

## EXPERIENCES OF PARENTS HAVING CHILDREN WITH CHRONIC KIDNEY DISEASES: A QUALITATIVE STUDY IN PESHAWAR, KHYBER PAKHTUNKHWA

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### ABSTRACT

Chronic Kidney Disease is main problem of concern worldwide. Millions of children are affected with Chronic Kidney Disease every year. The disease not only affects the health of the children but it is also associated with a variety of complications among the parents. Parents of children with chronic kidney disease experience social, psychological and mental health issues. To explore the experiences of parents having children with chronic kidney diseases. A qualitative study was carried out in Institute of Kidney diseases Peshawar to highlight the experiences of parents of children with chronic kidney diseases. Data were collected from overall 13 participants using semi structure guide. All required approvals from university, hospital and consents were granted from the participants before collection of the data. A total of 13 participants were included in the study. Overall, 98 open codes were identified in the study. After axial coding and thematic analysis, a total of 16 categories were contributed to four themes such as Care Burden, Intense Grief, Psychological Distress and Adaptation Barriers. The findings of the study concluded that the parents of children with Chronic Kidney Diseases experience in mental health issues. The parents bear excessive care burden and facing difficulties in coping with the problems.

**Keywords:** Experiences, Parents, Child, Chronic Kidney Diseases

### INTRODUCTION

Chronic Kidney Disease (CKD) also known as chronic kidney failure, CKD is a condition in which the kidneys are unable to excrete blood waste products or extra fluids from the blood (Perico & Remuzzi, 2012; Romagnani et al., 2019). CKD is considered the main problem of concern for many diseases and Globally, CKD is considered the 12<sup>th</sup> leading cause of death. Worldwide, approximately 697.5 million cases reported with the prevalence of 9.1% (Ellen F, 2020). In 2017, CKD contribute to 1.2 million deaths. In addition, CKD contributes to 35.8 million disabilities, 7.6% (1.4 Million) cardiovascular deaths (Carney, 2020). The

prevalence of CKD is not only high in the adult population but also impacts the pediatric population badly. Worldwide, the prevalence of CKD among the children population is approximately 18.5-58.3 per million children. Similarly, the mortality rate is 30 time high in pediatric population from CKD compared to the adult population (Craven et al., 2017).

The most common treatment modality of CKD among pediatricians is hemodialysis. Hemodialysis is a complex and multidisciplinary treatment. Hemodialysis is usually performed twice a week and one session takes four to five hours. In addition to the

hemodialysis, the patient needs nutritional supplements, blood transfusion. The arteriovenous fistula (AVF) needs extra care at the hospital as well as in the home (Rushing, 2016; Thorsteinsdottir et al., 2017). The disease itself and the treatment may also carry a variety of complications in children. The common complications of CKD and hemodialysis are hyperkalemia, hypertension, anemia, proteinuria, acidosis, metabolic bone diseases, growth failure, cognitive impairment, infections, arteriovenous fistula malfunctioning, and bleeding (Rushing, 2016).

The curable rate of CKD among the pediatric population is also very low. The children and their families experience a very tough time facing the disease complications and treatment. Usually, the disease goes through a longtime treatment such as dialysis or another treatment option of kidney transplantation. Both the treatment options have severe complications such as infection, and other associated complications which prolonged hospital stay (Wong et al., 2016).

The severity of complications, co-morbidities, and life expectancy depends on the treatment provided to the children. The care to the children with CKD is not only provided in the health care setup but these children are equal treatment in homes. The role of caregivers is very important to provide good and standard care to these children. Effectively management of children with CKD not only overcomes the symptomatic burden of disease but also prolongs the life expectancy of patients (Caskey & Morton, 2017; Levy Erez et al., 2016).

The children are always dependent on their parents. The parents are involved in the direct and indirect care of the children. The mothers are usually involved in direct care such as hygiene care, medication, feeding, care of fistula, and symptomatic care. The fathers are usually involved in indirect care such as financial support and hospital care (Khorsandi et al., 2020; Tong et al., 2017). Children with CKD undergo through prolong treatment. Most of the care is provided in the home. In the hospital setting only symptomatic and hemodialysis are performed (Darwish et al., 2020).

