

## **Transitions in Psychological Well-being and Life Orientation: The Phenomenon of Post Traumatic Growth after Renal Transplantation**

**Fatima Kamran**

University of the Punjab

**Jane Ogden**

University of Surrey

This qualitative study was carried out to study how renal transplant recipients (RTRs) following a successful transplant in Pakistan perceive their experience and life before and after the transplant. The aim was to explore recipients' perceptions and transitions concerning their personality and life orientation as a consequence of a major surgical experience. The study focused on how the recipients perceived the impact of losing native kidneys, their coping and adjustment with altered life styles before and after the transplant. Using in depth interviews, twenty participants (10 males, 10 females) were approached at the renal follow-up clinic and asked to describe their transplant experiences and compare their physical functioning, family and social life and psychological well-being pre- and post-transplant. Out of twenty, 14 agreed to share their experiences in the qualitative interview. A thematic analysis revealed that transplantation brought positive changes in their psychological well-being. Participants tended to have an optimistic attitude towards life focus regarding past, present and future plans & concerns. The themes explaining these transitions included; 'post traumatic growth' as indicated by an optimistic attitude & personal growth' as a consequent impact of transplant, 'gratitude', 'emotional morbidity' and 'transplant related fears, anxieties & uncertainty' about possible future consequences & risk vulnerability and future concerns. Most recipients perceived themselves as 'changed beings' regarding their behaviors, beliefs and interpersonal relationships.

*Keyword.* Renal Transplant Recipients (RTRs), Quality of Life, Posttraumatic growth (PTG), Psychosocial, Life orientation, Thematic Analysis

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Fatima Kamran, Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan.

Jane Ogden, University of Surrey, England.

Correspondence concerning this article should be addressed to Fatima Kamran, Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan. E-mail: fatimakamran24@yahoo.com

End Stage Renal Disease (ESRD) is a debilitating chronic kidney condition involving kidney failure requiring the patient to either depend on dialysis as a lifelong need for survival or renal transplantation which is not only expensive but needs the patient to be physically eligible as a transplant candidate such as absence of other serious co-morbid conditions such as diabetes. The number of patients with ESRD has steadily increased in recent decades (Watson & Dark, 2012). It requires the patient to either depend on dialysis or renal transplantation for survival. Transplantation is preferred as the treatment of choice due to fewer risks and improved quality of life along with better survival rates (Tonelliet al., 2011). Interestingly, renal transplant is the most common kind of transplant all over the world (Watson & Dark, 2012). Since mostly people with ESRD undergo this major surgical procedure, the physiological and psychological consequences and Quality of Life (QoL) of renal patients after transplantation has become the focus of researchers. There is a significant need of incorporating patients' perspectives in health care is universally recognized because such incorporation may improve quality of health care as well (Pittens, Elberse, Visse, Abma, & Broerse, 2014).

According to previous researches, post-transplant is related 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 Qualitative research aims to explore the underlying environmental, personal, clinical and psychosocial factors/experiences influencing recipients' perception and satisfaction with QoL (Tonelliet al., 2011).

Recipients tend to describe three main priorities that include their post-transplant coping, family life and mastery to adapt with the demanding and lifelong treatment. The patients' illness affects the family as well and patients therefore indicate that research should focus on their relatives and the family as a social system. Since life after transplantation also requires complying with doctors prescribed management, there is a need to develop strategies that facilitate them to remain independent and keep control over their own life to promote increased life satisfaction and psychological well-being (Schipper & Abma, 2011).

A phenomenological analysis of the semi-structured interviews identified four themes relating to the physical changes encountered (inactivity), physical recovery (health transition); changes made to the transplant recipients life styles (modification); and outlook. Most recipients report a good quality of life, which was often comparable to their pre-transplantation lifestyle. However, the initial recovery

process was often difficult and was related to the physical changes instigated from their multi-organ failure and intensive care stay, which can present numerous physical and emotional challenges (Sargent & Wainwright, 2007).

The efficacy of renal transplantation is considered as the most desirable treatment option for patients with renal failure. Although transplantation is assumed to bring recipients' life closer to normal there are new challenges and altered life styles after renal transplantation. However, research needs significant insights and processes of psychological growth as reflected in the perceptions and experiences of renal patients after transplantation (Howell, Tong, Wong, Craig, & Howard, 2012).

Since transplantation is agreed to have best possible health outcomes, the other related aspect involves the psychological impact and consequences of transplantation. Mostly recipients tend to report satisfaction with overall quality of life after transplant; however, there are individual differences in the perceptions and experiences of recipients. There is sufficient evidence that transplant recipients' perceptions of their disease and body image may have an influence on their physical recovery (Calia, 2011; Consoli, 2012; De Pasquale, Pistorio, & Sorbello, 2010; Látos, Barabas, & Lazar, 2012; Pérez-San-Gregorio, Martin-Rodriquez, & Diaz-Dominiquez, 2009).

