal representation of both genders. Out of 20 participants, 17 (10 high scorers and 7 low scorers) completed the interview.

Table 1. Characteristics of Participants with high scores on QoL Index

Case No	Gender	Age	Marital Status	Education	Occupation	Monthly Income	Time since Transplant	Renal Function	QoL Means
25	Male	38	Married	MBA	Business	Rs.2,00000	2 yrs	B	28.59
20	Male	30	Married	Masters	Financial Analyst	Rs.1,50000	3 yrs	A	28.38
17	Male	38	Married	Graduation	Govt. officer	Rs. 64,000	4 yrs	B	28.37
74	Male	32	Married	School Level	Business	Rs.10,0000	3 yrs	B	28.35
119	Male	30	Single	School Level	Business	Rs.1,25000	3 yrs	C	28.08
110	Female	28	Single	Masters	Housewife	Rs.50,000	2.2 yrs	A	27.66
88	Female	36	Married	MBA	Banking	Rs.1,55000	3 yrs	A	27.24
114	Female	27	Divorced	School level	Business	Rs.1,50000	1 yr	B	26.77
32	Female	31	Single	Graduation	Education	Rs. 48,000	1 yr	B	26.71
104	Female	30	Single	Masters	Education	Rs.1,85000	1.8 yrs	B	26.58

*Rupees,

*Renal Functions Key: A = Excellent, B = Good, C = Satisfactory, D = Poor

Procedure: The semi-structured interviews were conducted in the native language (i.e. Urdu) due to the recipients command and ease of expression in their own language. The researcher was present at the clinic when patients visited the renal clinic for their follow-up. Interviews were recorded with the participant's permission and later translated into English transcripts. Kidney functioning was calculated by measuring level of serum

creatinine in the blood, and grading into A–D with A excellent (less than 1.0 mg dL), B good (1.1 to 1.3 mg dL), C satisfactory (1.4 mg dL,) and D poor (< 1.4 mg dL), (dL = milligrams per deciliter of blood (mg/dL) indicating cause for concern. The grading categories were determined by the renal clinic as a criterion for assessing renal functions. The characteristics of participants are shown in [Table 1](#) and [Table 2](#).

Table 2. Demographic Characteristics of low scorers on QoL Index

Case No	Gender	Age	Marital Status	Education	Occupation	Monthly Income	Time since Transplant	Renal Function	QoL Means
134	Male	26	Single	Masters	Unemployed	Rs.45,000	2.4 yrs	C	16.39
56	Male	28	Single	Graduation	Unemployed	Rs.40,000	3 yrs	C	16.84
77	Male	45	Married	School level	self employed	Rs.35,000	3 yrs	B	19.66
70	Male	34	Divorced	Graduation	govt. officer	Rs.50,000	2.6 yrs	B	16.41
143	Female	40	Divorced	School level	Housewife	Rs.45,000	2.5 yrs	B	12.08
66	Female	35	Separated	Masters	Education	Rs.50,000	3 yrs	B	14.26
48	Female	45	Divorced	School level	Housewife	Rs.1,00000	2 yrs	C	16.79

*Rupees,

*Renal Functions Key: A = Excellent, B = Good, C = Satisfactory, D = Poor

3. Data Analysis

Thematic Analysis was used to identify a limited number of themes which adequately reflect their textual data. Themes that emerge from the informants' stories are pieced together to form a comprehensive picture of their collective experience. The aim is to analyse informants' talk about their experiences (Mahrer, 1988; Spradley, 1979; Taylor & Bogdan, 1984). Transcripts were analysed to identify similar themes emerging in a passage of text that appeared to have a particular meaning. Across the dataset, themes were compared for similarities and differences, both within and across interviews. Common themes were clustered into categories. The transcripts were re-read and checked to clarify emerging sub themes and super ordinate themes so that the titles of the categories reflected the totality of that experience.

Seven key themes were identified including; relationships, social comparisons, life orientations, coping, health professionals/medicalization, self-identity and impact. The recipients were asked about their life before and after the transplant with reference to familial and social adjustments, coping strategies, perceptions of self and others. These themes pervade their perceived QoL but differed among high and low scorers.

