**Title: Hidden family costs of “free” pediatric hemodialysis: A cross-sectional pilot study from Karachi, Pakistan**

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**Abstract**

Treatment of children with End Stage Kidney Disease (ESKD), requiring maintenance dialysis poses unique challenges. In LMICs, lifelong treatment places significant stress on the overall family unit. Families face serious financial, social and psychological consequences despite free treatment. This cross sectional study utilizing primarily quantitative methods, supplemented by two case studies is set in Sindh Institute of Urology and Transplantation, a tertiary care hospital in Karachi, Pakistan providing free treatment. Fifty-two caretakers of children receiving hemodialysis for more than five years participated. Findings reveal that additional financial challenges may send the entire household into financial catastrophe. Social problems include migration from native cities, impact on the education of the sick child along with changes in lives of siblings. One-third of primary caretakers screened positive for anxiety/depression. Healthcare professionals practicing in developing countries ought to remain cognizant of the socioeconomic realities of families caring for children with chronic illnesses.

**Introduction**

Significant medical advancements have enabled physicians to provide life-saving treatment to children suffering from End Stage Kidney Disease. Dialysis technology has improved long-term survival among children whose kidneys have less than 15 percent functionality. While the treatment of choice for children suffering from EKSD is renal transplantation since it provides better quality of life and long-term survival (1), some patients may not be eligible to receive it due to various reasons (2, 3).

One of the medical options then remains maintenance hemodialysis, which poses different medical as well as social challenges not only for treating physicians, but also for the entire family unit (4). This is magnified within the context of collectivist societies that tend to rely on kinship networks for support.

Hemodialysis (HD) requires commuting to a dialysis unit twice or thrice per week. The duration for each session is between 3 to 4 hours. Among children, HD poses additional challenges since they have to be transported and accompanied to the unit by adult family members, who are also compelled to leave their daily routine for these sessions. Furthermore, these children require extra care at home, and medical emergencies may necessitate unscheduled visits to the hospital. Researchers have identified multiple stressors in the physical (5), psychological (6), social(7) and financial(8) perspectives of caregivers.

In many parts of the developed world, healthcare is generally more accessible compared to many low and middle-income countries (LMICs) since citizens are covered through either the welfare system or the health insurance. The social service department of the dialysis unit if deemed necessary may provide the cost of dialysis including transportation to the centre, along with provision of other support services (9, 10).

On the other hand, within the context of LMICs, accessibility to healthcare is extremely limited. Public expenditure on health in India was a mere 3.53% of the Gross Domestic Product (GDP) in 2017-18 whereas in Pakistan, it stood at 2.90% (11). The healthcare system in many South Asian countries is deeply fragmented with scattered healthcare services provided by the public sector. The governments have relinquished majority of responsibility of healthcare to the private sector, which charges a high price for provision of service, thus making financial accessibility extremely difficult for a large portion of the population. In Pakistan, for example, 24.3% of population lives below the poverty line (12) whereas out-of-pocket expenditure on health amounts roughly to 60.24% (13). Against such a backdrop, treatment for ESKD remains unaffordable for a large majority, despite the fact that the cost of dialysis and transplant in India, for instance, is 20 times less than USA (14).

In Pakistan, in subsidized healthcare centers or within government-funded programs, the expenditure on dialysis was estimated to be $1680 per person per year in 2011 (15). Recent estimates from a public sector hospital suggest that the cost has now increased to $2000 per person every year. However, despite free treatment provided, the economic consequences of ESKD tend to be high for families (5). This study undertaken in Sindh Institute of Urology and Transplantation (SIUT), a public sector hospital in Karachi, Pakistan attempts to explore the social, economic and psychological impact on those families who are receiving “free” maintenance hemodialysis. The results of this study provide an insight into the gravity of economic and psychological consequences experienced by families whose children are on dialysis, living within developing countries.

**Methods**

***Study Design***

The study followed a prospective cross-sectional study design, primarily employing quantitative methods for data collection supplemented by two case studies in order to provide a deeper insight into the struggles of the families whose lives are drastically changed due to the ongoing dialysis of a child. This paper is part of the thesis undertaken to fulfill the requirements for the Masters in Bioethics (MBE) by the first author (AL) from Centre of Biomedical Ethics and Culture (CBEC), SIUT, Karachi, Pakistan.

***Study Site***

This study was carried out in the hemodialysis unit of SIUT, which has more than 160 stations that provide dialysis round the clock, 6 days a week. The hospital policy dictates no patient is denied treatment. About 80,000 sessions were performed on children below 18 years of age in 2016 (16).

***Participant recruitment and selection***

This research used non-probability sampling. Participants were considered eligible if they were the primary caretakers of children less than 18 years of age at the time of initiation of dialysis and receiving regular maintenance dialysis for more than a year. Only those children who were not candidates for live related kidney transplant, either due to non-availability of primary organ donor or had a primary disease with a high rate of recurrence were included in the study. Fifty-five primary caretakers met the inclusion criteria. However 3 refused to take part in the study therefore, responses were collected from 52 primary caregivers.

Out of those 52 primary caregivers, two families facing extraordinary challenges were asked for additional information through informal interviews presented as case studies.

