

# Resilience: A Coping Strategy for Physical and Psychological Challenges faced by Chronic Kidney Disease patients

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## ABSTRACT

**Aim:** To explore the lived experiences of patients suffering from chronic kidney disease (CKD) to understand how the physical and psychological challenges associated with the disease influenced their life and what role did resilience play to cope up with the physical and psychological challenges.

**Method:** The present study is qualitative in nature and used the phenomenological research design to study the lived experiences of CKD patients. Thirty seven participants were selected through purposive sampling from the nephrology departments of three government hospitals of Lahore which included Jinnah Hospital, Sheikh Zayed Hospital and General Hospital. Data was collected through in-depth interviews.

**Results:** The study revealed that resilience is a major factor which helps to cope up with the physical and psychological challenges associated with CKD by reducing stress, developing a positive self-image, encouraging to fight back, finding alternative treatment options and increasing the will power of CKD patients.

**Practical implications:** Findings of the present study will be helpful for the health care professionals and clinical psychologists to develop strategies and training programs which can increase resilience among patients. Training the patients and care givers regarding how to fight with CKD will lead to an improvement in their quality of life.

**Conclusion:** Resilience enables CKD patients to have a self-worth and brings them back to life by motivating them to participate in the normal activities of life. On the basis of these results, it is expected that this factor can be helpful for the health care professionals, caregivers and patients themselves in order to minimize the negative impacts of the disease through counseling.

**Keywords:** Chronic kidney disease, Resilience, Physical challenges, Psychological challenges

## INTRODUCTION

Chronic illnesses are defined as the long-term health disorders that interfere with the social interaction and role performance of its sufferers<sup>1</sup>. According to the concepts of medical sociology, chronic illness creates disability which is defined as lack of physical functioning by some, and as social discrimination by others<sup>2</sup> that highly impacts the quality of life (QOL) of individuals.

Likewise, chronic kidney disease (CKD) is a global health issue imposing high financial costs to the entire health system on one hand and influencing the QOL of patients on the other. CKD is also known as the independent cause of cardiovascular diseases in many cases<sup>3</sup>. It was recognized as the 27<sup>th</sup> major cause of death in 1990 which rose to 18<sup>th</sup> major cause of death in 2010 globally<sup>4</sup>. In year 2013, the deaths due to CKD related cause reached to approximately 1 million. However, in 2015 around 109.9 million people from high-income countries and 387.5 million in lower-middle income countries were reported to have chronic kidney disease<sup>4</sup>.

The global prevalence of CKD was reported to be 11 to 13% in the year 2016 with majority of the cases at the third stage of disease<sup>5</sup>. According to Bikbov (2020), the global prevalence of CKD in 2017 was 9.1% with 1.2 million deaths<sup>6</sup>. CKD greatly influences the (QOL) of individuals. Within the arena of health care, QOL is viewed as a multidimensional concept, encompassing emotional, physical, material, and social well-being<sup>7</sup>. It is not only restricted to the physical health condition of an individual, but rather includes the ability to participate in and enjoy the social activities of life.

QOL is determined by the experiences of life and the living conditions in which individuals find their own selves. Literature shows that CKD patients experience a decrease in their QOL at all stages of disease<sup>7</sup>. This decrease is due to reduced physical functioning and role functioning. Additionally, many physical and psychological challenges are faced by the patients such as anxiety, depression, trauma, negative self-perceptions, loss of social life, dependence on others and stigmatization<sup>8</sup>.

People suffering from CKD experience a compromised and impaired QOL when compared to the general population. CKD has major impacts on the biological (physical), and psychological domains of an individual's QOL that further impact the overall life of the sufferer. The physical impairments associated with CKD include fatigue, poor sleep, lack of mobility, low energy levels, infertility, weight gain, skin problems, lack of ability to work and neuromuscular problems. The physical changes occurred due to the disease undermine the self-esteem and confidence of individuals that lead to compromised intimacy and changes in perceptions of roles within the relationships that also lead to difficulty in developing new relationships<sup>9</sup>. On the other hand, the psychological challenges faced by patients include depression, stress, negative self-perceptions, fears and trauma leading towards lack of ability to cope with the disease<sup>10</sup>.