The transcripts reflected some very interesting insights into the dynamics and mechanisms behind varying perceptions of QoL discussed with each emerging theme as follows;

3.1. Relationships

The notion of relationships emerged throughout the transcripts with recipients describing how relationships impacted QoL and in turn how their surgery impacted upon their relationships. The recipients focused on their family relationships and the impact of transplant on their bonding and interactions. According to them, the attitude and behaviour of their family, friends, partners/ spouses, relatives and colleagues, ultimately affected their coping and adjustment process pre and post-transplant. A positive interaction improved their coping in case of high scorers whereas for low scorers estranged relationships and feelings of being a liability and unwanted not only developed a feeling of being distant and undesirable but also reduced their QoL satisfaction.

A married young woman who had a transplant 2 years ago, said;

'I don't feel I am the same person anymore, who was considered so important in every big family decision and valued as I used to exert and do so much which I can't do now,such as...ironing clothes for the whole family, cooking all meals, and other household chores....I get tired, my blood pressure rises...and I get the negative vibes from people around me....making me feel that I am not as useful and wanted as I used to be before my transplant'.

The above narration clearly shows a change in physical capacity of the recipient making her less active in household chores due to her health which makes her feel less useful due to the attitude of her family members. In high scorers, the transplant experience appeared to bring the family closer and strengthen their bond as they shared a critical phase together and most recipients attributed

their successful coping and recovery to their family support, love and care as witnessed by the care and concern shown to them during their illness process.

For example a young business man who had a transplant 3 years ago and had a high rating on QoL expressed:

'I never took my family seriously until I lost my kidneys and was almost bed ridden....during my illness, I realized how loving and caring they are and without their support I could have never made it....I value my family more than anything now and we share a new but strong bonding...'

For the less satisfied recipients, the quality of relationships deteriorated and made them feel left out and more of a liability. They revealed their negative experiences with close friends, relatives and colleagues during their illness and said that their transplant experience made them see the bitter reality and real behavior of people around them.

For example, a married male recipient who was a government employee reported;

'...my illness has helped me recognize so many people and I am thankful to my illness in a way because those jealous people who are my enemies were exposed when they neither turned up to see me when I was hospitalized nor showed any concern...may be they hoped that I won't survive and were happy on my kidney failure...but see they are helpless and hopeless now because I am back...'

It was found that particularly, female RTRs, scoring low on QoL satisfaction expressed their insecurity about maintaining the marital relationship and attributed unpleasant events such as divorce and disturbed marital life to their transplant that made them perceive it as a lifelong financial liability and less desirable in physical attraction for their partners/ spouses.

A separated young female recipient attributed her disturbed marital life to transplant and said;

'My husband has lost interest in me due to my de-shaped body, the extra kilos that are due to medication side effects and he does not feel like having sex as he used to before my illness...this is so depressing and I feel so low, wondering if physical attraction is the only thing that this relationship was based on?'

Most female RTRs, whether married or single, seemed to be preoccupied by their physical appearance that influenced their relationship especially with husbands, partners and future prospects of getting married. Therefore the above negative experiences of changed social and family relationships reflect how and why recipients felt low and reported a less satisfied quality of life. Their negative interactions and behavior of people around them made them feel unwanted and dependent. Interestingly, on one hand, where some recipients developed a new insight into the significance of familial bonding, the low scores realized how some relationships change negatively in critical times. This theme points towards the process of returning back to the family and social set up, adaptation, settling and adjustment after having a kidney transplant.

3.2. Life Orientation

It reflected the recipients' attitude and approach towards life in general and health with a transplanted kidney in specific. Their health concerns at present and future chances of healthy survival closely associated life

orientation, relationships, self identity and coping. All these factors influenced each other e.g. changes (both positive & negative) in close relationships modified the recipients life orientation and vice versa.

Life orientations also differed significantly. The recipients with increased QoL satisfaction expressed more gratitude and, optimism with a focus on the present instead of apprehending about the future. However, the less satisfied RTRs appeared more pessimistic about their future and over whelmed with their apprehensions about the uncertainty regarding the normal functioning, survival and longevity of their grafts. The high scorers, despite their concerns about graft functioning and survival, expressed their faith in predestined time.