The prolonged treatment, variety of complications, dependability of the children and increase care burden not only impact the parents physically but also impact the parents psychologically (Shroff et al.,

2011; Wong et al., 2016). Dealing with these entire complications and problems, the parents of the child adopt the extra role of health care professionals (Bignall & Goldstein, 2015; Geense et al., 2017). Studies reported that parents of children with CKD experience poor quality of life. Being a central role, the parents impact their health by providing different interventions at home, dealing with frequent dialysis, prolonged medication, and delivering nutrition supplements. Also, the parents of children with CKD reported poor QOL (Gayomali et al., 2008; McKenna et al., 2006). Besides, the parents of a child with CKD also experience mental health issues. The literature highlighted the experiences of parents and revealed that the parents of children with CKD experience stress, fatigue, disrupted peer relationships, bonding, financial issues, restriction in daily life activities, and difficulty fulfilling daily life activities (Aier et al., 2022). The basic purpose of the study is to explore the experiences of parents who have children with CKD. This study may have a variety of implications on the community level and health sector. The findings of the study will explore the experiences of parents which affects their life through different perspectives. The study will help in developing policies and guidelines which will help facilitate the parents of children with CKD.

## **METHODOLOGY**

A Phenomenological Qualitative research study design was carried out in the Institute of Kidney Diseases (IKD) Hayatabad, Peshawar. The study was complete within six months after initial approval from Advance Studies and Research Board (ASRB), Khyber Medical University. This was a qualitative study and the sample size for the study was based on data saturation. Overall, 13 participants were included in the study based on data saturation. Non-probability sampling technique was used for the current study. Participants were included in the study using the Purposive sampling technique.

Parents of children (age less than 18 years) with chronic kidney diseases were included in the study. Chronically ill parents or parents having children with other severe co-morbidities were excluded from the study. Data from the participants were collected using a semi-structured interview guide developed by the researcher after a discussion with experts. Initially, the topic of the study was approved by the

Institute of Nursing Sciences (INS), Khyber Medical University (KMU). The study was presented at AS&RB Khyber Medical University and approval was granted. Data was collected via interviews and focus group discussions (FGDs) including audiotape recording. The primary researcher served as a source of data collection himself. Data were collected through in-depth interviews (IDI's) and focus group discussions (FGDs) of the parents via audio recording and field notes to capture the impression. Data were analyzed using the thematic analysis approach. The six steps recommended by Braun and Clark were followed.

In the very first step, all audio recorded information has listened and initial analytic induction was noted. In the second step, the audio recordings were reviewed many times, and codes were generated from all the information. Relevant data were extracted from the open codes. Open codes were categorized to make axial codes. In the third step, selective codes were made from the axial codes. All the codes were repeatedly checked for errors. In the fourth step, themes will be generated from selected codes. Themes were then reviewed to assess whether the themes represent the whole story. The themes which didn't represent the whole story were excluded. In the fifth step, names were identified for all the generated themes. Finally, the themes were supported by representative quotes from the participant's responses. The analysis of all the themes was written in detail to provide the readers with a holistic view of the research.

**RESULTS**

A total of 13 participants were included in the study. The mean age of the participants was 36.14 years. The majority (46.15%) of the participants were from the age group of 31 to 40 years. 23 % of participants were from the age group of 20 to 30 years and 41 to 50 years respectively. Only 7.5% of participants were from the age group more than 50 years. The majority (61.53%) of the participants was female and 38.46% of participants were male. In addition, the majority (38.46%) of the participants was educated to secondary level, 23% participants were having primary level education, 5.38% participants were educated to graduate level and the same proportion was illiterate. 7.65 participants were educated to the intermediate level. Results are given in Table 1.

**Table 1**

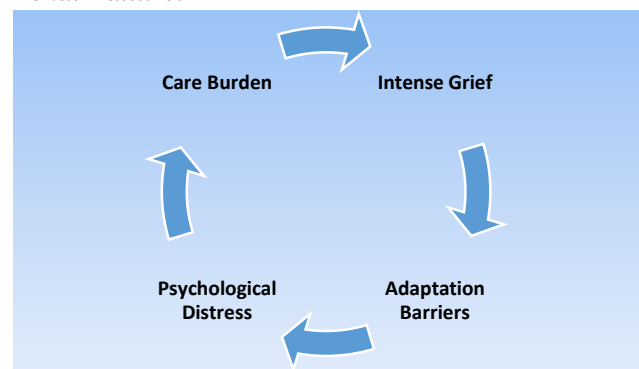
*Socio-Demographic profile of the participants, n=13*

	Frequency	Percentage
<b>Age of the participants</b>		
20 - 30 Years	3	23
31 - 40 Years	6	46.15
41 - 50 Years	3	23
More than 50 Years	1	7.6
<b>Gender of Participants</b>		
Male	5	38.46
Female	8	61.53
<b>Education of the Participants</b>		
Illiterate	2	5.38
Primary	3	23
Secondary	5	38.46
Intermediate	1	7.6
Graduate level	2	5.38

Overall, a total of 98 open codes were identified in the study. After axial coding and thematic analysis, overall, 16 categories were contributed to four themes such as Care Burden, Intense Grief, Psychological Distress and Adaptation Barriers. Results are shown in Figure 1.

