Dialysis Decision-Making, Dialysis Experiences, and Illness Perceptions: A Qualitative Study of Pakistani Patients Receiving Maintenance Hemodialysis

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Editorial, ●●●
ABSTRACT:

Rationale and Objective: The incidence and prevalence of patients with kidney failure requiring dialysis are increasing in Pakistan. However, in-depth perspectives on kidney care from Pakistani people requiring maintenance dialysis are lacking.

Study Design: Qualitative interview study.

Setting and Participants: Between September 2020 and January 2021, we interviewed twenty adults receiving maintenance hemodialysis in two outpatient dialysis units in Pakistan. We asked open-ended questions to explore their experiences with various aspects of kidney care.

Analytical Approach: We recorded, transcribed, and then using a phenomenological approach, thematically analyzed interviews.

Results: We observed the following six main themes: (1) Patients perceived various supernatural phenomena as causes of their illness and chose traditional medicine for CKD treatment. (2) Patients expressed dissatisfaction with their physicians’ communication. They felt poorly informed and resented their decision to initiate dialysis. (3) Family members tried to dissuade patients away from dialysis but also provided support once dialysis was initiated. (4) Patients and families found it challenging to afford dialysis and transplantation and also to arrange for transportation. (5) Women found it challenging to fulfill their obligations as wives and mothers while receiving maintenance dialysis. (6) Patients seemed reluctant to discuss end-of-life care.

Limitations: We collected data from only two hospitals in neighboring cities. Additionally, patients on peritoneal dialysis were not included.
**Conclusions:** Our findings shed light on patients’ perspectives on kidney care in Pakistan and call for financially feasible solutions to raise kidney disease awareness and improve patients’ experiences with dialysis. Physician training in communication and shared dialysis decision-making along with the development of culturally adapted decision aids are needed to improve CKD knowledge and shared decision-making. While financial challenges preclude many from receiving long-term dialysis, cost-effective strategies to improve the availability of other options (e.g., supportive kidney care, peritoneal dialysis, and transplantation) are still warranted.

**KEYWORDS:** Patient perspectives, Qualitative research, Dialysis decision-making, Challenges of Pakistani dialysis patients, End-of-life care, Developing countries, Kidney care, and Financial challenges
Plain-Language Summary:

Given the increasing prevalence of chronic kidney disease in developing countries, insights into the lived experiences of patients with kidney disease are much needed. Yet, patients' voices on pre-dialysis and dialysis care in Pakistan are lacking. In this qualitative study of 20 Pakistani people receiving dialysis, we found that patients had illness misperceptions and were dissatisfied with physicians’ communication and dialysis decision-making style. Family members initially discouraged patients from dialysis but also tended to offer support after dialysis initiation. Women experienced difficulties fulfilling their roles as mothers and wives while continuing to receive dialysis. Dialysis and transplantation affordability and reluctance to plan for the end-of-life were also other themes.
The incidence of kidney failure in Pakistan is growing\(^1\) and access to kidney replacement therapy (KRT) is problematic. Only a minority of Pakistani patients can afford dialysis; the annual costs of dialysis exceed the annual average household income.\(^2\) Consequently, many individuals receive less than thrice-weekly hemodialysis or avoid dialysis altogether, leading to early death.\(^2\) Moreover, there are few trained nephrologists in the country,\(^1\) and most practice in urban centers,\(^1\) meaning that chronic kidney disease (CKD) care in rural areas is most often entirely lacking or mainly provided by general practitioners.\(^3\) Thus, not surprisingly, patients commonly present to nephrologists when uremic, and many start urgent dialysis without prior dialysis education and preparation.\(^4,5,6\) Previous quantitative work on Pakistani people receiving maintenance dialysis has highlighted various gaps in clinical care and deficits in healthcare infrastructure including lack of preventive care,\(^1,7\) difficulties affording dialysis,\(^2\) refusals of KRT by majority of patients,\(^8\) inadequate dialysis-decision-making,\(^9\) CKD treatment by practitioners of alternate medicine,\(^10\) and poor end-of-life planning\(^9\) despite high kidney disease-related mortality.\(^11,12\) However, no prior qualitative studies have looked into the causes of these deficits within contexts of Pakistani culture, limited availability of resources, influences from religion, and local styles of healthcare delivery. Therefore, this phenomenological study asks: What are the lived experiences of persons with CKD making decisions about KRT options and receiving kidney care in a developing country like Pakistan?\(^13,14\)

