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Living with a Chronic Condition: A Study of Patients' Life Transitions with Renal Conditions

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Chronic diseases encompass many physical and psychosocial challenges altering individuals' life styles. The study is based on the theoretical framework of the 'response shift model' of quality of life which suggests that individuals living with the chronic conditions tend to re-conceptualize and reprioritize their responses accordingly. This study examines how patients' living with renal conditions describes their coping with the adverse side effects of mandatory treatment protocol on a lifelong basis. The study focuses on the physical, psychological, and sociocultural challenges faced by renal patients in a developing country where financial issues of affordability, disease burden, and stigma are some of the serious challenges causing psychological distress in these individuals. Using a qualitative approach, participants including 12 renal patients (6 men and 6 women) were recruited on criterion based sampling technique from the renal clinics in Lahore. Data was transcribed and thematically analyzed. The reported experiences of living with a lifelong condition revealed 8 emerging themes including approach-avoidance conflict, cost benefit analysis, locus of control, expectations, awareness and knowledge of side effects, health beliefs and future concerns, doctor-patient relationship, and acceptance. Most patients were aware of the side effects of drugs and reported distress.

Keywords. Renal conditions, treatment satisfaction, medication side effects, coping strategies, thematic analysis

Chronic medical conditions entail adherence to medications on a lifelong basis, which influences physical, psychological, and social

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Correspondence concerning this article should be addressed to Fatima Kamran, Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan. Email: fatimakamran.appsy@pu.edu.pk well-being of the sufferers affecting their quality of life (QoL) with altered lifestyles and challenges (Finnegan-John & Thomas, 2013). Literature suggests chronic conditions are not limited to the elderly, younger patients express greater psychosocial issues (Bonnaud-Antignac et al., 2017). There is a lack of research, particularly in Southeast Asia, on the effects of chronic diseases on QoL of patients (Pengpid & Peltzer, 2018).

End Stage Renal Disease (ESRD) involves kidney failure, managed by transplantation, dialysis and medications. In dialysis and kidney transplants, normal physical functioning can be restored; however, medications become mandatory for the patients (González et al., 2017). In the developing world, the treatment and management of chronic conditions is based mainly on traditional model where focus is on patient survival and not on improved QoL (Grey et al., 2006). Care does not meet standards of the developed world because of costs; patients have limited access and opportunities for hemodialysis (HD) that compromises in QoL, and the focus is on saving lives than improving QoL (Awuah et al., 2013).

The decision about possible treatments is made by the physician, nevertheless the patient is given the choice to accept an option as 'lesser evil' of them all (Harmsen et al., 2013). This creates an 'approach-avoidance' conflict for each possible treatment and the patient is caught among choices for treatment for the renal condition as a cost-benefit analysis assessing minimal adverse side effects for larger benefits for treating the condition (Salvadori & Tsalouchos, 2017); and despite combinations of medications, no medicine or group of medicines are side effect free (Moini et al., 2015).

The decision of choosing medications for renal patients is not limited to the initial phase (Kalluri & Hardinger, 2012), but is an ongoing process that requires constant monitoring and modifications of medications in collaboration with the health care team. And sometimes this becomes a hard decision because every drug has its own potential side effects and selecting one over the other the other simply means opting one poor drug over another poor one (Popoola et al., 2014).

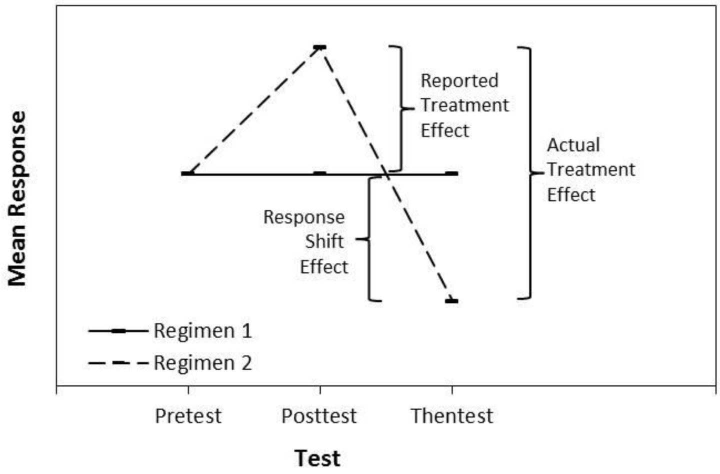
Medication side effects involve both physical and psychological symptoms such as skin problems, excessive weight gain, anemia, arthritis and osteoporosis, gout, gum problems, hair loss, high blood pressure, increased cholesterol and blood sugar levels, kidney damage, nausea, gastrointestinal and sleep problems, anxiety, mood swings and tremors (Wiseman, 2016). These side effects are managed either by changing doses or sometimes the medicines (Anghel et al., 2013).