**Figure 1:**

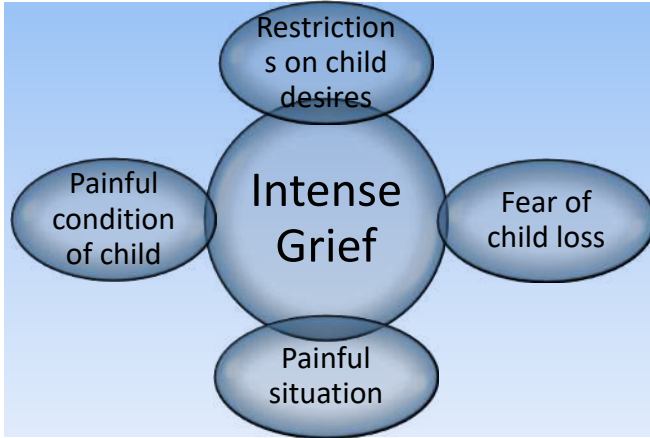
*Experiences of Parents having Child with Chronic Renal Failure.*



**Intense Grief**

The first theme was “Intense Grief”. This theme was generated from four categories. These codes are “Painful Situation”, “Restrictions on child desires”, “Fear of child Loss” and “Painful Condition of child. Results are shown in Figure 2.

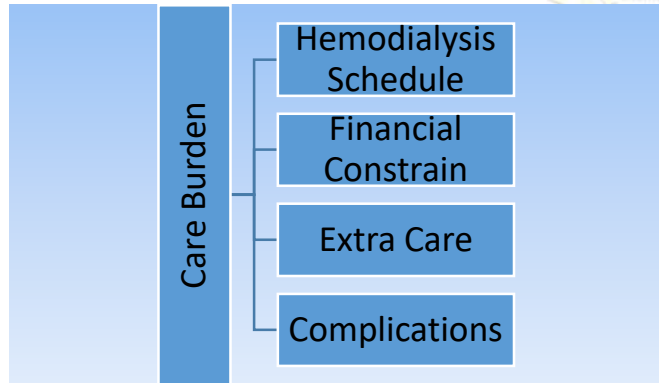
**Figure 2**  
*Intense Grief among Parents having Child with Chronic Renal Failure.*



**Care Burden**

The second theme was Care burden. This theme was generated from four categories. These categories were “Hemodialysis schedule”, “Financial Constrain”, “Extra Care” and “Complications”. Findings are displayed in Figure 3.

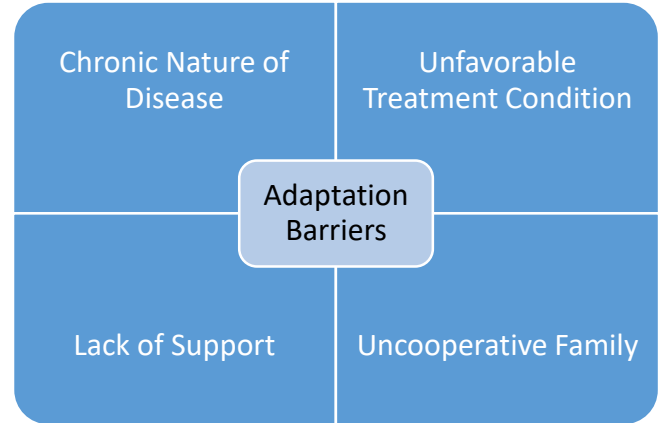
**Figure 3:**  
*Care Burden among Parents having Child with Chronic Renal Failure.*



**Adaptation Barriers**

The third there was adaptation barriers. This theme (adaptation barriers) was generated from four categories such as “Chronic nature of disease”, “Unfavorable Treatment condition”, “Uncooperative Family” and “Lack of support”. Data is given in Figure 4.