**Data Collection**

Data was collected in three ways. One included a researcher-administered questionnaire drawn specifically for this research containing close-ended questions about the social, educational and financial status of patient, parents and siblings. The other tool was a screening questionnaire known as Aga Khan University-Anxiety Depression Scale (AKU-ADS) validated within Pakistani population to screen primary caretakers for anxiety and depression (17). The first two approaches collectively took about 30 minutes per participant, in which participants provided extra tidbits of information, captured wherever necessary within the findings. The third method involved conducting two informal interviews of about an hour each with primary caretakers in order to gain an in-depth understanding of the impacts of dialysis on the family unit.

***Data analysis***

Quantitative data was recorded and analyzed using Statistical Package for Social Sciences (SPSS) version 22.0. Since the questionnaire mainly recorded categorical variables, these were analyzed using frequencies and percentages. The first author (AL) conducted the primary data analysis for the completion of his thesis. While writing the manuscript, the two authors reviewed the analysis again and reached mutual agreement upon themes. Reflections from case studies are included within the discussion section.

***Ethical Concerns***

Ethical approval for the study was sought by the Institutional Review Board (IRB) at SIUT. Informed consent from the primary caretakers and verbal assent from adolescents were obtained in all cases. Since the first author/investigator was also the primary care physician, prospective participants were reassured that refusal to participate will not affect treatment of their children in any manner. Data collection took place in the dialysis unit while the child was being dialyzed to avoid any extra visits thus ensuring participants’ convenience. Furthermore, data was collected in a closed space in order to maintain privacy. The obtained data was provided unique identification codes to preserve confidentiality. Participants who screened positive for anxiety or depression were offered priority, free-of-cost consultation by a psychiatrist at SIUT.

**Results**

***Participant Demographics***

The demographic profile of 52 caregivers is summarized in Table 1. The mean age of mothers was 40.7 ± 7.4 (24 – 55) years, while the father’s mean age was 47 ± 8.6 (30 – 66) years. Eighty eight percent of mothers were healthy and 66% were uneducated or had received education up to 5 grades only. Eighty-one percent fathers were healthy and 43% had received education up to 5th grade. Eighty four percent of these mothers were housewives while 31% and 29% of the fathers were working as salaried professionals and skilled workers respectively.

The demographic profile of children receiving dialysis and the education status of these children and their siblings is summarized in Table 2. The mean age of the children receiving dialysis was 15 years and, on an average, they were on dialysis for 4 years. There were 28 boys and 24 girls in this cohort. Seventy-seven percent of the children were unable to get a transplant due to unavailability of live-related kidney donor.

***Socioeconomic impact of dialysis***

The socioeconomic status of these families and other indirect costs borne by the families specially to commute to the hospital are tabulated in Table 3. The median monthly household income was PKR 24,000 (USD 2880 annually) with 80% of the families having a household income between PKR 11,000 to 50,000 (USD 110-500 monthly). In majority of the families, there was only one breadwinner, most commonly the father. Thirty five percent of families had to migrate because dialysis facilities were not available in their city. Most of them used public transportation or Rickshaws for commute to hospital, travelling up to 50 Km, at the expense of 536 ± 470 PKR (5 ± 4 USD) and spending 6 to 8 hours for every session of dialysis on average.

To overcome the financial challenges, some families had to take extraordinary measures to generate other sources of income like selling off their cattle, taking loans, getting help from other relatives and neighbors, and renting out portions of their homes. In one family, the maternal grandmother of the child had to resort to begging to help her daughter with the additional financial burden that had befallen upon the family after the child’s illness.

***Impact on Children’s Education***

Seventy-seven percent of children were receiving some kind of formal education before the initiation of dialysis, but, after their treatment, 91% children were deprived. When asked about the reason for this, more than 90 percent primary caretakers reported poor health. Others also stated that this was because coming for dialysis resulted in missing many school days making it difficult for children to cope with regular school. Another parent voiced her concern of going to school, *“He has to carry such a huge bag when he goes to school, and climb many stairs.”* Another mother also added, *“I feel very scared. You know he has a fistula on his hand. What if he gets hurt?”* Two parents, on the other hand, provided financial difficulties as the reason for discontinuing education.

In 35% of the families, the education of other siblings was seriously affected because of the ongoing dialysis of one sibling in the family primarily because siblings had to drop out of school after the initiation of dialysis.

***Psychological Impact of Caregiving***

The validated questionnaire to screen for anxiety-depression complex identified 19 (37%) primary caretakers with a score of more than 20 signifying presence of symptoms of anxiety and depression. These questionnaires were reviewed by a psychiatrist at the institute, and excluded those who mainly presented with somatic complaints. Eight (15%) caretakers were offered free psychiatric evaluation, out of which only 2 (4%) agreed to seek help. However, when asked the question about suicidal ideation/suicide, majority of the caretakers responded with *“Haraam [forbidden]* believing that such an act was one of *“cowardice.”* Participants also negated the presence of symptoms by stating *“Alhumdilllah [Thank God].”*

***Presence of external support***

Eighty-one percent of the families lived in nuclear setting. However, in 90 percent of the cases there were multiple family members providing extra support to the parents. This included the elder siblings and the grandparents who looked after the house when the parents were away with the sick child for dialysis sessions. In some cases, the neighbors helped, and in one instance, the landlord looked after the younger siblings when the mother was away with the child for dialysis session.

**Case Study 1**

Shehnaz[[1]](#footnote-1), 48 years old is Aasia’s mother. Aasia, now 18 years of age, has been coming to SIUT for dialysis since she was four years old. Apart from ESKD, she also has impaired vision and hearing. Shehnaz originally hails from a poor family in a small town of Sindh, about 200 km north of Karachi. Married when she was 20 years old to her paternal uncle’s son, Ahmed, a daily wager, she has undergone unimaginably difficult times.