Patients need to acquire knowledge about their prescribed medications and discuss their concerns with their health practitioners.

Individuals living with chronic renal conditions engage in problem-focused coping if the conditions are judged as reversible that is they can be ameliorated or abated; while emotion-focused coping is used when stressful consequences are considered unchangeable (Aburub et al., 2018). In most cases patients tend to use both ways of coping and are supported by families and the care teams when patients suffer from renal failures. In addition, patients seek solace in their faith, religion and resilience to address and understand disease-related stressors (Memory et al., 2022).

The study is based on the 'Theoretical Model of Response Shift & Quality of Life. According to this model, Quality of Life (QoL) can mean different things to different people at different times (Rapkin & Schwartz, 2004). Sprangers and Schwartz (1999) suggested the concept of 'response shift' (RS) to assess health related QoL. It refers to a change in the meaning of one's self-evaluation of QoL as a result of: (a) change in the respondent's internal standards of measurement (recalibration); (b) change in the respondent's values; or (c) redefinition of life quality (reconceptualization) (Rapkin & Schwartz, 2004).

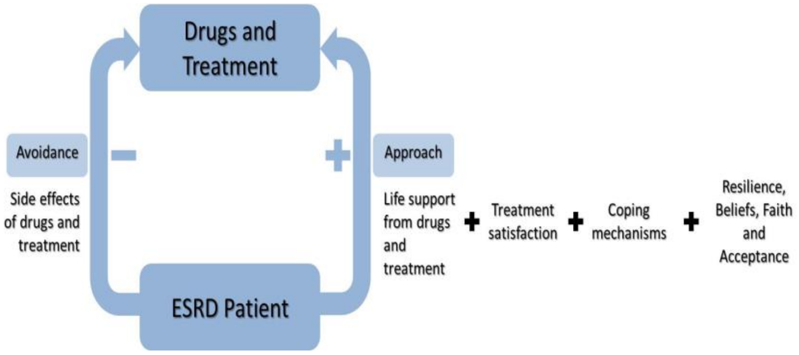
Figure 1: *The Then-test Approach for Response Shift Model (Sprangers & Schwartz, 1999)*



The 'Then-test approach' was introduced to measure RS (Sprangers & Schwartz, 1999). It involves a; Pre-test (baseline assessment done at beginning of study, i.e., before intervention/ change), the Post-test (subsequent assessment, i.e., after intervention/

change) and the 'Then-test' which is the retrospective assessment of first evaluation (Figure 1). However, in a qualitative study, we can inquire by asking the participants to compare pre and post phases of living with a chronic condition.

Figure 2. *Model of the Present Study*



Patients organize their perceptions and beliefs about their illness and treatment that directly influences their psychological well-being. Existing studies indicate that negative perceptions of the illness are associated with disease progression and a number of psychosocial outcomes in non-dialysis renal patients (Clarke et al., 2016). Jones, Shakespeare, McLaughlin, and Noyes (2023) concluded in a large-scale review of qualitative studies on renal patients that decisional preferences were based on gathering information and desire for transplantation which affected their readiness for kidney transplantation. They developed a new model integrating the theory of planned behavior and the adaptive decision maker framework to explain the findings. When the Renal Treatment Satisfaction Questionnaire (RTSQ) was used to measure satisfaction with renal treatment, patients indicated convenience, flexibility, freedom, and satisfaction had to be part of the treatment for patients to continue it (Barendse et al., 2005).