In order to cope up in such scenarios, people need to be resistant and fight back. Resilience can be defined as the ability to overcome the stressful circumstances by positive thinking and using problem solving techniques to adapt the altered condition<sup>11</sup>. Literature highlights that resilience is a major predicting factor in improving QOL of individuals suffering not only from CKD<sup>12-13</sup> but also from other chronic illness including bipolar disorder, breast cancer, and diabetes<sup>14-15-16</sup>.

Resilience could be further categorized into physical, mental, emotional and social resilience. Physical resilience is our body's capacity to meet physical challenges such as sickness or accidents, to heal or manage ongoing physical health conditions. Mental resilience is the capability of an individual to face challenging situations confidently through problem solving and finding alternatives. However, emotional resilience is how an individual manages his/her emotional responses to challenges and deal with their feelings and negative emotions such as anger, fear, vulnerability and sadness. Individuals who have the emotional strength to manage themselves through hardships can minimize the impact of the adverse situations on both their selves and others<sup>11</sup>.

On one hand, where resilience predicts better QOL, on the other hand, lack of resilience contributes in elevating the stress levels among patients of CKD that further contribute in reducing QOL among individuals<sup>12</sup>. Although it is well-documented that CKD

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patients suffer an impaired QOL, there is limited research focusing on role of resilience in improving the physical and psychological conditions of patients suffering from CKD in Asian populations <sup>9</sup>. Therefore, the present study has been designed and aims to explore the lived experiences of patients suffering from CKD to understand how the physical and psychological challenges associated with the disease influenced their life. And what role did resilience play to cope up with the physical and psychological challenges.

**METHODOLOGY**

**Research Design:** The present study uses the phenomenological research design to explore the lived experiences of patients, suffering from CKD, regarding the role of resilience to cope up with the physical and psychological conditions associated with CKD.

**Research site and Sampling:** The present study was conducted in three major government hospitals of Lahore that includes Jinnah Hospital, General hospital and Sheikh Zayed Hospital. The population of the present study comprised of adults suffering from CKD. Thirty seven participants were recruited from the nephrology departments of the mentioned hospitals using a pre-defined inclusion and exclusion criterion through purposive sampling.

**Inclusion Criterion**

- Clinically diagnosed for chronic kidney disease
- Registered themselves at hospitals for the treatment of chronic kidney disease.
- Patients above 18 years of age
- Informed Consent

**Exclusion Criterion:** Having any history of psychiatric problems (depression, anxiety, and psychiatric disorders before the diagnosis of CKD

**Data Collection Methods:** In-depth interviews were conducted to collect data from the participants using a structured interview guide developed based on the deductive codes identified from the literature. However, the interview guide was modified as per the new concepts and inductive codes emerged during the interviews. Interviews were conducted at the places convenient for the participants. Average time for each interview was sixty to ninety minutes.

**Transcribing and Analyzing Data:** The interviews were conducted in Urdu language and were then transcribed and translated into English language for analysis using Express Scribe Software. Data was analyzed through thematic technique. Major concepts highlighted by the participants in the data collected through interviews were identified. These concepts were categorized into codes. A code book was prepared which guided the coding of the entire data that were further arranged into major themes.

**Ethical Consideration:** Present study is a part of a broader study conducted for Ph.D Thesis, approved by Institutional Ethical Review Board of University of the Punjab (Letter No. D/5159/ACAD).

**RESULTS**

Five major themes that emerged during the data analysis include Physical challenges associated with CKD, Psychological challenges associated with CKD, Meaning of resilience, Role of resilience in improving the physical conditions of CKD patients, Role of resilience in improving the psychological conditions of CKD patients. Themes with their major emergent codes are illustrated in Table 1.

**Physical challenges associated with CKD:** Majority of the participants discussed that they used to have body aches, loss of appetite, unhealthy weight loss, lethargy, immobility, loss of energy, bad smell in breath and water retention. While talking about the physical challenges faced by participants due to CKD, one of the participants narrated: *“I feel severe pain in my kidneys and due to this pain I am unable to even walk until the pain gets*

*settled. Painkillers have to be taken under the prescription of the doctor only as they are not good for the kidney”.*

In addition, some of the participants highlighted that they often get blood in the urine and sometimes their urine gets blocked due to blood clots in the urinary track. One of the participants said: *“I get a bright red splash of blood in my urine and it was not one time, but rather it happens on a regular interval of few days or sometimes weeks. My doctor prescribed me blood clotting medicines after which I started getting huge clots in my urine that eventually resulted in urine blockage”.* The participant further added: *“I have to rush to the hospital emergencies at unexpected times to treat my urine blockage: Another participant stated that: “my kidneys were weak since childhood and my body used to retain water as I didn’t used feel like going to the washroom for long hours”.*