### **Theoretical Framework**

The concept of posttraumatic growth (PTG) is quite a popular one with this population. It is referred to as a positive change experienced as a result of the struggle with a major life crisis or a traumatic event. The term posttraumatic growth describes the idea that human beings can be changed by their experiences with life challenges. This theme has prevailed in ancient spiritual and religious traditions, literature, and philosophy. What is reasonably new is the systematic study of this phenomenon by psychologists, social workers, counselors, and scholars in other traditions of clinical practice and scientific investigation (Calhoun & Tedeschi, 2013).

Post traumatic growth mainly involves five areas. Firstly, experiencing major life crises develops an insight about new opportunities and possibilities that were not present before and a desire to indulge into struggle to utilize these. A second area is a change in relationships with others. Some recipients experience closer relationships with some specific people with an increased sense of

connection to others who suffer. A third area of possible change is an increased realization of one's own strength, "if I lived through that, I can face anything". A fourth aspect of posttraumatic growth involves a greater appreciation for life in general as they tend to value the regained health a second chance to live. The fifth area involves the spiritual or religious orientation. Some recipients tend to experience a deepening of their spiritual lives; however, this deepening can also involve a significant change in one's belief system (Látos et al., 2015).

Recent Developments indicate that investigating growth has become a main area of investigation in scientific inquiry both quantitative and qualitatively specially in evaluating health outcomes and assessment of treatment efficacy. Tedeschi and Calhoun are considered as pioneers in this area being major contributors in introducing the term 'posttraumatic growth' in 1995. The development of the Posttraumatic Growth Inventory, a self-report assessment of the construct was first presented in their book *Trauma and Transformation: Growing in the Aftermath of Suffering*, and later in an article published in the *Journal of Traumatic Stress* (Tedeschi & Calhoun, 1996). Since then, there is an extensive literature that highlights the positive aspects and changes developed as a consequence of stressful and traumatic events (Linley & Joseph, 2004), a burgeoning measurement literature (Joseph & Linley, 2008).

The areas examined to study growth outcomes also include medical conditions such as life threatening illnesses such as; cancers, cardiovascular disorders, neurological disorders & injuries and organ failure.

Most research has been carried out on older adults, but there is also a growing awareness of the relevance of this work to young people (Joseph, Knibbs, & Hobbs, 2007). Therefore, this qualitative study recruited young adult kidney transplant recipients to share their experience of the process of growth.

Post traumatic growth has been found to be an outcome of a variety of psychosocial factors including religion and spirituality (Shaw, Joseph, & Linley, 2005), personality, coping, and social support (Linley & Joseph, 2004).

A variety of terms have been used to describe the concept of posttraumatic. It is sometimes also referred to as 'positive changes' that develop in the individual after stressful life experiences (Joseph, Williams, & Yule, 1993), 'stress-related growth' (Park, Cohen, & Murch, 1996), perceived benefits (McMillen, Fisher, & Smith, 1997), and thriving (Abraido-Lanza, Guier, & Colon, 1998), and most recently, adversarial growth (Linley & Joseph, 2004). It is notable that

the choice of the term 'post traumatic growth' clarifies how an individual's experience of pain and misery is grounded in a natural developmental process whereas other terms such as 'perceived benefits', 'positive changes' and 'adversarial growth' and 'stress-related growth' provide are not self-explanatory and only suggest that people perceive that they have benefited in some way.

The concept of growth is in line with the humanistic or person-centered perspective (Joseph, 2004) that also incorporates the concepts described in positive psychology suggesting a more comprehensive and clear theoretical analysis of growth through adversity (Joseph & Linley, 2005), referring to - the organismic valuing theory of growth.

The organismic valuing theory of growth is a valuable contribution towards clarification of the personal growth after a traumatic or stressful event. The organismic valuing process (OVP) refers to people's innate ability to understand and develop an insight in things that are important and beneficial for a meaningful and more satisfied existence, giving it a favour of humanistic, existential and person centered traditions. Just like the humanistic/existential perspectives, this theory assumes that human beings are intrinsically motivated to grow positively as an individual, especially after going through difficult life circumstances.

The theory clarifies the process of growth and information processing. It suggests that the new trauma-related information is processed in one of two ways – either existing assumptions are confirmed or they are disconfirmed. If assumptions are disconfirmed, then the new trauma-related information must be either be assimilated within existing models of the world, or existing models of the world must accommodate the new trauma-related information. Some preliminary support for OVP theory is beginning to emerge in qualitative (Joseph & Linley, 2006) and quantitative research (Ransom, Sheldon, & Jacobsen, 2008), and this promises to be an exciting avenue for future research. Considering this theory, it is important to gather more in-depth qualitative insights in the changes that may occur in individuals after transplantation to find how most recipients indulge into this process of growth after a life threatening experience of renal transplant and return to life.

The existential-humanistic perspectives on PTG have consensus on the idea that there is personal gain to be found in suffering. However, recently, the phenomena of growth following traumatic experiences has become the focus for empirical and theoretical work.