Ahmed passed away when he was 45 years old, leaving her with seven children who had numerous health issues. Shehnaz’s eldest son, Latif died when he was 14 years old due to kidney failure. Her daughter, Yasmeen could only study until the 10th grade, and since then has been helping her mother with household chores and taking care of her younger siblings. She has recently been diagnosed with kidney failure but does not require dialysis at the time. Her son, Nasir has post meningitis sequel acquired in early childhood, and now requires special attention. Another son Dilshad could not continue regular school because of learning difficulties combined with a stutter and now works with a local mechanic. Hamid is her youngest son, and goes to school.

Throughout these difficulties times, Shehnaz has drawn support from her father-in-law and paternal uncle. They live in a joint family system, and her basic financial needs are covered by her family.

She faces numerous issues in her commute to the hospital for Asya’s dialysis since all the earning male members of the family work on daily wages. After Ahmed passed away, the family decided to discontinue Asya’s dialysis. However, one day, *“Asya ko jhatke lage, aur woh behosh hogaye. Mujh say dekha nahi gaya, mein usko Karachi le aye buss mein baith kay [One day, Asya got seizures and fell unconscious. I could not tolerate this, I immediately came to Karachi in a bus]”* While she did not have money for the bus ride, the bus conductor took pity on her looking at her daughter’s miserable condition.

At SIUT, Asya was admitted in the ICU in a critical condition. She required mechanical ventilation but after almost one week, Asya was back to her usual state of health. Her father-in law- came on the third day to inquire about their status and then left. When Asya was discharged, her mother did not have enough money to take her home. Shehnaz took this to the doctor who took care of Asya in the ICU. In her own words, “*Doctor sahib ki ankhon me ansoo aa gaye. Unho ne us waqt jaib se ek hazar rupay nikal kur mujhe diye aur kaha ke ab hur maheene aap mujh se ye paise le lijye ga. Wo waqt hai aur aaj is baat ko 8 saal ho gai hai, wo pabandi se mujhe pehli tareekh ko paise dete hain.*” (The doctor had tears in his eyes. He immediately took out a 1000-rupee note (USD6) and gave it to me. He told me to take money from him every month. It has been 8 years now and he regularly gives me money on the first of every month).

Since then, a transporter has made special arrangement for Shehnaz to ride on specific buses with payment of just one seat with one-way tariff for a return trip. Shehnaz is grateful and has no regrets with continuing her daughter for dialysis, except “*Bus agar afssos hai to meri beti Yasmeen ke liye. Us ne kabhi aam bachon jesi zindagi guzari hi nahi. Humesha ghar ka khayal hi rukha. Ab meri bohat khwahish he ke us ki shadi ho jai leken koi humare ghar rishta nahi bhejta. Kehte hain in ke ghar me beemari hai* [The only regret I have is for my daughter Yasmeen. She has never lived a normal child’s life. She has always taken care of the house. I wish that she could get married but nobody sends us a proposal. They say that we have disease in our family]”

**Case Study 2**

Samina, 30 years of age, is the primary caretaker of her youngest brother, Hamza who has been on dialysis since the past five years. The entire family lived in their own house located in a  *katchi abadi* [slum] in Karachi. She has two older brothers and two older sisters, and three younger brothers, and two younger sisters. The older brothers and sisters after their marriage moved out of the family house. Soon after their marriages, both of Samina’s parents died within a span of few months, which put Samina as the head of the household.

When Hamza was initially diagnosed with the disease, the married siblings came forward to help. However, once they realized the chronic nature of the illness and the need for kidney transplant, their support gradually declined. The remaining members of the family including Hamza work to take care of the financial needs of the family. The brothers work as salespersons in a shop, while the sisters stitch clothes for a garment factory from home. Hamza has a small portable shop and sells chocolates, biscuits and other such goodies to children in the neighborhood.

When Hamza was evaluated for transplant, his blood group matched only with his eldest brother, Rahim and youngest sister, Farah. Rahim refused to donate because he was afraid that donating a kidney would make him sick, as well. Married with two children, he believed his primary responsibility was towards his children. Farah was 20 years old and single. Since the well-being of the donor is a top priority in every live related transplant program, Farah was not considered as an ideal candidate for donation since in SIUT’s experience; single women who donate kidneys carry a stigma and therefore have difficulty in getting married. The family therefore decided that Hamza would continue on dialysis until Rahim changed his mind.

During this time, Hamza acquired Hepatitis C, and could not respond well to the treatment due to side effects including fevers, body aches, and psychiatric complications such as agitation, and hallucinations. Samina recalls those times when it became extremely difficult for the family to take care of him. The financial burden also increased drastically since he required multiple out of schedule visits to the hospital. The siblings at home scarified their own needs by sharing additional household expenses.

When asked whether she ever thought about giving up Hamza’s care, and living her own life, *“Doctor sahib, kisi ko qurbani deni partee hai [someone has to sacrifice.] If her our parents had been alive, it would have been different. Now if I give up, who will look after him?”* She believed that her faith in God, *“Buss mein dua mangteen hun* [I pray to God]*”* allowed her to cope well with difficulties life had thrown at her, stating *“Mujhe apne Khuda per poora yaqeen hai. Wo kisi ko us ki bardasht se ziyada takleef nahi deta [I firmly believe in my God. I don’t think He gives us more pain than we can endure.”*

**Discussion**

This study was undertaken in a public sector hospital in a developing country where majority of patients live below the poverty line. According to the best of the authors’ knowledge, no such study that looks beyond the financial costs has been conducted within the Pakistani context although a study has previously assessed caregiver’s burden (18). However, the burdens that caregivers face can be extremely pervasive leading to significant upheavals in lives of families. An important insight that the current study provides is that despite free of cost treatment to all patients which supposedly minimizes the out of pocket expenditure for patients’ families, there are a variety of associated “hidden” costs.