Some of the participants mentioned that they had to entirely change their eating habits and restrict their diets to certain food items which were suitable for kidney functioning. One of the participants stated: *“I am foodie but due to this disease I am not allowed to eat high protein, fatty and oily food items. My diet has shifted to oil free vegetables and fruits”.* Another participant stated: *“I cannot eat spicy food as it causes itching in my body immediately. This never happened to me before this disease”.*

Table 1: Themes with Major emergent codes

Themes	Major codes	Title of codes
Physical challenges associated with CKD	Loss of energy Bleeding Body aches Loss of appetite	Deductive Inductive Deductive Inductive
Psychological challenges associated with CKD	Anxiety Depression Loss of sleep Negative self-image	Deductive Deductive Inductive Inductive
What is meant by resilience	The ability to fight back The ability to accept my condition Looking for alternative solutions	Deductive Deductive Inductive
Role of resilience in improving the physical conditions of CKD patients	Helped to find better treatment options Herbal treatment Strong will power Increased responsiveness towards treatment Encourages to find ways to deal with physical impairment	Inductive Inductive Inductive Inductive inductive
Role of resilience in improving the psychological conditions of CKD patients	Reduces stress and depression Developed a positive self-image and self-worth Increased confidence in capabilities	Inductive Inductive Inductive

**Psychological challenges associated with CKD:** Anxiety, depression, negative self-image and sleepless nights were the major psychological challenges associated with CKD. One participant mentioned: *“I watch myself in the mirror for hours continuously and cry because of my physical condition”.* Another participant stated: *“I started thinking that this disease is maybe a punishment given to me. I may have done something bad in life due to which I am in such condition”.* Another participant said, *“I used to roam around alone in house all night as I was unable to sleep due to constant stress in my mind”.*

**Defining resilience:** During the interviews participants highlighted their interpretation of resilience and what resilience means for them. Almost all of the participants defined resilience as their ability to accept their situation, adapt to the circumstances and fight back. They explained that it was definitely a shock for them initially when they were diagnosed with CKD. However, gradually they were able to adapt to the circumstances. One of the female participants stated: *“I am a resilient person by nature. And maybe that kept me going through this entire phase”.* She further added: *“it was definitely difficult to accept my condition at first. I used cry for hours. It took time and slowly I managed to gather myself and*

accept the state I am in". Another participant said: "I went in trauma and denial. I thought my life has ended. But then I realized that I can either let my mind get strangled by these things or I can try my best to find solutions to my problem". One of the participants narrated: "I have always had a tough life and when I was diagnosed with this disease, it was definitely a shock for me but since, I have always faced crunches in life I never lose my senses. I have prepared my mind to deal with it and get stared with the treatment".

Few participants discussed that resilience for them was not "accepting themselves". They mentioned that resilience for them was the feeling of fighting back and not losing hope that they will get back to normal one day. A participant narrated: "whenever I see myself in pain I tell my heart that I will not let this overcome my personality and I will fight back and make myself feel normal by responding well to the treatment".

**Role of resilience in dealing with the physical challenges:** An overwhelming majority of the participants highlighted that being resilient helped them deal with the physical challenges associated with CKD. They discussed that being resilient in the face of adverse circumstances encouraged them to find solutions for their physical conditions in terms of alternative treatments. One of the participants narrated: "This is my resilient behavior that made me discover the treatment of embolization to cure the bleeding caused due to CKD". One more participant stated: "I have found different herbal treatments for my disease and they have helped me a lot".

Along with this, instead of isolating themselves, participants mentioned that they started looking for ways to overcome their physical impairments to become able to participate in the normal activities of life. One of the participants stated: "Life is limited so I try to enjoy it as much as my health allows me. I try to participate in normal activities of life and this has brought me out of depression". She further added: "I definitely take my medicines and treatment regularly but I have not delayed the activities of my life for that one day when I will be cured but now I have adapted to the circumstances". Another participant said: "I bleed of and on due to which I used to have mobility issues. Earlier I used to get depressed but now my parents have arranged a separate car and driver for me so that travel comfortably.