The present study focus the transplant population for analysing if and how recipients experience PTG after a successful renal transplant.

There are three main theoretical perspectives on PTG, including; functional-descriptive model, the metatheoretical person-centered perspective, and the biopsychosocial-evolutionary view. It is proposed that these three approaches to theory offer different but comparable explanations, however, all these approaches suggest that stressful and traumatic events may consequently lead towards personal growth and positive change that has shown to have a positive influence specially on health outcomes (Joseph & Linley, 2006).

It is suggested that growth doesn't always occur directly after the trauma, instead it is a gradual and progressive phenomena that involves the individual's struggle with the new reality in the aftermath of trauma. This realization is the key in determining the extent each individual undergoes posttraumatic growth. This concludes that there are transitions that differ in extent in the overall well-being and life orientation of recipients undergoing an organ transplant that leads to their post traumatic self-growth.

The present study is based on the theoretical framework of Tedeschi and Calhoun (2004) that suggests that personal growth after trauma should be viewed as originating not from the event, but from within the person themselves through the process of their struggle with the event and its consequent challenges as in case of living with a transplanted kidney. A qualitative study would therefore be the most appropriate approach to investigate these inner personal processes that may contribute towards the phenomenon of post traumatic growth.

### **Rationale of Present Study**

Most studies of life post-transplant tend to investigate the role of clinical and psychosocial factors associated with improvements in physical functioning and overall QoL (Gentile et al., 2013). However, there is a need to gain an in-depth understanding and meaningful insights into the transplant experience and transitions not only in the physical health but also in the individual's mind, emotions, behavior, and attitude towards self, others and future life with a qualitative approach. This can shed light on the most important aspect of the changes not only in physical but psychological functioning, personality and change in life orientation as a consequence of a major surgical procedure such as transplantation. This can contribute new themes mostly not focused in quantitative research (Orr, Willis, Holmes, Britton, & Orr, 2007) towards an understanding of

individual's coping, adjustment and personal growth as a consequence of traumatic experience of loss and gain of a solid organ like kidney.

## **Method**

A qualitative approach using in-depth interviews was used to analyse how recipients perceive and compare their life pre and post-transplant. The focus was on the change they experienced in themselves and their life orientation.

### **Participants**

Semi-Structured/In depth qualitative interviews were carried out with Renal Transplant Recipients (RTRs) to explore the transitions in psychological well-being and life orientation. RTRs on regular follow-ups one year after successful transplantation were recruited through researchers' professional networks in renal clinics where recipients were approached as referrals from nephrologists. They were requested to participate in the qualitative interview. Twenty recipients with an equal representation of both genders (10 male & 10 female) were initially approached at three private renal clinics in Lahore. Out of twenty, fourteen completed the interview (6 females and 8 males).

### **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 interview guide comprised of general broad questions about recipients experience and life orientation both before and after renal transplantation. The interview questions were based on the theoretical model of post traumatic growth by Tedeschi & Calhoun (2004). The in-depth interview was designed to inquire about recipients description of how they experience a change in self, others and life in general initially after diagnosis of renal failure and then transplantation. They were asked to compare their overall life in different phases of treatment (pre and post transplant) and finally after restoration of health.

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 transcribed. 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.

Table 1

*Characteristics of Renal Transplant Recipients*

Case No	Gender	Age	Marital Status	Education	Occupation	Monthly Income	Time since Transplant	Renal function	QoL Means
1	Male	26	Single	Masters	Unemployed	Rs.95,000	2.4 yrs	A	16.39
2	Male	28	Single	Graduation	Unemployed	Rs.80,000	3 yrs	A	16.84
3	Male	37	Married	School level	self employed	Rs.75,000	3 yrs	B	19.66
4	Male	34	Divorced	Graduation	Govt. officer	Rs.70,000	4 yrs	A	16.41
5	Female	40	Divorced	School level	Housewife	Rs.95,000	2.5 yrs	B	12.08
6	Female	35	Separated	Masters	Education	Rs.85,000	3 yrs	A	14.26
7	Female	45	Divorced	School level	Housewife	Rs.1,00000	2.7yrs	B	16.79
8	Male	32	Married	Masters	Business	Rs.1,00000	3 yrs	A	16.88
9	Male	44	Married	Bachelors	Self Employed	Rs.2,00000	2 yrs	B	17.23
10	Male	41	Married	Bachelors	Govt.Officer	Rs.1,00000	5 yrs	B	18.89
11	Female	39	Married	Masters	Housewife	Rs.2,00000	5yrs	B	14.47
12	Female	33	Married	Bachelors	Housewife	Rs.2,00000	1 yr.	A	15.23
13	Male	47	Married	School Level	Landlord	Rs.4,00000	2.7 yrs	C	12.72
14	Female	35	Single	Masters	Education	Rs.1,00000	2 yrs	A	16.33

## Data Analysis

Thematic Analysis was used to identify themes that sufficiently 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 (Gentile et al., 2013; Howel et al., 2012). 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.

