

Perception of Psychological Distress and Support Among Patients with Chronic Kidney Disease (CKD) in Khulna City Corporation

SM Shamima Rahman, Ety Rani



Abstract: *Chronic Kidney Disease (CKD) is a significant global concern. This qualitative research study aims to explore the relationship between the perception of psychological distress and support for people living with CKD. The study employed a qualitative research design. The in-depth interview method has been used to collect data. The Shaheed Sheikh Abu Naser Specialized Hospital in Khulna City Corporation was purposively selected as the study area. A semi-structured interview schedule was used for collecting data from a purposively selected sample of 16 patients. The fieldwork duration was from October 5, 2023, to November 5, 2023. The study reveals that a majority of the participants were in the fourth or fifth stages of CKD. In the first or second stages, they received sufficient support from family, relatives, and neighbours. However, when they reached the 4th or 5th stages of CKD, they seemed to be a burden for their family. They were not financially stable to continue their dialysis, since they could not do any income-generating activities due to their illness. Additionally, they did not receive any financial assistance from relatives or organizations. They passed their life in a hard way. Since most of the participants were in the last stage of CKD, and could not get sufficient support, they suffered seriously from depression, anxiety and mental stress. By advancing knowledge of the relationship between support and psychological distress in this setting, the research will help develop targeted strategies to enhance the overall well-being of CKD patients and their support networks, thereby mitigating their psychological distress.*

Keywords: *Chronic Kidney Disease, Support, Psychological Distress.*

Nomenclature:

CKD: Chronic Kidney Disease

IDI: In-Depth Interview

I. INTRODUCTION

Kidney disease is becoming more common in Bangladesh at an alarming rate. Malnutrition and the prevalence of these diseases are directly correlated. The study involved recruiting 120 hemodialysis patients in Khulna, Bangladesh, who were of both sexes and had an average age of 45 ± 13.79 years [1]. Low social support satisfaction was revealed to be a major

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predictor of psychological distress in CKD patients. Bangladeshis had a higher overall prevalence of chronic kidney disease (22.48%) compared to people worldwide [2].

CKD has been recognized as a global public health burden due to its increasing incidence and mortality [3]. A recent thorough investigation found that the pooled prevalence of chronic kidney disease (CKD) in Bangladeshi adults is 17.3%, with a range of 12.8% to 26.0% [4].

Due to a lack of proper infrastructure and resources for CKD management, patients in Bangladesh encounter several physical, psychological, and social difficulties [5]. Almost 38% of CKD participants experienced moderate-to-severe depressive symptoms, and approximately 27% expressed moderate-to-severe anxiety [6]. Cross-sectional studies conducted regionally support these high numbers: research published in Scientific Reports in a nephrology clinic found that 58% of participating CKD patients had depression and 50% had anxiety [7]. Frequent dialysis and dietary restrictions are examples of treatment demands that perpetuate a sense of helplessness and dependence. Socially, patients frequently endure decreased social interactions, role shifts, and job withdrawal, all of which exacerbate feelings of powerlessness. Because dialysis and medicines are costly and require out-of-pocket payments, financial pressure is a major cause of grief in Bangladesh [8]. Patients exhibit higher levels of resilience and self-efficacy when they think that therapy and self-management (diet, medicine, and dialysis adherence) can significantly slow the progression of their illness [9].

Mental health issues are associated with psychological suffering. It might manifest in a variety of ways, such as anxiety, sadness, and other mental illnesses [10]. Chronic economic stress is created when families are forced to sell possessions, take out loans, or forgo therapy due to this financial toxicity. Research demonstrates that this kind of financial burden considerably exacerbates psychological suffering, including sadness, anxiety, and hopelessness [11]. CKD patients' perceptions of psychological anguish differ greatly depending on the stage of the disease and the type of treatment. While dialysis patients report stress from machine reliance, lifestyle constraints, and frequent hospital visits, pre-dialysis patients frequently worry about the course of their condition and the future of their therapy. In contrast, concerns such as graft rejection, returning to work, and reintegrating into everyday life are common for post-transplant patients [12].

The researchers identified a few gaps in the literature by reviewing the available information. Most research has been conducted in wealthier countries. The district of Khulna conducted

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no significant research on this subject. Furthermore, the scarcity of research on qualitative approaches in this field of study suggests a methodological gap. The goal of this study is to find out the connection between psychological distress and support among CKD patients in Bangladesh. The findings of the present study can contribute to achieving SDG 3 by improving the mental health and support of CKD patients.