**METHODS**

**Participant Selection**
Between September 2020 and January 2021, using a convenience sampling methodology, we invited 22 maintenance dialysis patients from two hospitals: Capital Development Authority (CDA) Hospital, Islamabad, and Bahria International Hospital, (BIH) Rawalpindi. CDA hospital provides free dialysis to its employees and their families (paid by insurance), while Bahria International Hospital is a private hospital where patients usually pay out of pocket for their dialysis but some patients’ dialysis costs are covered by charity and zakat (an annual tax paid by affluent Muslims to help underprivileged people). A study team member (S.M.) approached twenty-two patients and informed them of the purpose of the study; twenty agreed to participate and provided written consent. We considered participants eligible to participate if they were >18 years old, had been on dialysis for >3 months, had no cognitive impairment, and spoke Urdu or Punjabi. Participants were interviewed privately and in-person while undergoing dialysis. The study protocol was approved by the local IRBs of Capital Development Hospital and Bahria International Hospital and the IRB of Shifa International hospital (IRB #099-21)).

Data Collection

Semi-structured face-to-face phenomenological interviews (25 to 60 minutes) of the participants were conducted to elicit their perspectives and experiences regarding dialysis. The interviews were informed by literature from developing countries on dialysis patients' common challenges, discussions among investigators, and a phenomenological approach that focuses on the contextualized, whole person and life-world understandings with the goal of understanding issues at hand—the interview guide is in Table 1. The interviews covered participants’ perspectives on CKD care, dialysis decisions, ongoing dialysis care, health beliefs, alternative medicine usage, and
impact of dialysis on day-to-day life. The questions were translated into Urdu (7th-grade level), the national language of Pakistan, in consultation with an external Urdu language expert. After piloting the interview on five people receiving dialysis (responses not included in the thematic analysis of the current study), we made minor changes to the questionnaire. The audio recorded data was transcribed for analysis, and finally, patient names were changed to pseudonyms.\textsuperscript{16} (Table 2). COREQ criteria were used to report the study. No repeat interviews were carried out, and no transcripts were returned to the participants for comments or corrections. No field notes were taken during and/or after the interview.

**Data Analysis**

Four research team members, three of whom are of Pakistani origin (S.M., F.S., A.Z.) and one expert in qualitative methods (R.J.A), collaborated to code the data using MAXQDA 2021. Two researchers (S.M., A.Z.) coded the data independently and reached an agreement through discussions with the senior author (F.S.). Another researcher (R.J.A) then provided feedback on the final codes. During this process, thematic saturation—repeated, deep understandings of the themes present in the interviews—was reached.\textsuperscript{17} In accordance with the phenomenological approach, we drew on the procedure described by Barritt et al.\textsuperscript{18} and identified salient quotes, grouped those quotes by similarity, and subsequently identified common themes. Disagreements were resolved by discussions among authors.

**RESULTS**

**Patient characteristics**
All of the twenty patients who agreed to participate in the qualitative interviews shared a similar nationality, religion (Islam), and racial composition. The mean age of the participants was 45 years (SD±17.32), 13 were women and 18 were married. The mean duration of the interviews was 32 minutes (SD±8.5). We identified six major themes in our analyses.

**Illness misperceptions and traditional medicine as the initial choice of CKD treatment**

We found that misperceptions about the etiology of kidney disease were common among patients who frequently sought initial CKD care from practitioners of alternative medicine.