The themes emerging from the thematic analysis included; 'psychological impact & post traumatic growth' describing their orientations regarding the 'impact of transplant' on 'relationships' with significant others, (family, work and social life), 'gratitude', 'emotional morbidity', 'transplant related fears & uncertainty and their Future concerns' were the major themes. 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. The main questions inquired about the change and transitions they experiences as an individual after the transplant. These themes pervade their perceptions of how life changed after transplant. The transcripts reflected some very interesting insights into their individual life experiences. The Psychological Impact & Post Traumatic Growth revolved around the following themes;

1. Optimism
2. Gratitude
3. Self-Identity
4. Emotional Morbidity
5. Transplant-Related Fears & Anxieties & Future Concerns

## Themes

### 1. Optimism

Kidney transplantation not only changed their physical health incredibly but also their life orientation about self, others and life in general. It was manifested by their newly learned skills and coping strategies to deal with psychological distress & altered life styles. Life of post-transplant is marked with new challenges. Although health

status is significantly improved, the psychological consequences may be negative e.g. depression and anxiety or positive with an optimistic attitude indicative of post traumatic growth. Most recipients valued this second chance to be healthy and returning to life. They expressed their aspirations to make the best out of it and maximizing their potential to the most indicative of an optimist attitude towards life.

Although they discussed the challenges experienced after transplant such as strict medication adherence and adverse medication side effects, they still indulged in positive coping strategies. Valuing the benefits of transplant than suffering on dialysis made them cope well with the difficulties.

Recipient felt lucky for this second chance, and realized their duty to look after their kidney manifesting a sense of responsibility. The physical changes that occurred due to medication side effects, such as weight gain, hair loss and weakening of bones were not perceived as that dreadful when they made comparison with others on dialysis or whose transplant had not been particularly successful. A female recipient expressed;

‘I think, losing hair or gaining weight does not matter as long as I am healthy and having a normal life, with normal appetite and sleep, there are people on dialysis who are deprived of basic needs such as water and normal food and are living a restricted life’.

Another male recipient said;

‘I don’t fuss about taking my medicines strictly on time neither do I complain about the weight gain due to their side effect as I don’t have to go through the painful procedure of dialysis on twice a week basis’.

Recipients developed new goals and aspirations to maximize their potential with the feeling that they wanted to make the most out of this life which is like a second chance to live. Indulging in constructive activities, contributing towards society, caring for loved ones and enjoying each and every moment of life with a focus on positive attributes of life seemed to be their preference.

Coping strategies included distraction from negative thought by indulging in a busy routine. An active life style adoption also proved helpful in maximizing their worth, enhancing their self-worth. A recipient reported;

'Now when I compare myself with the dependent life on dialysis, I feel energetic and worthwhile. I work and I enjoy my work as it gives me a feeling that I am contributing something in life as I am fine and healthy'.

All health issues stay in background when the focus is constructive work. A young female recipient said;

'Work means sanity to me, this keeps my mind positively occupied and I don't have time to think about my condition or ruminate about the past miseries.

In order to cope effectively, recipients used humor as a strategy to lighten the gravity of negative side effects and avoidance of future anxieties and fears. Most recipients mentioned that it is important to laugh in the face of problems to cope with the difficulties of life with a transplant. Thus they had learnt to laugh at themselves. They joked about taking on the characteristics of the donor, when one recipient mentioned a change in food preference and interests attributing it to his donor;

'Since my kidney comes from a person who is a vegetarian, I have surprisingly started loving vegetables and fond of sports just like him'.

The main aspects of self-growth reflected in their attitudes and behaviors involved positive social comparisons with others, self-education & a sense of responsibility and positive reframing of beliefs towards self and life. Most participants appeared to be quite knowledgeable about their condition and the medication side-effects which enhanced their sense of being in control. They had detailed information about their condition, health promoting and health compromising behaviors. This sense of empowerment and internal locus of control also contributed towards post traumatic growth that facilitated their confidence to survive successfully with their condition.

Regularity in self-care and adherence to the follow-up schedule reflected their serious attitude and the significance they attached to care for the kidney. An attitude of acceptance and openness to seek medical care in times of need also marked their positive perceptions and trust in the renal health care services.

## **2. Gratitude**

The psychological impact of transplantation appeared to be predominantly marked with a sense of gratitude and obligation.

Participants had strong feelings of gratitude for their kidney, with such comments as:

'I feel really thankful to Allah for blessing me with health, and giving me a second chance to live, how many people can afford a transplant in Pakistan? I have no words to thank Almighty and my family for my journey back to life'.

Gratitude was attributed to the donors, their families and the health professionals as one participant expressed;

'I am in debt to the person who gave me a second life with his kidney; there are no words for the appreciation of the person who actually gave me my life back' (P4).

The feeling of gratitude was sometimes associated with guilt that someone had to live with one kidney in case of living donor. In case of un-related live donor, recipients had limited information about their donors and mostly didn't even meet them in person. They knew only the gender or age of the donor. None of them had a contact with the un-related donor or their families so there seemed an 'unfinished business' regarding gratitude.