II. METHODS

This study was descriptive. This study employed a qualitative research approach. The study area was Shaheed Sheikh Abu Naser Specialized Hospital in Khulna City Corporation, Bangladesh. This hospital is most familiar in Khulna city. Every year, many CKD patients are admitted to this hospital. For this reason, the researchers have chosen this hospital as the site for their study. The In-Depth Interview (IDI) method was applied in this study. Data were collected from 16 CKD patients using purposive sampling and informed consent. The participants were selected from CKD patients who received treatment at Shaheed Sheikh Abu Naser Specialised Hospital in Khulna City Corporation. A semi-structured interview schedule was developed to collect data by reviewing several literature sources. The data collected included respondents' socio-demographic information and their perceptions of psychological distress and support. Data were collected from October 5 to November 5, 2023, through face-to-face interactions with participants. All interviews were audio-recorded. Data were collected in the Bengali language and subsequently translated into English. After completing the fieldwork, the raw information was reviewed and processed to remove ambiguities. Using the thematic analysis model, data were manually analysed.

III. RESULTS

In the present study, the participants' ages ranged from 16 to 55 years. Half of the respondents were male, and half were female. Except for one, all of the respondents were married. Approximately 56 per cent ($n = 9$) of the participants' monthly family income exceeded 30,000 takas, while another 44 per cent ($n = 7$) of the respondents' monthly family income was less than 30,000 takas. A majority of the CKD patients' duration of disease was from 3 to 5 years, and they were in the 4th or 5th stage of kidney disease. Almost 69 percent ($n = 11$) of the CKD patients were undergoing dialysis.

A. Theme 1: Perception regarding support among CKD patients

This theme consists of five categories. There is support from family members, friends, neighbours, relatives, healthcare providers, cultural and religious organisations, and financial institutions.

i. Family Members

People with CKD's experiences, general health, and coping mechanisms are greatly influenced by their family dynamics. According to the majority of participants, their families provide them with strong support by demonstrating empathy, understanding, and compassion for these CKD patients who

may be experiencing psychological repercussions from their condition. Additionally, they stated that the general well-being of CKD patients is greatly enhanced by family members' practical support, including assistance with everyday chores, transportation to doctors' appointments, and medication management. According to an IDI participant, *"My family helps me with everyday work, and they provide my treatment expenses. They stand beside me when I feel so vulnerable, providing emotional support. They helped me by spending money on my treatment and coming to the hospital with me."*

-Participant 1, female, 16 years old

However, several participants (e.g., 4, 8, 9, 15) contended that they are subjected to family pressure rather than receiving enough family support. All of the responders, however, primarily emphasised that their family support had changed since the onset of their illness. Another IDI participant stated that:

"At the beginning of CKD, everybody stood beside me. Sometimes, I feel so bad thinking that I am pressuring my family. My family members are suffering for me, but I cannot live well. It gives me mental stress. In my 3rd stage of disease, everybody took care of me. After several years, it is my 5th stage of CKD. I found that my family members have changed."

- Participant 15, male, 55 years old

ii. Friends, Neighbours, and Relatives

The majority of participants ($n = 9$) reported receiving a special kind of emotional support from their network of friends. Friends understood the challenges the condition presented. They offered understanding, solidarity, and support. According to one of the participants,

"I spend most of the day with my friends. Some of my friends are well-employed, and when I face any crisis, such as needing financial help, they are always ready to assist me as much as possible. I feel so lucky to have them by my side. My neighbours are also helpful."

- Participant 10, female, 34 years old

However, another participant expressed a different opinion. He added that support from friendship and social networks does not always come. He argued,

"They have moved away from me. Nobody comes. Nobody wants to stand beside a CKD patient. Our friends and neighbours came once, but not for a long time. They do not come because they do not want to help me financially. It seems a harsh reality for me to cope with emotionally. My friends rarely call me, and sometimes I feel I am unknown to my relatives (He said, with a crying voice)."

- Participant 3, male, 53 years old

iii. Healthcare Provider's Support

When it comes to educating CKD patients about their condition, its course, and available treatments, healthcare professionals play a critical role. The majority of participants expressed dissatisfaction with the support they received from healthcare practitioners.