One of the biggest challenges faced by families of children on hemodialysis is financial. In developed countries, where additional expenses are provided through insurance, parents still report a significant financial burden, including parental inability to work efficiently, and difficulties encountered in working overtime (8). Increased burden and poor outcome in families with low socioeconomic status have been reported in studies from countries with high GDP like Netherlands (19), Saudi Arabia (7), New Zealand (20), USA (21) and Canada (22). In these studies from developed countries, families who cannot afford insurance or are not receiving treatment are either not addressed or excluded from the study therefore the financial burden on such families cannot be assessed. As the current study from a developing country showed, with low monthly household income, and the high transportation cost (particularly when commuting from other towns/cities) made the supposedly “free” dialysis unaffordable for majority of the families.

Participants reported numerous financial challenges including borrowing money, and selling off livestock to bear the other expenses such as costs of relocation and transport expenditure associated with hospital visits at least twice a week. For families who live below the poverty line, an illness in the family can send the entire household into a health shock recognized as a financial catastrophe (23). Many physicians are cognizant of this reality highlighting this as a key dilemma in their clinical practice (24).

The study also revealed that one third of the families had to change their permanent address after the initiation of the child’s dialysis. To move to a mega-city without sufficient resources, a lot of commitment and sacrifice from the entire family is required. Moreover, finding a nearby residence, job and educational facility for other siblings also prove extremely challenging. Previous studies on the experiences of caregivers have also documented that due to the major change that occurs in family lives following the diagnosis of a chronic illness, caregivers experience disruption in their daily schedules, while also accommodating long-term life goals due to the illness of their children (25). A study conducted in India within a dialysis centre also indicated that families temporarily relocate to other cities where such services are available, but with the consequence of loss of livelihood for the entire family (26).

When chronic illnesses strike one member of the family, extended social support from other family members within the kinship network, and neighbors can prove to be a source of assistance. In response to the question about support at home, 90% of the caregivers in the current study had other family members who were providing support. Even though there were only 20% families cohabiting in a joint family setup, and the rest had a nuclear family setting, with few exceptions, the whole family participated in providing care. In most cases, the elder siblings or grandparents looked after the household while the parents were away at the hospital. Case Study 2 from this paper illustrates the amount of sacrifice that elder siblings had to make in order to ensure the continuity of dialysis for their younger brother.

These findings provides interesting insights in terms of the role of extended family particularly within the largely collectivist societies, like Pakistan. Despite the fact that many families were located in a nuclear setting, parents of the sick child relied on the extended family network for occasional support. This also corroborates the finding from Tong et al, who while identifying the wide spectrum of challenges that parents face, stated that social support in all domains is essential to help families who are caring for a sick child (27).

The presence of this social support in these families could be one of the key contributing factors that provides strength to these parents/caretakers to continue the treatment of their child in societies with a cultural orientation to Pakistan. For Shehnaz in Case Study 1, her father-in-law and other members of the family took care of her and her children’s basic needs. A study from Brazil also supports this proposition (28). For families who lack external familial support beyond the immediate members, dropping out of the dialysis may appear to be the only recourse. This study did not delve deeper into the various ways that kinship circles are involved in “helping out” a family burdened by the illness. However, further studies utilizing qualitative methods may be useful in this regard.

Nevertheless, the limited role of family members should also not be discounted. As evident in Case Study 2, the eldest brother showed extreme reluctance to donate his kidney to the younger brother. For the elder brother, his own children were a greater priority highlighting his reluctance to donate. This is supported by other evidence from the institute (29, 30). Along with that, the married siblings did not extend their assistance to Samina as she handled Hamza’s illness once they realized that it was a life-long affliction requiring significant care.

The constant stress due to uncertainty and child’s illness on caretakers has been extensively researched (31-33). Even in non-life threatening skin conditions of a chronic nature, 36% of 118 parents were screened positive for anxiety (34). Among caregivers of children receiving PD at home the prevalence of depression was reported to be 28% as compared to 5% in healthy controls (3). In a study of 60 families of children on dialysis by Fielding et al (1999) in England, multiple socio-demographic factors were identified that were associated with parental anxiety and depression. Out of multiple variables studied, lower socioeconomic status, large families, limited support from other family members and parents of young children were identified as higher risk factors for developing depression (35).

In the current study, almost one third of parents screened positive for symptoms of anxiety and depression. However, more than half of these patients exhibited only somatic symptoms like frequent headaches, indigestion and symptoms of fatigue. This finding is supported from previous studies in the country: Pakistani population, particularly women tend to present with somatic complaints of depression and anxiety (36, 37). Symptoms of clinical anxiety/depression requiring treatment by a psychiatrist were found in only 17% of caretakers. This is in contrast to 28% reported by Tsai et al in Taiwan (6).