**Illness misperceptions**

Most of the patients in our study attributed their illness to both medical diagnoses and supernatural causes. Fifteen participants stated that their illness came from diseases; for instance, Khadija narrated, “I have diabetes since childhood…. It [the kidney problem] is because of this [diabetes].” On the other hand, 11 participants stated that their illness came from supernatural causes. Anum noted that she married very young and had children, so “Nazar [the evil eye] has afflicted me.” Similarly, we found black magic to be a recurring theme among patients as a cause of their current illness. Irum mentioned, "I have had it [black magic] confirmed by two to three places [holy persons]. They have said the same thing that this [disease] was caused by black magic. ”

**Traditional medicine as the initial choice of CKD treatment**

The participants' beliefs about the underlying cause of their kidney disease affected their initial choice of CKD treatment. Namely, superstitious beliefs led 11
participants to seek spiritual healers/alternative medicine practitioners to treat their CKD. Qasim reported, “There is a darbar [religious place]. They [spiritual healers] say to go there and drink the water, and Allah heals them [the patients]. We have gone there already once; we also brought back some water. We felt a little improvement. I passed a little urine too. We will go there again to bring water.” For some participants, alternative medications took precedence; as Huma reported, “I did not want to undergo dialysis. I used homeopathic medications. This [medication] stopped the progression [of my disease]. Then when I once suddenly fainted, dialysis was started immediately.”

**Dialysis patient’s experiences with physicians and the healthcare system**

Patients expressed dissatisfaction with physicians’ communication and felt frustrated with the amount of dialysis information. These lapses in informed decision-making frequently led to sentiments of mistrust and resentment against dialysis as described in the sub-themes below.

**Frustration with physicians’ communication**

When patients did choose dialysis, most patients were dissatisfied with their doctors. Patients complained that doctors did not take enough time to explain their disease, the expected course of therapy, and the treatment alternatives. Sehar commented, “If they (doctors) talk in a good way then the patient becomes happy. There are many doctors who give less time. The patient should be considered a human being. The patient is not even asked about how they are feeling.” Hassan while sharing his experience stated, “The doctor said that dialysis is needed but did not tell me its total duration. They should had explained to me in more detail.” Similarly, Ayesha reported, “The doctor said your kidneys would recover after two or three dialysis sessions. Now it is the second
year of dialysis. Dialysis is still being done. Now even I cannot urinate. I would not have opted for it if they had not given me such hope.”

Our study participants, therefore, desired that “Doctors should explain better and give more time” and “should talk” directly to the patient.

Mistrust in physicians and poor dialysis education

Almost all patients received initial CKD care from general practitioners rather than nephrologists. Dialysis patients tended to be dissatisfied with their physicians. Ayesha mentioned, "I didn’t know what a stupid doctor he was! He said I had intestinal TB [tuberculosis]. He ended up giving me TB medication.” Another patient Hassan while reporting the side effects of the prescribed treatment, said, “I had dengue fever. I stayed in the hospital. The medicine I got there created the problem [kidney disease].”

Given their reported poor communication and lack of trust in physicians, it may not be surprising that patients lacked accurate information about dialysis and their prognosis. Ayesha said, "They do cleaning with this machine. I do not know what things [they] remove from the inside [the body] with this machine." In addition, three patients reported that the machine removes essential nutrients from the body: Salman said, “I need strength. I eat everything.” Regarding prognosis, Khadija recounted that doctor gave her false hope of full recovery by saying that she “would recover after two or three dialysis sessions.”

Resentment against dialysis initiation

Many participants in our study expressed resentment against dialysis and its rigorous schedule. These participants had either missed dialysis or thought of withdrawing from dialysis at least once in their life. For instance, Umar reported, “I have
skipped dialysis many times... but, then the condition worsens, and my son brings me back for dialysis.” Similarly, Khadija stated, “The doctor has now advised thrice-weekly dialysis. But, because of the children, I do two times.” Furthermore, participants advised against dialysis to future dialysis patients. As Rabia suggested, “I would recommend against dialysis”; similarly, Irum reported, “I should not have started dialysis. I cry at home. Last evening, I was saying that I am fed up.”