A male recipient who had his transplant 3 years ago said;

'The time of our birth and death is predestined no matter what we do, we can't change our destiny but at least I am surviving despite an organ failure'.

The high scorers considered themselves lucky to have an illness with a cure rather than a disabling condition that could have no replacement therapy e.g. cancer or aids. The low scorers instead, blamed the health professionals and social system for their renal failure. It was evident when one male recipient who had a transplant 2 years ago said;

'...if I am here with a transplanted kidney at such a young age, it is simply because of the inefficient doctors who were not able to either diagnose or treat my illness at all. They are a part of medical mafia who wants to earn money through by having more people having a transplant'.

It is not very clear whether the negative life experiences particularly transplant related, influence their life orientations or vice versa. When asked about the reason for their negative perceptions of health professionals and society exerting a stressful influence on them, they tend to attribute it to their experiences with health care and social system during and after their renal failure.

A low scorer male recipient who works for a multinational company and had a transplant just one year ago said;

'People don't value human beings they are just concerned with their benefit...If I am sick ...I am useless and have no value for my friends and company and they won't have me for nothing...they only value my work and this is so sad'.

Another male recipient who had his transplant 4 years ago expressed his anger towards the doctors, blaming them for his condition;

'Doctors are the most heartless creatures on earth...I wonder if they have any human emotions at all...will they treat their own family members with the same insensitive and rude behavior, the way they deal their patients? They only value a patient who gives them lots of money otherwise they treat you like animals...may be worse'.

These accounts reflect that the recipients' perceptions and orientations are influenced by the kind of experiences they had during their critical times. Those who were given quality care, treated with care and concern, developed a positive orientation towards their family, social relations, health care system and medical professionals and the ones with a negative experience perceived it otherwise.

3.3. Social Comparisons

The notion of social comparisons was also apparent in participants' descriptions of their responses to having a transplant. These comparisons reflect how healthy or physically functional the recipients feel after a transplant to verify the claim that transplantation brings recipients life closer to normal.

Self-perceptions refers to an individual's evaluation of his/ her overall physical health functioning, coping and subjective well being' after transplant. The recipients differed in self perceptions when they compared themselves to other people. When they were asked as how they perceive themselves compared to healthy individuals without a transplant, in most cases, the recipients who were more satisfied with their life and transplant (high scorers on QoL) did not compare themselves to healthy people. Instead they considered themselves better and privileged to resume a normal life after being ill for a long time. They viewed that no comparisons can be made in their situation as reflected clearly when one recipient said;

'There is no comparison possible...I don't compare myself to those who did not have a kidney failure? I can compare myself to those who had it and are still suffering on dialysis and I feel luckier and thank God to get a donor at the right time and resume my normal life'.

Another female recipient who had her transplant 2 years ago also confirmed this faith and said;

'...I can only compare myself to my condition before the transplant and that's why I am so happy to be lucky enough to afford a transplant and a successful one...what if I had died with renal failure or stayed on dialysis?'

The low scorers responded with a negative perception when comparing themselves to healthy individuals. They also viewed that there is no comparisons between them and healthy people but their orientation differed to the high scorers. An unemployed male who had a transplant 2 years back said;

'...how can I compare myself to a healthy person? A healthy person is normal and has no issues of affording lifelong medication suffering with devastating side effects and living with this future uncertainty of losing the kidney anytime....what do they know of a life with a transplanted kidney...'

Social comparisons highlighted the recipient's sense of normality or low self image with a transplant and a further analysis of the mechanisms responsible for a certain type of self and others perception can be explored.

3.4. Coping/ Self-care/ Compliance

The strategies adopted by the recipients to adjust and deal with the routine challenges of life after transplant refers to coping and self-care skills. According to Dean (1989), self-care refers to 'the range of behaviours undertaken by individuals to promote or including adherence to medication, dietary and exercise recommendations; monitoring symptoms; maintaining physical function; executing medical regimens and making decisions about seeking care' It involves recipients' behaviours, attitudes and the knowledge of their significance (Gordon, Prohaska, Gallant and Siminoff 2009).Coping involves recipients dealing with the altered physical health status, relationships, future goals and aspiration, self-image, etc. manifested by his/ her behavior and functioning in domestic, social and

occupational life such as 'Self care'. Coping involves both psychological and behavioural aspects.