Perceived stigmatization, social comparisons and financial barriers are important sociocultural factors for renal patients in a developing low-income country like Pakistan. Despite advancements in treatment, issues of non-availability of treatment and its affordability affects quality health care. Most patients in Pakistan cannot afford superior quality expensive brands of drugs, which are limited to upper classes only (Rizvi et al., 2013). Datta et al. (2019) reported that medication cost coverage and household catastrophic health expenditure have strong associations. The findings inform policies toward ensuring access to necessary healthcare and reduction of financial hardship. A recent study (Mallick et al., 2022) Investigating QoL in Pakistani renal patients concluded that most of the patients belong to lower or middle socioeconomic groups whose own sense of QoL is overshadowed when given a second chance at life which was portrayed by the discrepancies in the perceived vs actual QoL graph. They found a common recurring theme that the difficulties they might have faced post-transplant were insignificant in comparison to their gratitude of getting a second chance to live. This study also highlights the significant contribution of factors including; immunosuppressants, fear of injury and transplant rejection, etc. in the first-year post-transplant. Demographic factors including income, age, location, etc. did not appear to have a major impact. Such studies facilitate and guide clinicians towards the improvement of long-term outcomes of renal transplantation in Pakistan.

Rationale of the Study

The present study explores how do renal patients perceive, accept and cope with the challenges of an altered life with a chronic condition. The focus is to understand their experiences of treatments and its impact on their psychological wellbeing. There is a need to explain the distressing experience of being dependent on mandatory medications and experiencing no option but to endure the severe medication side effects to survive. This can shed light to understand individual differences in beliefs, perceptions and coping strategies adopted by individuals experiencing long term physical conditions. It is essential to understand the factors that influence their medication adherence and treatment satisfaction in either way. This knowledge can highlight significant issues affecting QoL of individuals living a life with compromises.

Method

A qualitative approach was undertaken to gain a deeper insight and understanding of how patients living with a life threatening renal condition describe their life changes due to treatment and medication effects as well as psychological and financial burden on a long term basis.

Sampling Strategy and Participants

Purposive sampling was used to get information rich cases about the parameters that we aimed to study. Therefore, criterion based sampling strategy was employed to choose participants that satisfy certain specified criteria that helped us to separate out the information rich samples. It included only those hemodialysis and renal transplant recipients on regular and similar medications (pre-dialysis), It was decided to interview adults below the age of 40 years since literature shows that other comorbid conditions tend to occur in older age groups. An equal representation of both genders was ensured. Out of twenty, 17 agreed to share their experiences in the interview but only 12 completed the interview.

Procedure

The interview protocol was developed based on the existing literature on the psychosocial consequences of the renal transplantation. The interview protocol framework was comprised of four phases: ensuring interview questions align with research questions, constructing an inquiry-based conversation, receiving feedback on interview protocols and piloting the interview protocol. The interview questions asked patients to describe their journey of treatment and challenges of living with renal conditions. The focus was to understand how these individuals differ in their experience of the process of 'acceptance' and 'coping' with long term medication and how it affects their wellbeing. Semi-structured interview comprised of general questions inquiring about their expectations, experience and coping with the demands of their current treatment over time, its impact on their life and the nature, and severity and frequency of treatment and its side effects. The analysis compared the different phases of treatment and subsequent physical and psychological impact based on the theoretical model of Response Shift (Rapkin, & Schwartz, 2004) because this model assesses change in perception of quality of life consequent upon change in patient's internal standards, values and redefining the QoL at different stages. No time duration was set for the interviews to allow a free flow of information. The average time for interview was 40-45 minutes. The interviews were recorded with the participant's permission to be transcribed later.