**Role of the family**

Many family members initially discouraged patients from starting dialysis but were often helpful after the decision to initiate dialysis was made. Ayesha explained, “The family members said not to do it... all the family members said the same thing.” Nevertheless, family members, in-laws, and spouses seemed instrumental in supporting dialysis and treatment adherence. Rabia said, “Right now, my parents are taking care of my children. Otherwise, I wouldn't know how to come here [for dialysis]” Osama while mentioning his family support said, “My wife and daughter take care of me.” Similarly, Ramsha mentioned, “My son cares a lot about me and does everything.”

**Effect of financial difficulties**

Financial hardships were pervasive and affected all aspects of kidney care as illustrated in the sub-themes below.

*Difficulties affording dialysis*

Many of the challenges of life on dialysis revolved around financial considerations. Patients reported a lack of adherence and distress due to a lack of funds. Hassan narrated, “One cannot ask people for money. At maximum, one can ask one to two times.... Once, I said I would do dialysis once a week, but after four days, my health got
very bad, and I had to do it again.” Ramsha expressed distress that her husband was her only support: “We have four daughters and no son. We come from Wahh city for dialysis and cannot afford petrol and food. When there is only one breadwinner, it becomes difficult. Yes, our house is also rented out. There is no other support.”

Dialysis impacted individuals and families’ abilities to earn a living; Hassan sold his water plant business to pay for dialysis treatment, his only source of income, and he said, "I feel weak all the time…now I do nothing.” Family members of patients on dialysis also feel indirect impacts on their employment. Anum commented, “If he [my husband] comes with me, then he cannot go to work.”

Patients requested free [government-funded] dialysis units. As Hassan reported, “I have seen so many people who are going through this condition and crying. They cannot afford dialysis. Some government hospitals offer free dialysis, but there is not enough capacity.” Furthermore, due to financial constraints, some (7/20) patients moved from self-pay to charitable [free] dialysis. Still, even free dialysis did not allay all financial concerns and barriers. Patients still reported difficulty affording the fistula surgery to initiate dialysis and buy their medications.

**Difficulties affording and finding transportation**

Transportation was also a felt difficulty for dialysis patients, who find it difficult “to come and go” and “get tired.” Some patients come from great distances [up to 35 Kilometers] and/or face limited transportation options to obtain treatment. Travel expenses add to the total treatment cost. Maria commented on the cumulative difficulties: “Sometimes Uber comes late- there is a lot of tension… this Uber has ruined my life.”
Ahmad pointed out that transportation was also a barrier to seeking treatments: “The cardiologist should come here. We are poor people. Nobody is here to help us.”

**Difficulties affording kidney transplantation**

Most patients reported that they did not see dialysis as a long-term solution and would be perfectly willing to undergo kidney transplantation. Finances, of course, are an issue; some patients, like Rabia, simply “cannot” afford a transplant. Other patients worry that a transplant will leave their families financially vulnerable: “If it were just a transplant [cost], I would have done it, but there are a lot of problems. Our family is big. I don’t want to spend everything; I wish to spare enough money so that if I die, my family would not have a problem.” Long transplant wait time is somewhat common universally, but it posed unique challenges for patients such as Anam in the context of the Pakistani healthcare system which depleted all her financial resources receiving tests to prove her eligibility for transplantation. “I was thinking about the transplant, and I have spent three to three and a half lakh rupees [approximately $2065] for tests- I couldn't afford to proceed anymore.”