The recipients who scored high on QoL index, showed an attitude of acceptance and motivation to adhere to the recommended follow-ups.

Coping is described as a dynamic process of adjusting with the altered life styles and challenges post transplant. The types of coping strategies reported by the recipients included; religious, emotive and problem focused coping. There appeared a prominent trend of religious coping involving meditation and faith in God that enables them to go on.

A high scoring married male recipient who had his transplant 4 years back when he said;

'Allah (God) saved my life and gave me a second life...another chance to live and I seek His strength to give me the courage to live with it happily and He always gives me whatever I ask...'

They focused on will power and faith in God along with their problem solving approach that enables them to cope well with difficult situations as a female single recipient who was highly satisfied by her life ever since her transplant two years back as she said;

'I believe in the thought of I can & I will so this makes me do even the impossible things but all I have to do is to give it a try and have complete faith and trust in God...who never disappoints me'

The less satisfied recipients seemed to indulge in emotive coping as reflected by their excessive blaming attitude, anger and frustration on losing their native kidney. They tended to keep focusing on how and why they had a kidney failure, sometimes blaming the doctors for misdiagnosing or not getting timely / quality health care. A single female recipient who had her transplant 3 years ago said;

'I have to live this life of a transplanted patient just because they (doctors) did not know their job, they get marks and pass using unfair means, and we are at their mercy to be killed or live like this..'

Another male recipient who had his transplant 4 years back said;

'you can't call it living a life....this is no life...I am still living like a patient who has to take his medicines daily...see the doctor and get blood tests done regularly...is this what you call a normal life? I can't do the stuff I wanted to, I left my hobbies and aspirations...I'm just dead!'

The negative emotions and feeling of loss are predominant among those with a lower satisfaction with life. A young single female recipient who had her transplant 2 years back expressed her concerns about coping in future married life and said;

'How can I do all the things that a normal woman is expected to do? ...specially when and if I get married, can I bear children? Can I live a normal married life? I can't...so how can I cope normally...I can't even pursue the career or studies of my choice with this health.'

In this study, an attitude of gratitude, and motivation to cope with acceptance of life as it is, was found more among the success stories. The more satisfied recipients described themselves as 'lucky to have a second chance' to live and valued their improved health compared to pre transplant phase.

3.5. Self-Identity

The notion of participant's self-identity also permeated the transcripts. Their self-image being a transplanted individual appeared to be a quite significant theme that not only influenced their coping and relationships, but their adjustment in social and occupational life as well. The high scorers had a positive self-image and viewed themselves worthwhile as compared to the less satisfied with QoL and developed feelings of being less capable. Body image also appeared to affect their self-identity indirectly since they expressed that excessive weight gain (obesity) and loss of hair due to medication side effects made them physically less attractive. The low scorers expressed their self-identity as that of a patient indicating an assumption of a sick role.

The contrasting/ varied life orientations also resulted in different impacts on their self-identity found to be closely associated with social comparisons. The more functional and socially adjusted they perceived themselves, the better their self-image. The success cases had a more positive self-image with a desire to indulge in maximizing their potential. Their feeling of being worth and a positive attitude towards themselves is particularly reflected by contrasting perception of high and low scoring female recipients. The less satisfied group expresses a low self-image attributing it to the adverse physical side effects e.g. excessive weight gain and loss of hair. Most female recipients seemed preoccupied with their body image making them less desirable for their partners and they reported it to be a factor in worsening their marital relationship.

A young female recipient after one year of transplant said;

'My husband always loved my fit and in-shape figure and even though he doesn't say it verbally but I can feel the change in his attitude towards me due to my obesity and now it is very seldom that he would feel a need for physical intimacy...this makes me feel so insecure and I dread if he starts taking interest in other women.' This sounds more like relationships??

Another low scorer female recipient who got divorced just after 8 months of her transplant attributed her divorce to her obesity. She said;

'My husband was a typical man.....he discarded me since I was a burden on him with life-long medication and in return he was not getting what he expected out of me.....I am a fat woman and he doesn't love me anymore. His love was for my slim body not me....but at least I have seen his true face...though at a heavy price....'