According to one of the participants, “*Doctors only prescribe medicine and suggest continuing dialysis according to the levels of our disease and illness. However, they barely give attention to our psychological well-being. Even though they do not talk to me positively, I can mitigate my anxiety.*”

-Participant 7, female, 27 years old

Another participant speaks out that-

“*The nurses often come to know my physical condition; doctors do not come until the patient is in a serious condition. As we undergo dialysis, we expect their good wishes for our well-being. Nevertheless, they do not do that. Nurses only ask about our physical problems. The doctors do not stay during dialysis time. They only come at their rounding times.*”

-Participant 10, female, 34 years old

iv. Cultural and Religious Support

This qualitative result revealed the patients' comprehensive level of religious and cultural support. Eleven participants in this study concentrated on cultural communities, which frequently exhibit a strong sense of solidarity and family. These communities may share similar views on health and illness, fostering a supportive environment for individuals with chronic kidney disease. According to one of the participants,

“*My neighbours sometimes come to visit my home to see me. They provide a good understanding of my condition and recommend that I keep faith in Allah. It helps me to mitigate my mental stress.*”

-Participant 5, female, 50 years old

In the same way, another participant stated that-

“*In our dialysis patient community, we maintain a cordial relationship and understanding among us. We support each other mentally and emotionally, which also strengthens us in times of severe conditions. I find emotional support and serenity in religious activities like prayer and meditation.*”

-Participant 14, female, 40 years old

v. Financial Aid

Individuals with chronic illnesses or renal disease may be eligible for financial assistance or other forms of support from nonprofit organisations. According to four participants, they have previously received financial assistance from charitable organizations in small amounts. Others, on the other hand, rely on their relatives, friends, and neighbours. In many instances, this financial assistance is short-lived. One of the participants stated that—

“*My husband is the only earning member of our family. He has a small salary, which he uses to cover our household expenses and my medical costs. Nevertheless, he cannot cope with this financial cost. Sometimes, he used to lend money. We applied for financial charity several times, but their assurances did not work. (In a crying voice, she said).*”

-Participant 12, female, 31 years old

The results of this study demonstrated that financial challenges significantly affected the psychosocial well-being of patients with CKD. The patient's health may eventually deteriorate as a result of these challenges, which can lead to stress, anxiety, and depression. Patients had to pay for a significant portion of the treatment, which made them feel vulnerable financially while undergoing treatment. They have no other way to get out of this financial strain.

Another participant disclosed that-

“*I had two small pieces of homeland and cultivated land. When I started dialysis, I had to sell these lands to bear my dialysis expenses. At present, no land is left. I am scared of bearing this treatment cost*”

-Participant 2, male, 39 years old

B. Theme 2: Psychological distress among CKD patients in Khulna City Corporation

The psychological anguish experienced by CKD patients in Khulna City Corporation was investigated in this qualitative study. Participants (N=16) discussed their psychological distress situation. This topic includes three categories—emotional distress, social isolation, uncertainty, and fear—that are associated with how CKD patients perceive support.

i. Emotional Distress

Every participant in this study (N=16) concentrated on worries regarding the results of dialysis or kidney transplants as well as their necessity, both of which might cause elevated stress and anxiety. One of the participants stated that—
“*My batchmates are attending school, but I cannot. Sometimes, I see them going to school-by-school bus, and at the same time I go to the hospital by bus for dialysis. This makes me sink into depression and anxiety, that life changes (She said, taking a deep breath).*”

-Participant 1, female, 16 years old

Some of the respondents also spoke out that they had certain types of stress, anxiety, and depression due to financial barriers. A respondent said that-

“*Who will bear the extra cost of treatment? I am a car driver. I am unable to perform my job adequately daily. Yesterday, I earned only 300 takas by driving the car. Today, I came with three hundred takas for my dialysis. It gives me more depression, anxiety, and stress.*”

-Participant 4, male, 38 years old

ii. Social Isolation

This study demonstrates how misconceptions about CKD, its causes, and its consequences on individuals can lead to social isolation and stigma for patients. Discrimination, negative views, and misconceptions are sometimes associated with stigma, which can lead to feelings of embarrassment or loneliness. Out of all the participants, twelve reported that their impairment occasionally made them feel alone. Among the participants, one revealed that—
“*Sometimes I feel so lonely. My wife tries to spend time with me, but most of the time, I stay away from other family members. I cannot walk properly. That is why I cannot go outside.*”

-Participant 6, male, 39 years old

iii. Uncertainty and Fear

These results demonstrated that each person's CKD course can differ significantly. While kidney function may decline more rapidly for some individuals, it may decrease more gradually for others. This uncertainty about the future might lead to anxiety and panic. Several participants displayed a sense of dread and uncertainty.

One of the participants said that- “*Sometimes I had bad dreams related to death in*



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the middle of the night. I felt so afraid at that moment."