Results

The qualitative inquiry used an Inductive thematic analysis approach to analyze the transcripts. Inductive thematic analysis entails deriving meaning and identifying themes from data with no preconceptions. Since the present study aimed to analyze the data without any expected outcomes, therefore an inductive approach was used. Interviews were recorded and transcribed for the purpose of analysis. After familiarization with the data, an 'Open Coding' was done adopting an inductive approach. The data was examined with as few preconceived notions as possible. The aim was to be "open" to the various possibilities of meaning in the data so that the representations of meaning contained in a research project's codes are as close to the data as possible (Charmaz, 2014; Saldaña, 2021) The coding was done and then subsequently themes were identified. The themes were cross validated by two researchers who coded the data individually. The Cohen's Kappa values were calculated for the interrater agreement for the emerged themes. The values ranged from .66 to .94 indicating substantial to near perfect agreement. The following are the major themes that emerged from the data. The above expression is a clear manifestation of patients' acceptance and feeling of being helpless with no escape from the negative medication side effects in order to keep the kidneys functioning. The themes emerged from the data are summarized below in context of response shift model (see Table 1).

Approach-Avoidance Conflict

Living with a lifelong physical condition implies mandatory medication adherence irrespective of the adverse side effects with distressing physical and psychological consequences. The participants described themselves entrapped into an approach avoidance conflict as they had no choice but to take these medications for survival but at the same time, they wanted to discontinue due to the adverse side effects. A woman expressed her helplessness saying that; "My life depends on these immunosuppressants which are also damaging my kidney simultaneously which distresses me …still I am forced to continue taking these as I have no other option but to continue irrespective of these negative effects on my health and physique".

Patients' Expectations

The study revealed what patients have expectations from their physicians and treatment. Most patients expected that the treatment will make them symptom free and as healthy as they were before developing this condition. They tend to have positive expectations and minimal side effects. Some of the participants even considered themselves as 'being cured' and hoped that at some point, they might be treatment and medication free. This unrealistic perception when challenged by their physician, caused distress, and developed an initial feeling of 'being depressed and helpless. A middle-aged married woman expressed her expectations when she said:

> "I knew it involves a long treatment and many medications, but I assumed that after a few years may be…when I become stable…I will get rid of these medicines and be as normal as I used to be once."

Another participant said:

> "I was told by my family that if I cooperate fully and take my medications, get my tests done regularly, then I will be taken off from these medicines that are causing me trouble…but after a year in this treatment …now I have come across the reality that this is going to be a part of my life and I have to continue it for the rest of my life."

Locus of Control

The participants described themselves as having little or no control over the decision of treatment modality and type of medication. They perceived themselves as passive beings whose life decisions regarding medication and treatment were controlled by the doctors. One participant described his feelings as; "I cannot decide anything about my treatment. Whether I like or don't like it, I have to comply as I am told by the doctors who don't understand how I feel when these meds play havoc with me and I have to take this just because I have no other way out". This expression reflects that individuals attribute their treatment to doctors and do not feel an internal locus of control over their choice of medication and treatment.

Health Beliefs and Future Concerns

Health belief refer to individual's perception of vulnerability and treatment that affect one's decision on behavior of health (Daniati et al., 2022). Participants expressed the belief that self- monitoring and compliance to suggested treatment protocol and lifestyle changes can optimize their health status. A man with renal disease said:

> "I need to take care of myself to delay the adverse consequences, I can't risk my health being casual as it will be a heavy cost that I will pay for neglecting my health."

However, they expressed serious concerns about treatment efficacy in the long run. Most participants expressed a feeling of insecurity about their future health and functioning. A middle-aged woman said:

> "I am almost 50 and have lived with my transplant for 18 years but I feel so anxious and uncertain about my future health and life as the clock is ticking and I don't know when it stops ticking."

The above statement clearly reflects the fear and uncertainty about future as experienced by individuals living with a chronic condition.

Awareness and Knowledge of Consequent Side Effects

Sometimes ignorance is a bliss because having knowledge of all possible side effects, tends to make patients anxious and depressed. The idea that a range of physical side effects may happen any time, causes a state of uncertainty, fear and anxiety which is distressing for most individuals.

A participant reported that:

> ‘I never read the side effects given on the leaflet with any medications as I thought it is not worth it, but when I started to experience swelling of gums, bleeding gums, weight gain and hair loss…I then asked my doctor and he told me that this happens sometimes but we have to keep your kidney safe…so you need to accept it’

Another woman reported:

> ‘I wish I never knew the forth coming side effects, but since I am in the habit of inquiring and asking about all possible side effects so this awareness made me so depressed and I am in a constant state of being anxious …. what might come up next…?’