The prevalence of depression/anxiety was expected to be much higher in this cohort due to the presence of majority of risk factors including lower socioeconomic status. However, the reason for this low prevalence could also be explained due to strong extended familial support, which has been known to have a negative association with stress and anxiety (38). Another possible explanation could be the use of religion as a coping mechanism. When participants were asked about whether they had experienced any thoughts or preoccupations with suicide, majority of them expressed that it was forbidden in Islam. In a society in which religion pervades every aspect of life, religious beliefs that condemn suicide along with a firm belief in God as seen in Samina’s case, can also cushion people against the negative mental health effects of chronic conditions.

A major impact was noted on the education of children receiving dialysis. Eighty percent of the children were receiving some kind of formal education before the initiation of dialysis but after the start of treatment, the trend reversed with more than 90% children not getting any formal education. Poor health was cited as the factor for this. This therefore indicates the deeply personal costs that are attached when children are undergoing dialysis within low-income countries. In developed countries, special arrangements in the timing of dialysis are made to facilitate education of children. Tutors are made available in the dialysis unit who ensure that these children are able to continue their education (39). In developing countries, such arrangements may not be possible/feasible or too expensive to afford. Adjustments in the dialysis schedule may also be very difficult because of limited facilities requiring a long commute to the hospital.

Within the family unit, chronic disability and illness of one child can affect other siblings, since parents devote most of the energy and time to the sick child. Financial and psychological stresses on parents aggravate the situation further. It has both direct and indirect impact on the upbringing, mutual relationships, family dynamics and behavior of other siblings (40-43) As this study revealed, 35% caretakers stated that education of other siblings was affected. Out of these 18, half did not send other siblings to school at all and another quarter dropped out of school after the initiation of dialysis. Others reported poor performance and inability to go for higher education. While this could also be due to the cost of education in itself, since participants of this study belonged to lower socioeconomic strata, it also highlights the number of ways that lives of other children in the family may be affected (44-45).

Other significant impacts were noted on other siblings due to the presence of illness in the family. In Case 1, Shehnaz’s eldest daughter, Yasmeen was unable to live her childhood to the fullest because she had to help her mother out with household chores since Shehnaz was busy taking care of Aasya. The impact of the illness is multifold; Yasmeen was also unable to get married because of the stigma due to the “disease” present in her family.

This study found that caring for a child with chronic illness has far-reaching consequences which manifest themselves in different ways, including the “hidden” costs, figures of which do not lend themselves into economic evaluations. Moreover, the findings from the current study also provide a richer context of families who come for dialysis. This is useful information for healthcare practitioners within developing countries. The numerous difficulties and the considerable strain that families experience despite receiving free treatment may very well be one of the causes of the high dropout rates which are typical within developing countries. Although no official statistics are available from within Pakistan, experience from India has demonstrated a high dropout rate of 47% in publicly funded dialysis facilities (46).

It becomes important then for physicians to tune into these difficulties, and respond to them during the process of decision-making and counseling the families, something also identified previously (4).

While this study is novel in terms of its contribution to the literature from the perspective of Pakistan, there are some limitations to this study. The primary weakness of the study is the limited sample size which means it cannot be generalized to the whole country. However, in the experience of the first author who heads the pediatric nephrology department of the institute, a large number of families come to the institute with similar stories/backgrounds. Furthermore, areas unexplored in the current work include detailed assessment of impact on siblings and role of religion as a coping mechanism, which are best addressed through a qualitative inquiry. It would also be worthwhile to look at families whose children have been transplanted and compare quality of life with families whose children are on dialysis.

Nevertheless, the study provided a glimpse into the considerable difficulties experienced by families, which gives useful insights to physicians to deal with patients in a more empathetic fashion, and to not only treat the disease, but attempt to cure the illness.

**Conclusion**

This pilot study reflects the seriousness of ESKD as an illness in developing countries. The cost of maintenance dialysis is significantly high making it difficult for people from lower socioeconomic status to access it. Even if the medical treatment is provided completely free of cost to the patients, families face severe financial, social and psychological burden. Further in-depth studies utilizing qualitative modes of inquiry are required to study these factors in more detail in order to develop targeted interventions.

**Acknowledgments**

*Financial Disclosure:* The authors declare that they have no financial disclosures for this research.

*Contributions:* AL conceived and initiated the research as part of his thesis, collected and analyzed the data, and wrote the manuscript. SS provided help in data analysis, and wrote the manuscript.

*Acknowledgments:* The research would not have been possible without the useful and constant guidance of faculty members at CBEC, SIUT including Drs. Farhat Moazam, Aamir Jafarey and Bushra Shirazi. AL would like to acknowledge his daughter, Tasneem Ali for her contributions in proofreading drafts of thesis. The authors are grateful for the help from the institute’s psychiatrist, Dr. Naim Siddiqui who helped in screening of caregivers for anxiety/depression.