'I couldn't even thank him and his family for what they did for me....i can never repay back and I wish I had a chance to tell them how much this means to me'.

Gratitude appeared to develop an insight about being the privileged among others with terminal illness without a treatment. This positive belief and realization facilitated them towards an overall optimistic attitude and satisfaction with life post-transplant.

### **3. Self-identity**

The transplant experience influences not only the physical health but also the self-image and identity of the recipient. Transplantation can result in a psychosomatic crisis which needs bio-psycho-social resources to be utilized by the recipient for a healthier adaptation to the new kidney. This may cause changes in self-representation and identity, depending on the psychosocial factors such as; role of personality, family & social support, medical professionals & health care and health outcomes of transplant. A successful transplant restores health but the self-identity and image a recipient develops is determined by a complex interplay of the factors mentioned (De

Pasquale et al., 2014). A young female recipient expressed a positive self-identity despite adverse medication side effects which made her lose her hair and weight gain;

‘Although I have lost my long beautiful hair that I once used to have, and I am not slim anymore that makes me concerned and a bit upset too at times but what I have gained means much more to me and that is health!.....what good were my long hair when I couldn’t even be at my own, and not even desire to look at myself???’

The above narrative clearly reflects that the female recipient is minimizing the apparent physical attributes of being attractive and maximizing the significance of restoration of health which helps her positive self-identity. Other recipients did express their concerns about physical issues such as weight gain, unwanted hair growth, surgical scar, hair loss and other medical issues causing physical changes but mostly they tend to feel satisfied being the privileged ones to resume a normal functioning reflecting a good self-identity.

A male recipient said;

‘I am happy that I got my independence back, I feel worth something, I am not sick any more, I can pursue my aspirations and goals after regaining my health and this means everything to me’.

The above narratives reflect that a healthy self-image and esteem is linked with a positive health outcome and satisfaction with overall Quality of Life. Recipients’ psychological well-being is directly influenced by the self-identity developed after going through the transitions from a sick role to a healthy one (Frieson, 1998).

#### **4. Emotional issues & morbidity**

Most recipients tend to feel elated and experience a sense of relief and hope after a successful transplant. However, with the passage of time, that initial optimism may be tinged with other feelings. They tend to apprehend about the possible negative consequences of which fear or rejection is the most distressing as reported by a female recipient after 5 years of transplant;

‘So far its going smooth and fine but I cant help worrying what may happen in coming years or even next few months, every time its time for a lab test, I need reassurance and

support to cope with this tension and need to hear that all is well and will stay well'

The above expression is a manifestation of apprehension which is one of the common psychological consequences of transplantation. The type of emotional need is quite unique for each recipient. Sometimes recipients need reassurance of kidney survival, others may need to avoid indulgence in any discussion about possible rejection and indulge in avoidance and withdrawal behavior. A male recipient said;

'ever since my transplant, I have stopped reading or thinking about negative things or possible adverse consequences as I want to stay relaxed and tension free... whatever has to happen will happen so why to keep my mind tense all the time?'

It seems a very complex combination of positives and negatives, which vary according to the Sociodemographic, personality factors and individual beliefs about the condition and life. Since it requires individual adjustment, therefore, it is not possible to predict how each recipient will respond and react psychologically to this change. Research indicates that the mind, body and behavior undergo a transition and recipients discover new 'selves'.

The mind experiences pleasure mixed with sadness over body changes, irritability from high steroid doses, guilt because the kidney came from another's loss (living or deceased). The behavior is normalized with a regain of appetite, fluid intake, sleep and sexual functions (Siegal, 1995).

However, emotional issues arise when adjusting to the new challenges of strict medication adherence and acceptance of adverse side effects. The lifelong high medication costs and regular medical care are a source of anxiety and financial stress

Family and peer group interactions are mostly reported when recipients express their joy at the physical improvement accompanied by a persistent fear of transplant loss. They also manifest their concerns about work interactions and their ability to perform at work

There can be considerable emotional morbidity after transplantation such as depression and anxiety that can be indicative of a need for emotional support not only by the close family members but also from the health professionals monitoring them at follow-ups. The most common emotional issues after transplant involve a need to feel secure and confident about the efficacy and longevity of the transplant.

### **5. Transplant-related fears and anxieties and future concerns**

Fear of rejection of the kidney pervades the post-transplant life of the recipients. They expressed anxiety and a feeling of uncertainty about future prospects of their transplant. A female participant said;

‘One is constantly living with the fear of transplant rejection, you never know what, how & when you just lose it, this is so horrible and makes me upset when I think about it.’

They tend to be preoccupied with medication adherence due to this fear of graft rejection as expressed by a male recipient;

‘I would feel guilty if I lose this kidney due to my negligence and I dread that time’.