The same experience of divorce is perceived quite differently by the other female recipient who scored high and showed increased life satisfaction. She got her transplant 4 years back and was divorced just after a year of her surgery. She was thankful to God to having her seen the true face of selfish people when she said;

'I am so relieved that God saved me from those selfish people who showed me their ugly face when the real test came....my husband never deserved me and that's why he ran away because he was not a man enough to own me.....I am far better without all that stress...'

Besides the different relationship experiences, their ability to achieve their aims and goals in life also

influenced their self-image and worth. A young male recipient who aimed to set up his own business said;

'I don't think I can do what I planned to do when I was normal...I mean healthy...well...with this transplanted kidney...I can't focus on my business and avoid public meetings fearing that I might catch an infection...so I have physical limitations and health issues that prevent me from achieving what was my dream'

Self-identity is described as an ability to contribute and achieve their goals in life that develop as a result of life experiences. The perceptions of self-identity reflect that each individual with a unique perception of life events and experiences and type of belief system, develops his/her life orientation that is modified by a multitude of socio demographic and psychological factors.

3.6. Medicalization & Health Professionals

Medication is a mandatory and lifelong component post-transplant to avoid rejection of graft. The participants showed an attitude of concern and compliance towards medication despite the adverse common side effects, including; weakening of bones, fatigue, skin problems, unwanted hair growth, swollen gums, and weight gain. All participants perceived side-effects as inevitable, and endeavored to adapt with varying success.

Doctor-patient relationship is an integral part of life after transplant and influences their recovery, physical health and psychological well-being. The nature of this relationship depends on the type of experience and interaction that develops their perceptions about health professionals. Success stories reported a positive view of health professionals and perceived them as saviors who helped them resume normal life and regain health. On the other hand, the less satisfied recipients blamed the health professionals to be inefficient because according to them, the doctors were unable to diagnose and treat them on time and due to this negligence, these patients had to undergo a transplant. Some less satisfied recipients even accused the doctors to be selfish and money orientated part of a mafia system, deliberately bringing patients to a verge of renal failure so that they can earn more money by conducting transplants.

Health care has been an important area of concern for all recipients. They shared their experiences with health care focusing on the attitude, efficiency and skills of the health professionals while dealing with them before and after the transplant. An interesting contrast was apparent in the description of this relationship among high and low scorers. The high scorers expressed gratitude, happiness and positive feelings about being helped by the health professionals to regain health and survive through this critical phase and life threatening illness whereas the low scorers blamed the doctors for not making a timely diagnosis of their renal failure and thus leading them towards a transplant.

A female high scorer married recipient who had her transplant three years back said;

'I am thankful to these life saviours who helped me survive and have another chance to live with my family...God bless them and I am really impressed that they helped me get out of that misery and pain....' Another male recipient said *'if I am leading a normal life today is because of Allah and his skilled human beings...the*

doctors who did my transplant and saved my life...not only my life...but made me re-enter the normal routine life as if nothing happened....'

There was anger, hatred and anguish reflected by the low scorer recipients who blamed the health professionals for their rude attitude and inefficiency. One male recipient who had his transplant just one year back said;

'...most doctors in Pakistan are playing with the lives of people without any checks on their illegal practice...they have made this sacred profession a money minting business and try to earn a lot of money no matter they have to put human lives at stake...I was forced to get admitted to a doctors private clinic and get a transplant in two days only ...is it possible to conduct all the matching and other procedures in just two days???? No way...he just wanted to grab me as a business opportunity so that any other doctor doesn't avail this golden chance.'

Adding to this negative attitude and behavior shown by the doctors, a female recipient said;

'...doctors are insensitive and heartless creatures....they give a damn to how a patient feels when they treat them like an object and how the family suffers through their hands...'

There was blame, anger, hatred and frustration predominant among less satisfied recipients based on their individual experiences with health professional that developed mistrust for doctors and health care system. However, those who had a positive experience of medical professionals and health care appeared to be thankful and expressed their gratitude finding themselves lucky to get a second chance to live.

3.7. Impact

Impact involves physical, psychological and social consequences of transplant, affecting QoL. The perceptions of their health status depended on physical and sexual energy pre-post-transplant, anxiety and stress related to family adjustments, financial issues, graft survival, lifelong dependency of immunosuppressant medication and executing family responsibilities. It gives a clear indication of the recipients' concerns and apprehensions about coping with altered life styles after having a kidney transplant.