Cost Benefit Analysis in Decision Making

In most cases, Individuals have to manage the condition by accepting the adverse side effects. The patients do indulge into reconceptualization, recalibration and reprioritization of their altered lifestyles and behaviors when they do a cost benefit analysis of the adverse side effects and the maintenance of their kidneys. There are some serious and physically distressing and handicapping side effects such as ‘gout’ which is a common side effect of taking immunosuppressant. A young working woman reported how it affected her routine life:

> ‘I have experienced two severe episodes of gout and it made my routine life and in particular, my work life quite difficult as I was not able to walk properly ….the doctor told me it is a common side effect of the medicine I take to keep my immune system suppressed and discontinuing this medication can cost me my transplanted kidney….I was initially very distressed and even skipped one dose of this immunosuppressant

> medication because the gout was hurting me so badly that for a moment I didn’t care about the consequence…but later I realized after weighing the pros and cons that I have to tolerate this pain to avoid another transplant….no other option…so I surrendered’

It seems that most patients reported a lack of or limited choice in treatment and medication as each drug has its own side effects which makes the process of decision-making quite difficult. In fact, most of the participants expressed that they have no choice but to accept whatever comes in the package to keep their kidneys working.

Doctor-Patient Relationship

Living with a chronic condition involves regular follow-ups, monitoring and interactions with health care team to assess health functioning. The nature of relationship with the physician and paramedics appeared to be of crucial significance to the patients. The way physicians communicate and deal with the patients determines not only their medication adherence but level of distress too. The participants reported that some doctors make things so comfortable and acceptable which relieve them of their apprehensions and stress. On the other hand, some individual dread visiting a doctor expecting some bad news about their health status. This apprehension was revealed when a transplant recipient shared:

> “I am always apprehending that something negative might come up and my doctor would give me some bad news, so I keep delaying my regular examination and visit”.

Acceptance

Since there is no choice but to opt for the limited range of medication options for co-morbid conditions occurring with the passage of time, e.g., gout, cardiovascular and skin disorders, they have to accept the consequences despite their respective negative effects. Acceptance comes as ‘no choice’ phenomenon and leads to depression and anxiety. The responses reflect the feeling of being helpless with no escape from the negative medication side effects.

The patients hope and expect to hear something positive from their physicians but when they fail to do so, the consequences are quite distressing. A male recipient expressed:

> “I have to take these medicines although they damage me in many ways…but the doctors have nothing less damaging to offer…. I can see they feel helpless too but what else can be done?”

Table 1: *Themes Indicating Aspects of Response Shift Depicting Perceived QoL of Renal Patients*

Aspect of Response Shift	Assumption	Theme/s	Example from participant 'responses	Mechanism/s
None	No change	Expectation from treatment	"I will get rid of these medicines and be as normal as I used to be once"	
		Approach-avoidance conflict	"…I have no other option but to continue irrespective of these negative effects…"	
		External locus of control	"…I cannot decide anything about my treatment…"	
Recalibration	change in the patient's internal standards of measurement	Awareness and knowledge of side effects	"I … asked my doctor and he told me that this happens … we have to keep your kidney safe…so you need to accept it"	Reframing expectations Social comparison
		Health beliefs and future concerns	"…I feel so anxious and uncertain about my future…"	
Reprioritization	change in the patient's values	Cost-benefit analysis	"…but later I realized after weighing the pros and cons that I have to tolerate this pain to avoid another transplant"	Coping Goal reordering
Reconceptualization	redefinition of life quality	Acceptance	"I have to take these medicines although they damage me in many ways"	Adherence

Table 1 describes how participants' responses depict different aspects of response shift. In the initial phase, there is no change in response to illness or treatment when the participants have lack of information and consequently unrealistic expectations and feelings that nothing is in their control. They are still gaining knowledge about costs and benefits of their treatment plan. The knowledge and information of side effects and change in their health beliefs and future concerns change their internal standards (recalibration). Reframing expectations and comparing themselves with others are the mechanism through which they see them in a new altered way. Cost-benefit analysis is a way to cope and reorder their goals (reprioritization). Finally, adherence to treatment leads to or is a result of acceptance and redefining quality of life for them (reconceptualization).