Participants reported that these fears and anxieties are not only experienced by them but also found in their close family members. A married female participant reported;

‘My husband’s always asking me, have you taken your tablets, when I get up in the morning, have you taken your tablets, don’t, miss your dose or the kidney will fail’.

The thought of the transplant failing was so fearful that two participants said that they would prefer death as compared to the painful life with dialysis. A single female recipient said;

‘I can never forget the painful experience of getting the fistula and getting the dialysis done thrice a week, I am horrified by the sheer thought of returning back to that stage and wish to die before that’.

Another male recipient also confirmed that;

‘The thoughts of going back on dialysis are make me horrified’.

Most recipients were concerned about the longevity and survival of the graft with reference to time factor. They seemed to be preoccupied with the fact that the transplanted kidney was time-limited.

A young, single male recipient who had his transplant just a year ago shared his experience saying that:

‘All the time I am trying to get information about the longest time a transplanted kidney survives, but at the same time, when I hear stories with kidney lasting for a year or so’ (S1).

They need hope to move on in life but at the same time the uncertainty of time a transplant lasts makes them anxious and fearful.

The recipients narratives focused on their future concerns focused not only about the longevity of their transplant but also the quality of their health status. A male recipient expressed his future concerns regarding his ability to achieve his professional and personal goals;

‘I hope my health stays that well that I can proceed to achieve my career goals and then also enjoy the fruits of my hard work. I hope to live healthy that long. The energy I have regained should be there till my goals are achieved.’

Another female recipient said;

‘I hope science develops more in this field and discovers a drug free solution to kidney failure or at least invent some medicines that don’t have the risk of developing cancers as I am horrified to know that my medications can cause cancers of any type and weaken my bones’

The above descriptions clearly reflect the health concerns of recipients in the long run. The recipients’ future concerns are focused around discovery of better newer medical treatments and longevity rates with maintenance of physical health.

A major future concern of both married and single recipients was their married/sex life. The divorced male recipient was extremely concerned about his sex life and if he would be able to have a successful married life in future, when he said;

‘I am not sure if any woman would be happy with me being a transplant recipient...honestly what to say of others...I am not sure about my own sexual ability anymore, I have not even discussed it with my doctor or friends as its embarrassing’.

Another married female recipient shared her concerns;

‘I am a bit worried about my married life as I am not the same as before, I mean before my kidney failure, I lost interest in sex completely during my dialysis phase, although I feel normal now and even otherwise...as you

know...ummm...my husband expects me to be the same as before but I am a bit anxious due to my physical changes, specially the surgery scar is quite embarrassing...I wonder how can I have a normal married life??'

These were quite personal but significant concerns of the recipients that needed to be addressed by the renal team as well as an issue to be considered for marital counseling. Without an in-depth investigation, such vulnerable issues would have never been identified.

### **Discussion**

Research on post traumatic growth focuses on three broad dimensions of growth. First aspect involves individual/personal issues as people may find that the experience of trauma no matter how painful, has improved the quality of their personal relationships, for example that they start valuing their friends and family more, and express gratitude e.g.,

"I have learned to value what I have in life, a caring family, and my children who make my life meaningful" (Participant 1)

Second, survivors may develop improved views of themselves in some way. For example, they may report to develop more resilience, character strength and emotional stability.

"This transplant experience has increased self-awareness and insight into minor as well as major events of life" (Participant No 5)

Third, survivors may report positive changes in life orientation, such as finding life more meaningful and focusing on what they have rather what has been lost.

"I have learned to value life and make the most out of it, I enjoy and live each day to the full, I don't care for everyday issues anymore, and want to contribute something positive to my and others life, I realize now the value of a healthy life which can't be compromised" (Participant No 8).

It is well argued that growth is a step further than resilience and involves going beyond previous levels of functioning (Joseph & Linley, 2008) and this qualitative study reveals the experiences of transitions in life orientation of renal transplant recipients influencing

their psychological well-being and post traumatic growth as a consequence of transplant. Briefly summarizing, these may include the overall psychological impact and positive changes in life orientation marked with feelings of gratitude to God Almighty, donors & their family, recipients' own family and loved ones, the renal team health professionals. Other issues focused around the need for strict medication adherence, self-care to keep the kidney healthy; need to get more awareness and knowledge about their condition; the efforts to 'feel normal and healthy and utilizing their life in the best possible way.

The restoration of physical health also implicates a psychic transplantation referring to the cognitive and emotional integration of the new organ (De Pasquale et al., 2010). Recipients tend to experience a variety of negative and positive emotions such as guilt, gratefulness, and fear (Schipper et al., 2013). However, research suggests that transplantation may also influence self-identity (Castelnuovo-Tedesco, 1983; De Pasquale et al., 2010). The recipients' mind, body and behavior undergoes a complete transition that also manifests the phenomena of Posttraumatic growth, which is referred to as "a positive cognitive process that is initiated to cope with traumatic events that extract an extreme cognitive and emotional toll" (Can et al., 2011, p.5).