Compliance with immunosuppressant medication also appeared to be a main impact of transplant. The success stories perceived compliance as a way of showing gratitude and protective behavior towards their transplanted kidney. They reported a firm belief in adhering to the lifelong immunosuppressant and diet plan recommendations to keep their grafts healthy and survive long. However, the recipients who reported lower QoL satisfaction considered medication compliance as an obligation that appeared to be too taxing for the rest of their lives. They also attributed the adverse medication side effects to the prolonged use of immunosuppressants and expressed their concerns about the negative impact of complying with these drugs.

A young female recipient, who gained excessive weight and unwanted facial hair as a side effect, expressed her helplessness and concern and said;

'I have become so unattractive at such an early stage of my life just because I have to take these poisonous medicines,...which are damaging my appearance...but I

have no choice and have to continue taking these as long as I live...do you think I can get a good life partner with this physical appearance...what can I do??? Nothing...but just give in to my destiny...'

The negative impact of medicine side effects was frequently reported by most recipients but single and female recipients were more concerned due to loss of physical attraction. However, the overall impact of having a renal transplant, when compared to pre-transplant phase, was markedly positive and most recipients found themselves to be closer to normal health functioning and were satisfied with their life post transplant.

The more satisfied with QoL had a positive view/perception of their self, health status, familial and social life with an attitude of gratitude and acceptance of life circumstances. In contrast, those with a lower QoL satisfaction expressed self-pity, being discarded by loved ones, resulting in low self-worth and feelings of anger and blame for loss of their native kidney. They attributed their kidney failure to delay and in efficiency diagnosis and treatment. The focuses of both groups differed in their attributions of having a kidney failure, transplant experience and outcomes and social comparison. The less satisfied described their life being marked with uncertainty, fear of graft loss and poor physical health status resulting in a low self-worth and a self-identity of a 'sick person' besides issues of affording lifelong medications. In particular, the young recipients with poor QoL expressed their apprehensions about future prospects and aspirations. In contrast, those with a higher QoL satisfaction had a positive life orientation, gratitude, acceptance of the transplant with its consequences, positive self-image, satisfaction with physical health status and positive self-identity.

4. Discussion

Recipients' perceived QoL seemed to be influenced by a multitude of psychosocial and personal factors. Briefly summarizing, these may include feelings of gratitude for donor, family and the renal team, or blame for kidney loss, social comparisons including the feeling of being either normal or 'not normal' and being treated differently from others. Although they do not negate the improvement in QoL post-transplant, but the extent of satisfaction with overall QoL seems to be influenced by a multitude of factors, including; individual characteristics, e.g. personality type, life orientation, environmental and financial conditions as well as quality of available health care.

Recipients face many new challenges and altered life style after kidney transplant surgery, such as new pathologies associated with mandatory immunosuppressant medications, uncertainty of graft survival, longevity and rejection and fear of graft rejection. They need to acquire new skills to take care of themselves, such as recognizing the signs and symptoms of impending infection and rejection. This suggests that once a transplant has been performed and the patient has been discharged with a functioning graft, the patient must continue to deal with a life of chronic illness (Luk 2004). The present study also reflected similar concerns and issues as described by recipients after their kidney

transplant. There are limited qualitative studies on QoL after renal transplant. Orr et al (2007) studies the experience of living with a kidney transplant, using thematic analysis, and identified themes including, medicalization; fear; gratitude; and coping. The authors found that these themes pervade the lives of the recipients and that the psychosocial effects of transplantation are long-lasting (Orr, Willis, Holmes, Britton, Orr 2007). The present study identified a lack of awareness about health promoting behaviors except for medication compliance and avoidance of infections. Although RTRs are required to practice self-care right after transplant and continue on lifelong basis to ensure graft longevity, but participants in this study lacked awareness about self-care practices including: staying well-hydrated, exercising, following a low-salt and low cholesterol diet, vigilant monitoring of vital signs, managing symptoms, wearing sun protection and avoiding contact with infections (Gordon et al 2009).