Discussion

The increasing rate of patients living with chronic conditions represents many challenges in modern healthcare. Besides clinical parameters to evaluate health outcomes and treatment efficacy, considerable research is devoted to examine psychological impact and social consequences of living with these chronic illnesses. Exploring the experiences, perceptions and coping mechanisms of these individual across diverse cultures is essential to identify barriers in the quality of health care (Tunsi et al., 2023).

Treatment efficacy is assessed by subjective QoL based on individuals' perceptions and satisfaction. This is not only reflective of actual health status but their psychological wellbeing as well. Therefore, it is important to understand the bilateral relationship between patients' symptoms severity, level of the disease and QoL (Shofany, 2017). Qualitative inquiries are required to answer diverse questions, such as: How chronic conditions affect the psychological wellbeing of the patients? Do treatment strategies and medications always alleviate the symptoms of the disease? If not, how do patients cope with the negative consequences of these medications?

The present study revealed some meaningful insights about the experience of living with the chronic renal condition and coping with the physical and psychosocial consequences. On one hand, the participants manifested an attitude of 'Acceptance of the unavoidable' situation/condition, resilience, and gratitude that facilitated their coping but on the other hand, we could also identify some of the psychosocial barriers and reasons for non-adherence, depression and uncertainty about future.

A prominent theme that emerged from self-reports of experiences with health care providers revealed the expectations of quality treatment and a supportive attitude to be provided to the patients by their health care providers. Their experiences, however, were not always positive, consequently affecting their treatment adherence. Such findings are consistent with another study that reported frustration among patients from delays in doctor's response, at the same time participants complains of heavy workload on the staff as a major cause of poor quality services (Kvarnström et al., 2021).

The present study suggests that an open and comfortable communication between the patient and doctor has a positive effect on health outcomes. Similar findings were reported where participants complained of poor communication between the healthcare providers negatively affecting patients' treatment satisfaction and health outcomes (Senitan & Gillespie, 2020).

Medication cost, a lack of awareness and knowledge of medication efficacy and side effects were found to be the main barriers in medication non-adherence (Nielsen et al., 2018). The individual expectations and beliefs tend to play a vital role in determining their acceptance, adjustment and coping with chronic renal condition. However, psychosocial factors and interactions also tend to affect their attitude and behavior (Muscat et al., 2021). The nature of doctor-patient relationship, awareness and knowledge and health beliefs seem to have a direct effect on patient's medication adherence and treatment satisfaction.

Even though some individuals reported severe and handicapping physical side effects of prescribed medication, but their trust and faith in the health provider determined their medication adherence and ultimately treatment satisfaction. Therefore, it is important to address patient beliefs not only about medications but their doctors as well. Counseling and supporting patients in coping with side effects of medications can facilitate an improved physical and psychological wellbeing. Patients must be involved as active participants in treatment decision making (Legido-Quigley et al., 2019).

Advancements in quality of health care is important for improved health outcomes with higher treatment satisfaction globally. A considerable health research suggests that incorporating patients' perceptions of expected quality care is essential to provide comprehensive and patient-centered healthcare. This qualitative study explores the overall process of acceptance, adapting and ultimately coping with a chronic renal condition in a sociocultural context. The psychosocial barriers are identified with a need to provide psychological support to these individuals struggling to improve their psychological wellbeing and overall QoL.

Implications

Future research needs to focus on psychological issues and sociocultural dynamics involving family members in effective counseling for medication adherence, depression and anxiety as a consequence of experiencing adverse medication side effects and financial difficulties. Developing countries with their limited resources need to improve their health care services by investing into updated training of health professionals with a focus on management of psychological aspects. Health care professionals need to consider patients' cultural and social background when providing counselling to vulnerable patients for improved health outcomes.

Conclusion

Identification of the psychosocial consequences of living with a chronic conditions sheds light on how these individuals conceptualize and describe their expectations of health care when describing their experiences.

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