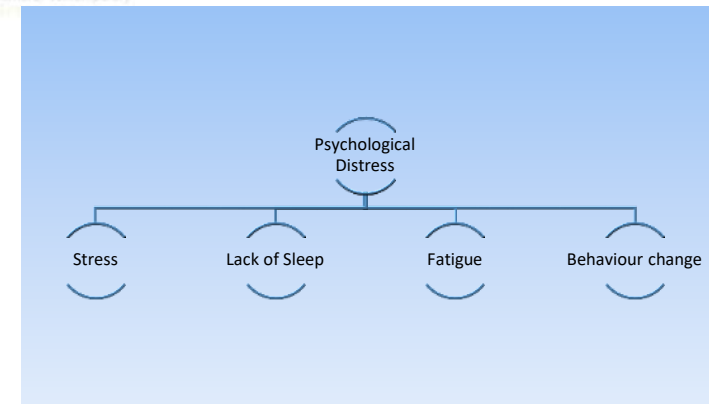
**Figure 4**  
*Adaptation Barriers among Parents having Child with Chronic Renal Failure.*



**Psychological Distress**

The fourth generated theme is Psychological Distress. This theme was generated from four categories. These categories were “Stress”, “Change Behavior”, “Fatigue”, and “Lack of sleep”. Results are given in Figure 5.

**Figure 5**  
*Psychological Distress among Parents having Child with Chronic Renal Failure.*



**DISCUSSION**

The findings of the current study revealed that the parents experience Intense Grief, Care Burden, Adaptation Barriers, and Psychological Distress. Similar to current study, a study reported that the parents having children with chronic kidney disease experience intrapersonal issues especially constant uncertainty, fatigue, workplace conflicts, impaired

peer relationship and domestic issues (Tong et al., 2014).

Similarly, the current findings were supported by another study. The findings revealed that mothers of children with CKD experience problem in daily life activity. CKD of children increase burden of care among the mothers which impact the quality of life of mothers also other children (Mieto & Bousso, 2014). In the same context, another study reported that parents experience barriers in family response to child care, barriers among families to cope with the care of the children, impact of care on the family members, and burden on parents to support the family (Failure & Hemodialysis, 2018).

In addition, different studies reported that parents of children with CKD deal with a variety experiences. Among these experiences, the most common experiences are stress among the parents, fatigue, disrupted peer relationships, bonding, financial issues, restriction in daily life activities, and difficulty fulfilling daily life activities (Noran M Abu-Ouf, 2016; Tong et al., 2016).

The experiences of parents are associated with the complication and severity of the disease. Majority of the complications among children with CKD are associated with hemodialysis. Half of the parents of children on hemodialysis experience problems in their jobs while impaired quality of life were reported among a considerable number parents (Kari et al., 2014). Similarly, a study reported mothers of children on hemodialysis experience psychological and emotional distress, mother restricted to diseased child, impaired family process, burden of care and self-devotion (Pourghaznein et al., 2018).

In the current study, intense grief and some sort of mental health issues were reported by almost all participants. Supporting the current findings, a study stated that parents of children with CKDs experience severe stress and anxiety (Sou'ub et al., 2018). Besides, severe depression was reported among 53% parents of children with CKD, 30% and 16.7% parents reported mild to moderate depression. Psychological burden was reported among 80% caregivers of children with CKD (Mahmoud et al., 2021). In the similar context, a study reported psychological symptoms among the parents of children with CKD. These problems such as depression, anxiety, tension, sleeping problems and emotional issues were more prevalent among the

female caregivers as compared to male because female are more involved in the care of children as compared to male caregivers (Cousino & Hazen, 2013).

The parents of children with CKD reported increase care burden while dealing with the complications, symptoms and problem associated with diseases and treatment. Besides, the parents also reported financial burden. Different studies highlighted the care burden of parents having children with CKD. The findings revealed that the parents experience huge care burden due to the disease process and treatment of the children with CKD. The disease and its treatment is associated with severe complications which needs more involvement of the parents in the care of children with CKD as compared to normal children (Geense et al., 2017). Supporting the current findings, different study reported the financial burden on the parents due to the CKD of their children. Approximately, 87.2% parents of children with CKD experience financial hardships which not only impact them but also impact the whole family (Medway et al., 2015).

In the current study the parents of children with chronic kidney diseases experience Adaptation Barriers due to the chronic nature of disease and prolong and complicated treatment. A variety of the studies supported the current findings and revealed that the parents of children with CKD experience barriers in their social and personal lives. The parents face difficulties in coping with the psychological issues, prolong nature disease of child, social activities, complications, intrapersonal issues, maintaining strong bond with the family members and actual role in the family. Eventually, all these factors are associated with impaired quality of life among caregivers of children with CKD (Darwish et al., 2020).

## **CONCLUSION**

Overall, 13 participants were included in the study. A total of 98 open codes were identified in the study. After axial coding and thematic analysis, overall, 16 categories were contributed to four themes. The parents of children with CKD experience Intense Grief. The parents also experience huge care and financial burden while managing the disease, treatment and complications of children with CKD. Similarly, the parents face barriers in adaptation to

handle the disease, treatment and complication among the children with CKD. Besides, the parents also experience physiological symptoms such as stress, tension and mental health problems.

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