Although it is a very significant aspect for psychological consequences of transplantation, there is very little research evidence focusing the relationship between posttraumatic growth and physical well-being of recipients after transplant (Látos et al., 2015). This qualitative study found that recipients underwent a positive personality transition. Their narratives of transplant experiences reflect a strong relationship between posttraumatic growth and physical as well as psychological well-being. Participants described their experiences of growing psychologically from the stressful transplantation experiences to development of an optimistic life orientation and personal growth. It is found that Posttraumatic growth involves a quality of transformation, or a qualitative change in functioning, unlike the apparently similar concepts of resilience, sense of coherence, optimism, and hardiness (Updegraff & Taylor, 2000). Researchers have also argued about the nature of PTG suggesting that it mutually interacts with life satisfaction and the development of life goals and it is a dynamic process not just a static outcome (Tedeschi & Calhoun, 2004). Recipients who appear to be more satisfied with their quality of life and have meaning and future aspirations in life seem to report more personal growth.

Post traumatic growth appears to be a prominent health promoting phenomena. Therefore, besides recognizing the improvement in psychological well-being and quality of life post-transplant, it is also important for the renal team and families to focus interventions that facilitate the recipients to harbor positive life orientation with an optimist attitude and positive health beliefs which may modify health outcomes. In case, the positivity in beliefs and behaviors is not emphasized or supported, it may cause negative psychological consequences, health risks, disappointment and frustration, risking and delaying the process of adjustment to altered life styles and reducing overall quality of life.

### Conclusion

The study traces the journey of transition and the process of self-growth experienced as an evolution as a consequence of a major surgical procedure like renal transplant, highlighting the significance of individual efforts to accept, adjust and cope successfully in life after transplant. The main aim and aspiration of the recipients seemed to prolong the survival time and longevity of their kidney with an improved and satisfactory quality of life. The findings suggest that posttraumatic growth may serve as a protective factor in relation to consequent health outcomes after transplant.

### References

- Abraido-Lanza, A. F., Guier, C., & Colon, R. M. (1998). Psychological thriving among Latinas with chronic illness. *Journal of Social Issues, 54*, 405-424.
- Calhoun, L. G., & Tedeschi, R. G. (2013). *Posttraumatic growth in clinical practice*. New York: Brunner Routledge.
- Calia, R., Lai, C., & Aceto, P. (2011). Preoperative psychological factors predicting graft rejection in patients undergoing kidney transplant: A pilot study. *Transplantation Proceedings, 43*, 1006-1009.
- Cann, A., Calhoun, L. G., Tedeschi, R. G., Triplett, K. N., Vishnevsky, T., & Lindstrom, C. M. (2011). Assessing posttraumatic cognitive processes: The Event Related Rumination Inventory. *Anxiety, Stress, & Coping, 24*(2), 137-156.
- Castelnuovo-Tedesco, P. (1983). Organ transplant, body image, psychosis. *Psychoanalytic Quarterly, 42*, 349-363.

- Consoli, E. (2012). Person-centered approach in the medicine of organ transplants. *Transplantation Proceedings*, *42*, 1123-1126. Retrieved from <http://www.psicoanalisiit/psicoanalisi/osservatorio/articoli/osservaing1132.htm>
- De Pasquale, C., Veroux, M., Indelicato, L., Sinagra, N., Giaquinta, A., Fornaro, M.,...Pistorio, M. L. (2014). Psychopathological aspects of kidney transplantation: Efficacy of a multidisciplinary team. *World Journal of Transplant*, *4*(4), 267-275. doi:10.5500/wjt.v4.i4.26
- Frieson, C. W. (1998). Relationship between hope and self-esteem in renal transplant recipients. *Transplantation Proceeding*, *29*(8), 3739-40. doi:10.1016/S0041-1345(97)01092-0
- Gentile, S., Beauger, D., Speyer, E. S., Jouve, E., Dussol, B., Jacquelinet, C., & Briançon, S. (2013). Factors associated with health-related quality of life in renal transplant recipients: Results of a national survey in France. *Health and Quality of Life Outcomes*, *11*(88).doi:10.1186/1477-7525-11-88
- Howell, M., Tong, A., Wong, G., Craig, J. C., & Howard, K. (2012) Important outcomes for kidney transplant recipients: A nominal group and qualitative study. *American Journal of Kidney Diseases*, *60*(2), 186-96.
- Joseph, S., & Linley, P. A. (2006). Growth following adversity: Theoretical perspectives and implications for clinical practice. *Clinical Psychology Review*, *26*, 1041-1053.
- Joseph, S. (2004). Client-centred therapy, post-traumatic stress, and post-traumatic growth: Theoretical perspectives and practical implications. *Psychology and Psychotherapy: Theory, Research and Practice*, *77*, 101-120.
- Joseph, S., & Linley, P. A. (2005). Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Review of General Psychology*, *9*, 262-280.
- Joseph, S., & Linley, P. A. (2006). Growth following adversity: Theoretical perspectives and implications for clinical practice. *Clinical Psychology Review*, *26*, 1041-1053
- Joseph, S., & Linley, P. A. (2008). Psychological assessment of growth following adversity. In S. Joseph and P.A. Linley (Eds.), *Trauma, recovery, and growth: Positive psychological perspectives on posttraumatic stress* (pp. 21-38). Wiley: Hoboken.
- Joseph, S., Knibbs, J., & Hobbs, J. (2007). Trauma, resilience and growth in children and adolescents. In A. A. Hosin (Ed.), *Responses to traumatized children* (pp. 148-161). Palgrave Macmillan: Houndmills.
- Joseph, S., Williams, R., & Yule, W. (1993). Changes in outlook following disaster: The preliminary development of a measure to assess positive and negative responses. *Journal of Traumatic Stress*, *6*, 271-279.