It was highlighted by some of the participants that hope also plays a role in making individuals more resilient and helps them to fight for themselves. One of the participants who had survived an unsuccessful kidney transplant surgery narrated: "I hardly survived the surgery but I never lost hope to recover. That is why I kept on looking for another donor for myself and I am still looking for that".

**Role of resilience in dealing with the psychological challenges:** During the interviews, participants explained how resilience helped to face and cope up with the psychological challenges associated with CKD. The most important impact of resilience was on the psychological conditions of the patients. Accepting their physical condition helped to reduce stress and cope up with the depression. One of the participants stated: "I feel lighter since I have accepted myself despite my physical condition". Another participant mentioned: "Rather than leaving myself in depression I started to look for doctors and treatment options for my disease which was beneficial for me".

One of the most important findings highlighted by individuals during the interviews was that being resilient not only helped them to reduce their stress but it also led to the development of a positive self-image for majority of the participants. They developed confidence that they are still capable of doing many things and are as normal as other members of the society. One of the female participant narrated: "I dealt with my stress by telling myself continuously that I am capable to do many things like others". She further added: "this feeling gave me the courage to get up and act normal and strive for myself". A married male participant stated: "when I saw my children I understood that I have no time to loose hope. I have to get better for them as they need me. So I started looking for solutions".

## DISCUSSION

Findings of the current study revealed that resilience played a vital role in improving the QOL of individuals suffering from CKD in terms of better physical and psychological conditions. Resilience was defined by patients as their ability to accept their situation, adapt to the circumstances and fight back. Being able to accept their condition and adapt to it helped individuals cope up with the trauma and denial associated with the disease. It helped them to develop a positive self-image and self-worth by having a feeling that they are still "capable" of doing many things. The negative health experiences associated with the disease led to depression and a feeling of being useless among patients which was reduced because of high levels of resilience.

Resilience helped them to develop the feeling that they are normal and worthy people of society like others and they have an equal to lead a normal life, participate in leisure activities and have a social life. These findings are congruent with the previous studies which show that resilience acts a source to fight with the psychological distress associated with disease. Also, it increases the life satisfaction among individuals and improves their quality of life. It has a stress buffering effect on individuals suffering from chronic diseases<sup>17-18</sup>.

Studies in the literature suggest that patients with high levels of resilience are more likely to have less depressive symptoms and resilience also reduces the severity of depression among individuals suffering from chronic illnesses. Individuals having high levels of resilience are able to adapt to the situation and cope up with the stress<sup>19</sup>. Therefore, resilience is important during the recovery phase of patients suffering from chronic diseases. Resilience interventions should be developed for patients as it may help in reducing their stress and improve their psychological condition hence improving quality of life<sup>20</sup>.

Psychiatric disease such as depression and anxiety are highly prevalent in patients suffering from chronic diseases. Resilience acts as a protective shield against such psychiatric conditions<sup>21</sup>. Patients who have gone through kidney/renal disease or replacement are unable to participate in their daily routine activities due to the comprised health conditions associated with kidney disease. Such inability to participate in routine activities makes individuals feel that they have lost their freedom which leads towards a negative self-image and low self-esteem<sup>22</sup>. Resilience helps individual to cope up with such negative psychological conditions and stress before and treatment which make them more responsive towards the treatment.

Another study in the literature found an inverse relationship between the resilience scores and anxiety and depression scores, which suggests that high resilience scores may protect against the development of psychiatric diseases, of which there is high prevalence in chronic conditions<sup>23</sup>. The present study extended the findings of previous studies which suggest that resilience is a source of developing feelings of control and capability among individuals suffering from chronic diseases. The individuals started feeling that the disease is curable and nothing out of control.

Furthermore, an individual develops a feeling that he/she is capable to find ways such as a therapeutic diet or medicines to cope up with the disease. Resilience makes individuals more adaptive towards changes by leading them towards a healthier way of life which eventually decreases the pressure caused by the disease<sup>24</sup>. Along with this, resilience allows individuals to address their physical health in an appropriate manner and to maintain a relatively good whole health state, resulting in a better health related quality of life<sup>25</sup>.

## CONCLUSION

This study concluded that resilience plays a major role in coping up and improving the physical and psychological conditions of CKD patients. It enables them to have a self-worth and brings them back to life by motivating them to participate in the normal activities

of life. On the basis of these results, it is expected that this factor can be helpful for the health care professionals, caregivers and patients themselves in order to deal with the impacts of the disease.

**Conflict of interest:** Nil

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