**Table 1: Demographic Profile, Health status, Education and Occupation of Parents**

|  |  |  |  |
| --- | --- | --- | --- |
| **Fathers**  n | 51 | **Mothers**  n | 52 |
| Age mean ±Sd (range) | 47.04±8.57(30-66) | Age mean ±Sd (range) | 40.75±7.38 (24-55) |
| **Health** |  | **Health** |  |
| Healthy n (%) | 42 (80.8) | Healthy n (%) | 46 (88.5) |
| Expired n (%) | 6 (11.5) | Expired n (%) | 3 (5.8) |
| Chronic Disease n (%) | 4 (7.7) | Chronic Disease n (%) | 3 (5.8) |
| **Education** |  | **Education** |  |
| Post Graduate n (%) | 3 (5.8) | Post Graduate n (%) | 1 (1.9) |
| Graduate n (%) | 5 (9.6) | Graduate n (%) | 3 (5.8) |
| Intermediate n (%) | 4 (7.7) | Intermediate n (%) | 3 (5.8) |
| Secondary n (%) | 17 (32.7) | Secondary n (%) | 11 (21.2) |
| Primary n (%) | 8 (15.4) | Primary n (%) | 5 (9.5) |
| Uneducated | 14 (26.9) | Uneducated | 29 (55.8) |
| **Occupation** |  | **Occupation** |  |
| Salaried Professional n (%) | 16 (30.8) | Housewives n (%) | 44 (84.6) |
| Skilled workers n (%) | 15 (28.8) | Stitch Clothes n (%) | 4 (7.7) |
| Personal Business n (%) | 8 (15.4) | Housemaid n (%) | 2 (3.8) |
| Manual Laborer n (%) | 11 (21.2) | Nurse n (%) | 1 (1.9) |
| Unemployed n(%) | 1 (1.9) | Sells Books | 1 (1.9) |

**Table 2: Demographic Data and Education status of children and their siblings**

|  |  |  |  |
| --- | --- | --- | --- |
| **Age at initiation of dialysis (mean±SD(range))** | | 10.55 ± 3.2 (3-17) years | |
| **Gender**  Male  Female | | 28 (53.8%)  24 (46.2%) | |
| **Years on Dialysis (mean±SD(range))** | | 4.65 ± 3.27 (1 – 14) | |
| **Reason for no Transplant**  No available donor  Psychiatric or Mental ailment  De novo Disease  Physical Complications of ESKD  No willing Donor | | 40 (76.9%)  4 (7.6%)  4 (7.6%)  3 (5.8%)  1 (1.9%) | |
|  | |  | |
| **Education Status of children on dialysis** | |  | |
|  | **Before HD n (%)** | | **After HD n (%)** |
| **Going to School** | **41 (79%)** | | **5 (8%)** |
| **Not receiving any formal education** | **11 (21%)** | | **47 (92%)** |
| **Reasons for no education** | **n = 11** | | **n = 47** |
| Poor health | 6 (50%) | | 43 (91%) |
| Mentally weak | 3 (25%) | | 2 (4%) |
| Financial issues | 1 (8%) | | 2 (4%) |
| Too young to start | 1 (8%) | | - |
| No tradition of sending girls to school | 1 (8%) | | - |
| **Impact of dialysis on education of siblings** |  | |  |
| **No effect on education of siblings** | **36 (65%)** | | |
| **Education effected due to dialysis (Total)**  Did not go to school at all  Dropped out of school  Poor performance  Could not go for higher education | **18 (35%)**  8 (15%)  5 (10%)  3 (6%)  2 (4%) | | |

**Table 3: Financial Status of the families and commute to the hospital**

|  |  |
| --- | --- |
| **Number of Bread winners**  1  2  3 or more | 32 (62%)  11 (21%)  9 (18%) |
| **Household monthly Income**  Mean  Median  Less than 10,000 PKR (USD 100)  11,000 to 25000 PKR (USD 110 - 250)  26000 to 50000 PKR (USD 260 – 500)  More than 50,000 PKR (USD > 500) | 28,588 ± 21,159 PKR (USD 274 ± 203) \*  24000 PKR (USD 230)  5 (10%)  24 (46%)  18 (34%)  5 (10%) |
| **Primary Breadwinner**  Father  Mother  Brother  Joint Family  Uncles and Grand Parent | 37 (71%)  2 (4%)  3 (6%)  7 (13%)  3 (6%) |
| **Other sources of Income**  No additional source  Contribution by other family members  Rent from a shop/agricultural land/portion of house  Sold house/cattle  Support from NGO/Community members  Grandparent begs on street | 33 (63%)  10 (19%)  4 (8%)  2 (4%)  2 (4%)  1(2%) |
| **Family Structure**  Nuclear Family  Joint Family | 42 (81%)  10 (19%) |
| **Change of permanent address due to dialysis**  Yes  No | 18 (34%)  34 (66%) |
| **Distance travelled**  0 to 25 Km  26 to 50 Km  More than 50 Km | 13 (25%)  34 (65%)  5 (10%) |
| **Means of Transportation**  Public Bus  Rickshaw \*\*  Motorcycle  Car | 22 (42%)  15 (28%)  9 (17%)  6 (13%) |
| **Average time spent in hospital per session**  Less than 6 hours  6 to 8 hours  8 to 10 hours  More than 10 hours | 3 (6%)  31 (59%)  10 (19%)  8 (16%) |
| **Mean expense for commute per session** | 536 ± 470 PKR (Range 80 – 2500) |

**\*USD conversion rates are according to the market value at the time of study**

**\*\* Rickshaw is a 3 wheeled scooter with capacity of 1 to 3 passengers. A common relatively low cost rented mode of transportation in Pakistan**