- Látos, M., Barabás, K., & Lázár, G. (2012). Mental representation of the new organ and post-transplant patient's anxiety as related to kidney function. *Transplantation Proceedings*, *44*, 2143-2145.
- Látos, M., Devecsery, A., Lázár, G., Horváth, Z., Szederkényi, E., Szenohradzky, P., & Csaba, M. (2015). The role of body image integrity and posttraumatic growth in kidney transplantation: A 3-year longitudinal study. *Health Psychology Open January-June 2015*, *1*(8). doi:10.1177/2055102915581214
- Linley, P. A., & Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, *17*, 11-21.
- McMillen, J. C., Fisher, R. H., & Smith, E. M. (1997). Perceived benefit and mental health after three types of disaster. *Journal of Consulting and Clinical Psychology*, *65*, 733-739.
- Orr, A., Willis, S., Holmes, M., Britton, P., & Orr, D. (2007). Living with a kidney transplant: A qualitative investigation of quality of life. *Journal of Health Psychology*, *12*(4), 653-62.
- Park, C. L., Cohen, L. H., & Murch, R. L. (1996). Assessment and prediction of stress-related growth. *Journal of Personality*, *64*, 71-105.
- Pérez-San-Gregorio, M. A., Martín-Rodriquez, A., & Díaz-Dominiquez, R. (2006). The influence of post transplant anxiety on the long-term health of patients. *Transplantation Proceedings*, *38*, 2406-2408.
- Pittens, C. A., Elberse, J. E., Visse, M., Abma, T. A., Jacqueline, E. W., & Broerse, J. E. W. (2014). Research agendas involving patients: Factors that facilitate or impede translation of patients' perspectives in programming and implementation. *Science and Public Policy*, *41*(6), 809-820.
- Ransom, S., Sheldon, K. M., & Jacobsen, P. B. (2008). Actual change and inaccurate recall contribute to posttraumatic growth following radiotherapy. *Journal of consulting and clinical psychology*, *76*(5), 811.
- Sargent, S., & Wainwright, S. P. (2007). A qualitative study exploring patients perceived quality of life following an emergency liver transplant for acute liver failure. *Intensive Critical Care Nursing*, *23*(5), 272-80.
- Schipper, K., & Abma, T. A. (2011). Coping, family and mastery: Top priorities for social science research by patients with chronic kidney disease. *Nephrology, Dialysis Transplantation*, *26*(10), 3189-3195. doi:10.1093/ndt/gfq833
- Schipper, K., Abma, T. A., Koops, C., Bakker, I., Sanderman, R., & Schroevers, M. J. (2013). Sweet and sour after renal transplantation: A qualitative study about the positive and negative consequences of renal transplantation. *British Journal of Health Psychology*.
- Shaw, A., Joseph, S., & Linley, P. A. (2005). Religiosity, spirituality and posttraumatic growth: A systematic review. *Mental Health, Religion, and Culture*, *8*, 1-11.

- Siegel, B. R. (1995). Post-renal transplant compliance: The cognitions, emotions, and coping behaviors. Retrieved from <http://www.stanford.edu/dept/HPS/transplant/html/compliance.htm>
- Tonelli, M., Wiebe, N., Knoll, G., Bello, A., Browne, S., & Jadhav, D. (2011). Systematic review: Kidney transplantation compared with dialysis in clinically relevant outcomes. *American Journal of Transplantation, 11*(10), 2093-2109.
- Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry, 15*(1) 1-18.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*, 455-471.
- Tedeschi, R. G., & Calhoun, L. G. (2004). A clinical approach to posttraumatic growth. In P.A. Linley & S. Joseph (Eds.), *Positive psychology in practice* (pp. 405-419). Hoboken, NJ: Wiley.
- Updegraff, J. A., & Taylor, S. E. (2000). From vulnerability to growth: Positive and negative effects of stressful life events. In J. H. Harvey & E. Miller (Eds.), *Loss and trauma: General and close relationship perspectives* (pp. 3-28). Philadelphia: Brunner-Routledge
- Watson, C. J. E., & Dark, J. H. (2012). Organ transplantation: Historical perspective and current practice. *British Journal of Anaesthesia, 108*(1), 29-42.

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