**Issues of womanhood**

The women in our study, in particular, experienced unique challenges on dialysis that revolved around their roles and identities as mothers and wives. Ramsha talked about her children, “In fact, the mother sees nothing but her children.” She continued, "I feel guilty because I am the reason for their problems." Another mother, Anum, elaborated, “We live alone [without any family support], and I have to do everything myself—the work that normally takes two hours, I do in six hours. I don't have that much money. If we can find someone from welfare to help, that would be beneficial.” Married women, such
as Khadija, also experienced difficulties: “I live with my in-laws. I have to take care of everyone. People often visit our home. In the beginning, there was a housekeeper, but now I work by myself. Now I do all (household) work before coming for dialysis, and when I go back, I do everything myself.” Similarly, Rabia commented, “I would say don’t do dialysis, especially if you have children, don’t do it at all.”

End-of-life care

Most (19/20) patients seemed reluctant to discuss end-of-life care; “I do not want to discuss this now.” However, when asked about their plans for the remainder of their lives, they valued life prolongation and felt that life was controlled by the divine. Most (18/20) participants wanted all resuscitative measures [CPR, mechanical ventilation] to be taken in an emergency. For instance, Salman suggested that "One should try ... the man never knows if a person can get better ... one should work hard until the end....” Similarly, Ahmad stated, “One should try. If it is Allah’s will, then it [the heart] will start working.”

DISCUSSION

Our findings provide insights into the experiences of Pakistani dialysis patients. Our patients’ experiences are rooted in influences from their culture, such as beliefs in supernatural phenomena and hopes of cure from traditional healers. Patients’ perspectives describe inadequacies of the Pakistani healthcare system, including dissatisfaction with physician communication around delivering knowledge, helping with dialysis-decision-making, and providing anticipatory guidance regarding end-of-life care. Many patients considered families as pillars of support. However, major obstacles to receiving adequate
kidney care such as paying for dialysis, accessing kidney transplants, and managing daily
tasks still need innovative yet cost-effective solutions.

Patients’ religious and cultural beliefs [evil eye, black magic] shaped disease perceptions; faith healers and alternative medicine practitioners appeared to be
gatekeepers of initial CKD care. Alternative medicine practices are widespread in both
developed \(^\text{19}\) and developing countries.\(^\text{20}\) In a study of 111 Muslims in the United
Kingdom, most believed in ghosts, spirits, black magic, and the evil eye. About half
believed that these forces caused their physical and mental health problems and that
illnesses should be treated by both physicians and religious scholars.\(^\text{21}\) Similarly, Bengali
Muslim patients often attributed their illnesses to black magic.\(^\text{22}\) Previous studies among
patients with psychiatric illnesses have highlighted the belief that black magic or spirits
contribute to illness and have the potential for disease cure.\(^\text{23}\) Our study extends the
literature by showing such beliefs among patients with kidney disease.

Our study participants described lapses in informed dialysis decision-making.
Most participants complained that physicians did not take time to explain the disease and
its prognosis. This finding is consistent with prior work from other countries showing
poorly informed dialysis decision-making.\(^\text{24,25}\) Part of the reason for this finding may be
because of the pervasiveness of medical paternalism in Pakistan\(^\text{9}\) and also because of
families’ active role in decision making on behalf of patients.\(^\text{9}\) Another tension in the
decision–making process was that families tried to dissuade their loved ones from
dialysis initiation. Part of the intention may be to protect patients from the emotional
distress associated with disease diagnosis and suffering associated with dialysis.\(^\text{26}\)
However, once patients started dialysis as recommended by their doctor, families tended to become a source of support and purpose.27

Economic difficulties precluded some patients from accessing regular thrice-weekly dialysis and transplantation. These findings are consistent with previous literature from developing countries.28 In a study of 8500 hemodialysis patients in developing countries, approximately 60% were lost to follow-up within the first three months of dialysis initiation because of non-affordability.29 Similar to financial difficulties in receiving dialysis, in accordance with the prior literature, kidney transplantation also posed financial challenges to the study participants.30,31 In Pakistan, 90% of the patients with kidney failure are disfranchised from kidney transplantation.32 Transplantation in the government sector is free but has limited availability. In contrast, in the private sector, transplantation costs between $6000- $10,000, and is not affordable by the majority of the Pakistani population33,34 as 60% try to live on < $2 per day.33 All of these financial difficulties were further accentuated for women who additionally struggled to raise children and fulfill their traditional gender roles. Furthermore, Pakistani dialysis patients are on average, younger than their US counterparts, and thus more likely to be parents of not yet grown children.35