**References**

1. Web MD. A to Z Health Guide: Kidney Transplant Surgery [cited 2020 June 18]. Available from: http://www.webmd.com/a-to-z-guides/kidney-transplant-20666
2. Chandar J, Chen L, Defreitas M, Ciancio G, Burke G. Donor considerations in pediatric kidney transplantation. *Pediatr Nephrol*. 2020 Jan 13:1-3. Available from: <https://link.springer.com/article/10.1007/s00467-019-04362-z>
3. Peruzzi L, Amore A, Coppo R. Challenges in pediatric renal transplantation. *World J Transplant.* 2014 Dec 24;4(4):222. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4274593/>
4. Bignall OR, Goldstein SL. Childhood CKD affects the entire family. *AM J Kidney Dis*. 2015 Mar 1;65(3):367-8. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0272638614014681>
5. Thyen U, Sperner J, Morfeld M, Meyer C, Ravens- Sieberer U. Unmet Health Care Needs and Impact on Families of Children with Chronic Disabilities in Germany. *Amb Ped.* 2003;3:74-81. Available from: <https://pubmed.ncbi.nlm.nih.gov/12643779/>
6. Tsai TC, Liu SI,Tsai JD, Chou LH. Psychosocial effects on caregivers for children on chronic peritoneal dialysis. *Kidney Int.* 2006;70:1983-1987. Available from: <https://pubmed.ncbi.nlm.nih.gov/16985519/>
7. Kari JA, Alzharany M, El-Deek B, Maimani M, El-Desoky S. Social impact of dialysis on children and their families. *Ind J Ped*.2014;81(10):1020-1026. Available from: <https://link.springer.com/article/10.1007/s12098-013-1236-z>
8. Medway M, Tong A, Craig JC et al. Parental Perspectives on the Financial Impact of Caring for a Child with CKD. *Am J Kidney Dis*. 2016;65(3):384-393. Available from: <https://pubmed.ncbi.nlm.nih.gov/25245301/>
9. Medicare.gov The Official US Government Site for Medicine. Dialysis services and supplies [cited 2020 June 18]. Available from: <https://www.medicare.gov/coverage/dialysis-services-supplies>
10. Fischbach M, Edefonti A, Schröder C, Watson A, European Pediatric Dialysis Working Group. Hemodialysis in children: general practical guidelines. *Pediat Nephrol*. 2005 Aug 1;20(8):1054-66. Available from: <https://link.springer.com/article/10.1007/s00467-005-1876-y>
11. The World Bank. Current health expenditure % of GDP [cited 2020 June 18]. Available from: <https://data.worldbank.org/indicator/SH.XPD.CHEX.GD.ZS>
12. Asian Development Bank. Poverty in Pakistan [cited 2020 June 18]. Available from: <https://www.adb.org/countries/pakistan/poverty>
13. The World Bank. Out of pocket expenditure- Pakistan [cited 2020 June 18]. Available from: <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS?locations=PK>
14. Khanna U. The economics of dialysis in India. *Indian J Nephrol*. 2009 Jan;19(1):1. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2845186/>
15. Rizvi SA, Naqvi SA, Zafar MN, Hussain Z, Hashmi A, Hussain M, et al. A renal transplantation model for developing countries. *Am J Transplant*.2011;11:2302-7. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1600-6143.2011.03712.x>
16. Sindh Institute of Urology and Transplantation. Statistics [cited 2020 June 18]. Available from: <https://siut.org/statistics-gallery.php>
17. Ali BS, Reza H, Khan MM, Jehan I. Development of an indigenous screening instrument in Pakistan: the Aga Khan University Anxiety and Depression Scale. *J Pak Med Assoc*. 1998;48(9):261. Available from: <https://pubmed.ncbi.nlm.nih.gov/10028792/>
18. Shah HB, Atif I, Rashid F, Babar MW, Arshad F, Qamar W, Khan OA, Qadir ML. Assessment of caregiver burden of patients receiving dialysis treatment in Rawalpindi. *J Pakistan Med Assoc*. 2017 Oct 1;67(10):1498-501. Available from: <https://jpma.org.pk/article-details/8383>
19. Groothoff JW, Gruppen MP, Offringa M, et al. Mortality and causes of death of end-stage renal disease in children: A Dutch cohort study. *Kidney Int*. 2002; 61(2):621-629. Available from: <https://pubmed.ncbi.nlm.nih.gov/11849405/>
20. Walker RC, Howard K, Tong A, Palmer S C, Marshall M R and Morton R L. The economic considerations of patients and caregivers in choice of dialysis modality. *Hemo Int*,2016;20:634–642. Available from: <https://pubmed.ncbi.nlm.nih.gov/27196634/>
21. Hidalgo G, Ng DK, Moxey-Mims M, et al. Association of income level with kidney disease severity and progression among children and adolescents with CKD: a report from the Chronic Kidney Disease in Children (CKiD) Study. *Am J Kidney Dis.* 2013;62(6):1087-1094.Available from: <https://www.sciencedirect.com/science/article/abs/pii/S0272638613009918>
22. Danderson D, Dumont S, Jacobs P, Azzaria L. The Personal Costs of Caring for a Child with a Disability: A Review of the Literature. *Pub Health Rep*. 2007;122 (1):3-16. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1802121/>
23. World Health Organization. Designing Health Financing Systems to reduce Catastrophic Health Expenditure [cited 2020 June 18]. Available from: <https://www.who.int/health_financing/pb_2.pdf>
24. Mani MK. Ethical problems in renal transplantation: a personal view. *Indian J. Med. Ethics*.1995; 3(3),39-41. Available from: <https://ijme.in/articles/ethical-problems-in-renal-transplantation-a-personal-view/?galley=html>
25. Wightman A, Zimmerman CT, Neul S, et al. Caregiver Experience in Pediatric Dialysis. *Pediatrics*. 2019; 143(2). Available from: <https://pediatrics.aappublications.org/content/143/2/e20182102>
26. Jha V. End‐stage renal care in developing countries: the India experience. *Ren Fail*. 2004 Jan 1;26(3):201-8. Available from: <https://www.tandfonline.com/doi/full/10.1081/JDI-120039516>
27. Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics*. 2008;121(2):349-360. Available from: <https://pubmed.ncbi.nlm.nih.gov/18245427/>
28. Paula ÉS, Nascimento LC, Rocha SM. The influence of social support on strengthening families of children with chronic renal failure. *Rev Lat Am Enfermagem*. 2008 Aug;16(4):692-9. Available from: <http://www.scielo.br/scielo.php?pid=S0104-11692008000400007&script=sci_arttext>
29. Naqvi Sa, Rizvi SH. Constraints in living donor kidney transplantation. *Transplant Proc.* 2000 32(7):1483-4. Available from: 10.1016/S0041-1345(00)01299-9
30. Jawad F, Hussain Z, Ahmed E, Akhtar F, Hussain M. Problems of donor selection in a living related renal transplant program. *Transplant Proc.* 1998 30(7):3463. Available from: <https://pubmed.ncbi.nlm.nih.gov/9838596/>
31. Holm, K. E., Patterson, J. M., Rueter, M. A., & Wamboldt, F. Impact of uncertainty associated with a child's chronic health condition on parents' health. Fam Sys, & Health. 2008; 26(3), 282–295. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2873603/>