-Participant 1, female, 16 years old

Similarly, another participant stated,

"I sometimes feel anxious. Tensions arise, such as when I occasionally fall ill. At the early stage of this illness, I could not accept my disease. I know I will never be cured, and my dialysis will go through a running process (She said, taking a deep breath)."

-Participant 16, male, 45 years old

iv. Coping Strategy with this Disease

In this study, most participants coped with these situations in various ways. Following a diet was one of them. One respondent stated that-

"I maintain my dietary restrictions. I control my intake of sodium, potassium, phosphorus, and protein. This helps me to keep myself aware and better."

-Participant 14, female, 40 years old

They took several ways to reduce their depression, anxiety, and mental stress, such as saying a prayer, watching TV, using the internet, hanging out, and so on. A participant noted that-

"When I go outside, it refreshes my mind. If I stay alone at home, it creates anxiety. If I always stay worried, I will become ill, and this will affect my mental state. I try to keep myself busy doing my hobbies, which keeps my mind sound. When I feel light and fresh, I sometimes cook. I go outside. I host my friends and neighbours when they come to visit me. There are several ways to stay entertained, such as using the internet, watching web series, and going for a walk outside. It keeps both our mind and body healthy. To me, if the mind is good, the body is also good"

-Participant 11, male, 30 years old

IV. DISCUSSION

Nowadays, CKD is a global health concern. Understanding the psychosocial elements of CKD is essential for comprehensive treatment. This qualitative study investigated psychological distress and support among CKD patients in Khulna City Corporation, Bangladesh. People with chronic illnesses have a higher quality of life when they have family support [13]. In the present study, familial emotional support has played a significant role in mitigating the stress and adapting to this critical situation, which is consistent with research that highlights the beneficial effects of social support on coping with chronic disease [14]. The present study shows how crucial family support is in lowering mental stress, anxiety, and depression in Khulna CKD patients. The family is now regarded as the cornerstone of mental health since it provides empathy and understanding as well as motivation throughout difficult times. An unexpected but crucial finding of the current study was that stress had a pervasive negative impact on the psychological well-being of CKD patients in Khulna, according to the participants. The financial burden of CKD, which includes the cost of prescription medications, frequent medical visits, and the potential for income loss due to diminished job capacity, was identified as a primary source of sadness. Furthermore, in the present study, several participants expressed concerns about their ability to cover

necessary medical care and manage ongoing costs, which is similar to another study in which the researcher found that CKD is one of the most expensive conditions in Bangladesh's healthcare system, as dialysis is mainly paid out of pocket. With transportation and medicine excluded, dialysis sessions cost between 3,000 and 5,000 BDT, and most patients need two or three sessions per week [15]. Another study revealed a positive correlation between social support and self-esteem, which was consistent with the present study [16]. The findings of the present study revealed that when healthcare providers provide social support, self-esteem among CKD patients increases. Similarly, another study also shows that social support from healthcare providers can play a significant role in enhancing the self-esteem of CKD patients [17]. As a coping mechanism, patients with CKD in this study watched television, performed prayer, or spent time with family members.

V. CONCLUSIONS

In this study, CKD patients who have adequate support from their friends, family, and healthcare providers improved their mental health and experienced less psychological suffering. Conversely, those with chronic kidney disease (CKD) who receive little to no support are more likely to experience mental health issues such as anxiety and sadness. Therefore, healthcare providers should prioritize social support for patients with CKD as part of their overall treatment plan. For patients and their caregivers, interventions such as counselling, support groups, and educational initiatives may be helpful. To completely comprehend the reasons behind the intricate interaction between CKD patients' psychological suffering and their support pattern, more research is necessary. Nonetheless, the available evidence underscores the importance of social support as a vital component of comprehensive care for patients with chronic kidney disease (CKD), which can enhance their quality of life and overall health outcomes.

DECLARATION STATEMENT

After aggregating input from all authors, I must verify the accuracy of the following information as the article's author.

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- Funding Support:** This article has not been funded by any organizations or agencies. This independence ensures that the research is conducted objectively and without external influence.
- Ethical Approval and Consent to Participate:** Yes, securing ethical approval and consent from all participating individuals is essential. Researchers have obtained informed consent from all participants for data collection. Additionally, the highest level of confidentiality for the information has been maintained. Anonymity (pseudonymity) has been used to avoid disclosing participants' identities.



- Data Access Statement and Material Availability:** The adequate resources of this article are publicly accessible.
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