This study has several strengths and limitations. The strength of the paper is the voices captured in the paper; patient voices from developing countries are often neglected in the literature. We captured diverse patients from government and private hospitals, self-paying and non-self-paying status, and both men and women. However, we derived our study sample from only two hospitals in neighboring cities and because of the limited sample size and qualitative nature of our study, our findings may be less generalizable.
Further, we did not include patients receiving peritoneal dialysis due to its limited availability in developing countries such as Pakistan. Finally, participants were interviewed in an outpatient hemodialysis center, and this environment may be uncomfortable or distracting due to ongoing dialysis.

This study has several important implications. Our study calls for models of care where both doctors and traditional healers can practice collaboratively and provide CKD care. While such models may not be immediately available for dissemination and implementation, good starting points will be training both general practitioners and traditional healers in basic kidney care and establishing evidence-based recommendations for this model from their respective disciplines. Similarly, physicians including nephrologists can be trained in the basics of traditional medicine to promote a sense of acceptance and collaboration between the two disciplines. Borrowing from palliative care in the US, the concept of ‘primary nephrology care’ needs to be contemplated in Pakistan; perhaps nephrologists can be best used to serve more complex cases. A medical school curriculum in communication and decision-making skills may help partly address patients’ communication and decisional needs. Additionally, culturally adapted decision aids in Urdu that highlight local challenges and potential solutions (e.g., dialysis and transplantation costs, and available resources) may help patients make more informed decisions. We acknowledge that while there seems to be no immediate solution available to the economic challenges faced by many patients, educating patients about kidney disease, screening, and early prevention of CKD are good starting points. Integrating preventive care with the three most cost-effective treatments such as kidney transplantation, peritoneal dialysis, and conservative kidney management is needed.
Media campaigns in alliance with influential members of society to promote awareness of early disease prevention may also be useful.

In summary, the qualitative interviews of Pakistani patients receiving maintenance dialysis highlight significant issues in the Pakistani health care system in providing optimal person-centered care for people with kidney failure. These issues revolve around misperceptions about the etiology and treatment of their illness, dissatisfaction with physician communication regarding dialysis decision-making and disease management, difficulties affording dialysis, transportation, and kidney transplantation, and lack of focus on end-of-life planning. These insights call for cost-effective solutions to improve kidney failure care as the country strives to reengineer its healthcare system.

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Table 1: Semi-structured interview guide used for this study

<table>
<thead>
<tr>
<th>Question</th>
<th>Cues</th>
</tr>
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<tr>
<td>1. You have been on dialysis. Tell us how you started dialysis?</td>
<td>(Discuss dialysis decision making and chronic kidney disease education)</td>
</tr>
<tr>
<td>2. How has been your experience regarding receiving dialysis?</td>
<td>(Discuss highs and lows, hopes, fears, coping, and transportation issues)</td>
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<tr>
<td>3. Affording dialysis can be hard at times, tell us how you are managing finances for the dialysis?</td>
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<tr>
<td>4. What are your views on alternative medicine practitioners such as hakeems?</td>
<td>(Discuss if patients sought treatments such as Herbal remedies, Peers, Chinese medications, Black magic, Nazar)</td>
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<tr>
<td>5. Everyone will die one day. What are your thoughts on how you would like to die?</td>
<td>(Explore thoughts about stopping dialysis, prognostic understanding, would they want to receive CPR?)</td>
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<td>6. If you have to start the dialysis all over again, are there things that you would do differently?</td>
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<td>7. What would be your advice to others, who require dialysis?</td>
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<td>8. What would you suggest to the doctors to improve the whole dialysis experience for the patients?</td>
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<td>9. Is there anything else we need to talk about?</td>
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Table 2: Biographic details of interviewed patients

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