Ongoing research is also identifying the risk factors, stressors and issues of lack of knowledge and self care after transplantation. Skiveren, Mortensen and Haedersdal (2010) found that recipients did not perceive the threat of skin cancer as an important health problem and, therefore, did not prioritize sun protection, despite being aware of their increased risk of developing skin cancer. The authors suggested that the Health Belief Model can be used to identify and describe factors that influence decisions and behavior among RTRs.

The recipients described their individual coping strategies to deal with stress after transplantation. Question inquiring about stressors or concerns experienced by recipients post transplant revealed that the main stressors were fear of rejection, compliance with medication and side-effects of medication, uncertainty about the future, fear of infection and the cost factor. Since medication costs are not covered by insurance or government health services in Pakistan, so issues of affordability do affect medication compliance. Individual beliefs also affect medication adherence. A qualitative study described the beliefs, experiences and perspectives of RTRs on adherence and suggested that considering patients' attitudes, priorities, current life events, commitments, the support systems and healthcare services can plan interventions to promote concordance between prescribed medication and medicine-taking behaviours. This may improve treatment outcomes and mitigate the risks of non-adherence-related rejection (Tong, Howell, Wong, Webster, Howard, and Craig 2011). A similar study explored patients' perceptions of stress and QoL at different stages following a first, functioning renal graft: within six months, between one and five years and over five years later. They identified a number of concerns, of which fear of rejection was the most frequently mentioned, followed by stress generated through altered body image (a product of immunosuppressive therapy). Nevertheless, all reported a significant increase in QoL after transplantation, although improvement was least marked in patients in the intermediate group (1-5 years after surgery) who also experienced most stress (Fallen, Gould, and Wainwright 1997). Identification of stressors, among RTRs, would enable transplant teams to design interventions to help transplant recipients to cope with the demands of life with a renal graft (Kong, 1999). The cost benefit analysis confirms transplant efficacy. A qualitative

study exploring the experience of living with a kidney transplant found that 'despite the acknowledged difficulties' RTRs showed a firm and positive approach to cope well. The participants with more satisfaction with their QoL found the benefits of transplant much more than being on dialysis. They expressed a lot of gratitude to have this second chance to live and realized the importance of looking after the kidney. The participants related themselves to successful transplant stories and desired the same positive health outcome for themselves (Orr, Willis, Holmes, Britton, and Orr 2007).

The efficacy of therapeutic intervention addressing psychological issues among recipients is supported by studies. A study with both quantitative and qualitative components explored emotional issues among RTRs by comparing individual vs. group therapy vs. controls (who receive no therapy). Recurring themes described by patients during psychotherapy were analysed qualitatively by grouping into three categories of emotional problems (i) fear of rejection, (ii) feelings of paradoxical loss post-transplant despite having received a successful transplant and (iii) the psychological integration of the newly acquired kidney. Psychotherapeutic intervention was found to be an effective for addressing emotional problems. The recurring themes provided a baseline for psychotherapeutic exploration and resolution of these issues. Successful resolution of these issues was associated with lower depression and the redefinition of normality in daily living post-transplant (Baines, Joseph and Jindal 2002).

5. Concluding Remarks

It can be concluded that QoL satisfaction is determined by recipients' perceptions of health status, life orientation developed as a result of life experiences, beliefs and attitudes. Despite similar physical health status, recipients may differ in perceived QoL satisfaction due to psychosocial factors.

5.1. Clinical Implementations for Future Research

The analysis highlighted rich and meaningful insights and awareness about the perceptions and experiences of renal patients after transplantation. Differences in life orientations, perceptions and coping skills influencing satisfaction levels of QoL indicate the need to develop therapeutic plans to address these issues that can facilitate the recipients to cope with the demands of life with a renal graft, from the initial stages to resumption of work, family responsibilities and adjustments to routine life after transplant. It is important for the transplant team to consider recipients' personality, beliefs and emotional issues pre and post transplant for better physical and mental health outcomes (Orr, Willis, Holmes, Britton, & Orr 2007). Failure to do so risks disappointment and

frustration, potentially reducing or delaying adaptation to the transplanted kidney and compromising QoL. Previous research has not focused much on these issues since it has not been a major threatening factor for the overall viability of post-transplant adaptation, but there are implications for both clinical practice and theory.

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