

Dialysis Decision Making and the Patient Experience: Lessons From Pakistan

Katherine Rizzolo, Tala Al-Rousan, and Lilia Cervantes



Pakistan is the world's fifth largest country by population and a nation where chronic kidney disease (CKD) and kidney failure prevalence are rising. Kidney failure in Pakistan is a disease of the young; the mean age of

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individuals with advanced CKD is 42 years, compared with 63 years in the United States.¹ Much of the elevated CKD incidence has been attributed to the high prevalence of underlying comorbid conditions such as diabetes and hypertension and underdeveloped health care infrastructure as a result of low government budgetary allocations for health care, leading to underdeveloped primary health care facilities, limited access to subspecialty care, and high costs of kidney replacement therapy treatment for patients.^{2,3} As a result, many people receive late or no CKD care and counseling.⁴

Survey-based studies surrounding dialysis decision making in Pakistani individuals receiving dialysis have indicated that Pakistani individuals report inadequate predialysis conversations, and a majority regret their decision for dialysis.⁵ In other studies, people receiving dialysis in Pakistan reported poor quality of life due to dialysis-related factors,⁶ with those with higher levels of illness intrusiveness (the extent to which illness and treatment affects a person's life and activities) reporting a greater loss of quality of life.⁷ However, these studies are survey-based, which limits understanding of a patient's experience and perspective underlying these responses.

In this issue of *Kidney Medicine*, Malik and colleagues⁸ investigate the kidney care experience for Pakistani patients receiving dialysis. The authors utilized phenomenological qualitative research methods to investigate the dialysis experience of 20 individuals receiving in-center hemodialysis in 2 urban outpatient dialysis units in Pakistan. As opposed to survey studies, the nature of a qualitative study allows for eliciting the patient's experiences and perspectives, providing a glimpse into patients' values and priorities. Qualitative research is useful for understanding best approaches, challenges, and facilitators to share decision making as well as to gain insight into needed changes in practice and policy to inform health care in nephrology.⁹

In the current study, many patients believed supernatural phenomena caused their illness. Studies of other chronic diseases such as breast cancer illustrate the role of religion and spirituality in the Pakistani patient experience, mirroring the experience among patients in many parts of the world.¹⁰ In many low- and middle-income countries,

traditional medicine is often first-line and coexists with Western medicine.¹¹ In Pakistan, faith healers and traditional medicine practitioners often are the first to encounter a patient with a new CKD diagnosis. Patients will seek homeopathic, herbal, and spiritually based methods for treatment in addition to dialysis treatment.⁶ Malik and colleagues' findings illustrate the importance of aligning spirituality, religiosity, and traditional medicine in dialysis decision making in Pakistan and perhaps more broadly.⁸ Community-based and clinical interventions in CKD care may consider including factors such as spirituality, religiosity, and traditional medicine into health promotion efforts.

Another common theme was dissatisfaction with physician communication, which is a relatively common finding in developed and developing countries alike. In the United States, patients report inadequate predialysis education, and often, the full gravity of dialysis is not realized until after dialysis initiation.¹² In one study, 19% of US patients regretted their decision to start dialysis, 41% wished to focus on comfort care, and 71% wished to further discuss quality of life.¹³ In a cross-sectional survey study in Pakistan, the majority of patients receiving dialysis reported starting dialysis at their physician's request, and 62% regretted starting dialysis.⁵ Most patients reported not understanding their disease trajectory, and there was a large discrepancy between perceived knowledge of their CKD and understanding of progression of CKD to kidney failure.⁵ This finding aligns with another study in Pakistan demonstrating that half of individuals affected by CKD did not understand their prognosis or the reason for the medications they were prescribed.¹⁴ Further, another study found many Pakistani patients believed their kidneys would recover when dialysis was initiated.⁶ Malik and colleagues⁸ build on the drivers behind many of the findings in preceding survey studies; patients felt doctors did not spend enough time explaining the disease, course of therapy, and treatment alternatives. In addition, they felt the lack of information influenced their distrust of physicians. Overall, this perspective adds to the literature demonstrating that quality health care provider communication and trust improves the dialysis experience.

The themes of illness misperceptions and poor physician communication require an understanding of cultural context. Due to a high burden of communicable disease and natural disasters such as floods, the health care infrastructure in Pakistan is complex and underdeveloped.¹⁵ Specialized kidney care is scarce; there are approximately 80 nephrologists serving a population of 160 million, according to an estimate in 2004.¹⁶ As such, many patients

receive their care from general practitioners, who may not be trained in CKD or dialysis care¹⁶ and who may lack palliative care training to discuss conservative management and end-of-life care.¹⁷ In addition, Pakistani culture places less autonomy on the individual regarding medical decision making than many other cultures, and medical decisions are often made by physicians or the patient's family, rather than the patient themselves.^{18,19} Regardless of these factors, patients with chronic disease in Pakistan, similar to patients elsewhere, report that they wish to be informed about and involved in their own care.²⁰ Overall, these findings suggest that conversations with patients and their family require culturally responsive communication that considers a patient's cultural and religious preferences and in a way that is appropriate for their health literacy and education level.