Melissa K. Cousino, Rebecca A. Hazen. Parenting Stress Among Caregivers of Children with Chronic Illness: A Systematic Review. J Ped Psychology. 2013; 38(8):809-828. Available from: <https://pubmed.ncbi.nlm.nih.gov/23843630/>

1. La Clare, Heather L.The Impact of Childhood Chronic Illness on the Family: Psychosocial Adjustment of Siblings. (2013). Retrieved from Sophia, the St. Catherine University repository website: <https://sophia.stkate.edu/msw_papers/218>
2. Manzoni AP, Weber MB, Nagatomi AR, Pereira RL, Townsend RZ, Cestari TF. Assessing Depression and Anxiety in the Caregivers of Pediatric Patients with Chronic Skin Disorders. *Anais Brasil Derma*. 2013;88(6):894–899. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3900338/>
3. Fielding D, Brownbridge G. Factors related to psychosocial adjustment in children with end stage renal failure. *Ped Nephrol*.1999; 13:766-770. Available from: <https://pubmed.ncbi.nlm.nih.gov/10603116/>
4. Mian, Rubeena H, Grossman, LS. The Somatization of Depression in Native Pakistani Women. *Jefferson J Psych*. 1998; 14(1): Article 4. DOI: <https://jdc.jefferson.edu/cgi/viewcontent.cgi?article=1404&context=jeffjpsychiatry>
5. Rabbani F, Raja FF. The Minds of Mothers: Maternal Mental Health in an Urban Squatter Settlement of Karachi. *J Pak Med Ass*. 2000; 50(9). Available from: <https://jpma.org.pk/article-details/3088>
6. Forouhari S, Teshinizi SH, Ehrampoush MH et al. Relationship between Religious Orientation, Anxiety, and Depression among College Students: A Systematic Review and Meta-Analysis. *Iran J Public Health*. 2019; 48(1): 43-52. Available from: <https://pubmed.ncbi.nlm.nih.gov/30847310/>
7. Warady BA, Alicia M. Neu AM, Schaefer F. Optimal Care of the Infant, Child, and Adolescent on Dialysis: 2014 Update. *Am J Kidney Dis*. 2014;64(1):128-142. Available from: <https://pubmed.ncbi.nlm.nih.gov/24717681/>
8. Lavigne JV, Ryan M. Psychological adjustment of siblings of children with chronic illness. *Pediatrics.*1979;63:616–627. Available from: <https://pubmed.ncbi.nlm.nih.gov/440874/>
9. Stewart DA, Stein A, Forrest GC, Clark DM. Psychological adjustment in siblings of children with life threatening illness: a research note. *J Child P Psychiatry*.1992; 33: 779–784. Available from: <https://pubmed.ncbi.nlm.nih.gov/1601948/>
10. McKeever P. Siblings of chronically ill children: a literature review with implications for research and practice. *Am J Orthopsych.* 1983;53:209–218. Available from: <https://psycnet.apa.org/record/2013-42332-003>
11. Lobato D, Faust D, Spirito A. Examining the effects of chronic disease and disability on children’s sibling relationships. *J Ped Psych*. 1988;1:389–408. Available from: <https://academic.oup.com/jpepsy/article-abstract/13/3/389/1222310?redirectedFrom=fulltext>
12. La Clare HL. The Impact of Childhood Chronic Illness on the Family: Psychosocial Adjustment of Siblings. Available from: <https://sophia.stkate.edu/msw_papers/218/>
13. Wilson M. Families with Severe Medical Conditions in Children: Effects and Interventions. Available from: <https://sophia.stkate.edu/cgi/viewcontent.cgi?article=1413&context=msw_papers>
14. Shaikh M, Woodward M, John O, Bassi A et al. Utilization, costs, and outcomes for patients receiving publicly funded hemodialysis in India. *Kidney Int*. 2018;94(3):440-5. Available from: <https://pubmed.ncbi.nlm.nih.gov/30143062/>

1. All names have been changed to protect the identities [↑](#footnote-ref-1)