Notably, the high number of patients who regretted initiating dialysis in Pakistan may, in part, reflect poor quality of life in the setting of inadequate dialysis treatment. Pakistan spends 0.9% of its gross national product on health care, and full health care coverage is uncommon; about 73% of the population pays for health care completely out of pocket.² For people paying out of pocket for thrice-weekly hemodialysis, the cost is 4 times the average annual income in Pakistan.¹ As dialysis can be prohibitively expensive, many patients dialyze only once or twice a week, contributing to a higher symptom burden, higher mortality rate, and lower quality of life. Higher levels of illness intrusiveness are associated with lower quality of life for Pakistani people receiving dialysis in many areas, including physical health, psychological health, social relationships, and environment.⁷ Although quality of life was not addressed by Malik and colleagues,⁸ it is possible that inadequate dialysis treatment compounds quality of life, affecting patients' dissatisfaction with their treatment plan.

Affordability of dialysis is a major concern in many low- and middle-income countries where out of pocket treatment costs are high.²¹ The study by Malik and colleagues⁸ included individuals paying out of pocket for dialysis as well as individuals receiving charitable (free) dialysis. Among individuals receiving charitable dialysis, there were also financial constraints, often related to cost of transportation and income loss due to inability to work because of symptom burden and constraints on time from dialysis treatments. Overall, the inclusion of charitable dialysis units indicates that financial constraints to dialysis exist even for those not paying for dialysis, which must be considered as a factor in dialysis decision making.

Sixty-five percent of the study's sample self-identified as women, who reported unique challenges related to their roles as mothers and wives. Many women reported struggling to balance caregiving for their families with their dialysis treatments. Others relayed guilt that they were a source of problems and financial struggle for their family. These feelings of guilt may be especially high in a collectivist culture such as Pakistan, where family members are expected to care for the ill member of the family. In other

studies, women were found to have higher levels of illness intrusiveness and symptom burden⁷; Malik and colleague's interviews highlighted reasons why this may hold true.

The qualitative study by Malik and colleagues⁸ is an important contribution to the literature because they investigate the illness experience from the patient's viewpoint, providing a needed perspective on dialysis scarcity, physician communication, and end-of-life care. Recruitment from 2 hospitals with 2 different payment models allowed for a variety of perspectives on dialysis affordability. Some of the limitations of this study include its small size of 20 participants and low geographic variability. As Pakistan has 4 provinces, each with its own culture and regional language,⁴ more research including other areas of Pakistan is needed to expand on other barriers such as rurality, care access, and cultural variability in perspectives on dialysis care. Moreover, given dialysis use is rather uncommon in Pakistan, all these patients represent the minority of patients with kidney failure and may not represent the values of those patients who are not treated with any kidney replacement therapy.

Important lessons may be gleaned from this research, which may be applied across many low-resource countries. This study demonstrates that the patient experience may be improved by incorporating cultural beliefs and traditional medicine, as well as understanding the role of family and gender in decision making and daily life with kidney failure. In many low-resource countries, affordability of kidney replacement therapy and access to kidney care is a major source of inequity because of large out of pocket costs; in some studies, physicians reported not discussing expensive treatments as options because of financial concerns.²² Regardless, the study by Malik et al⁸ indicates that patients prefer involvement in their own care. Although larger changes are needed to improve access to kidney replacement therapies and kidney care in low-resource settings,²¹ an understanding of cultural, socioeconomic, and demographic factors affecting the patient experience on dialysis may serve to improve communication and care offered by general practitioners and nephrologists alike in these areas. Overall, the findings from Malik and colleagues contribute to the growing body of qualitative literature, which may be used to inform and improve kidney care in Pakistan and internationally.

ARTICLE INFORMATION

Authors' Full Names and Academic Degrees: Katherine Rizzolo, MD, Tala Al-Rousan, MD, MPH, and Lilia Cervantes, MD.

Authors' Affiliations: Department of Renal Medicine and Hypertension, University of Colorado, Aurora, CO (KR); Herbert Wertheim School of Public Health and Human Longevity, University of California, San Diego, CA (TAR); and Department of Medicine, University of Colorado Anschutz Campus, Aurora, CO (LC).

Address for Correspondence: Katherine Rizzolo, MD, Department of Renal Medicine and Hypertension, University of Colorado, Aurora 80045, CO. Email: Katherine.rizzolo@cuanschutz.edu

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