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## Dialysis Decision Making and Preferences for End-of-Life Care: Perspectives of Pakistani Patients Receiving Maintenance Dialysis

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### Abstract

**Context.**—Previous studies from the U.S. and Canada report deficiencies in informed decision making and a need to improve end-of-life (EoL) care in patients undergoing dialysis. However,

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there is a paucity of literature on these issues in Pakistani dialysis patients, who differ from Western patients in culture, religion, and available health care services.

**Objectives.**—To study informed dialysis decision-making and EoL attitudes and beliefs in Pakistani patients receiving dialysis.

**Methods.**—We used convenience sampling to collect 522 surveys (90% response rate) from patients in seven different dialysis units in Pakistan. We used an existing dialysis survey tool, translated into Urdu, and backtranslated to English. A facilitator distributed the survey, explained questions, and orally administered it to patients unable to read.

**Results.**—Less than one-fourth of the respondents (23%) felt informed about their medical condition, and 45% were hopeful that their condition would improve in the future. More than half (54%) wished to know their prognosis, and 80% reported having no prognostic discussion. Almost 63% deemed EoL planning important, but only 5% recalled discussing EoL decisions with a doctor during the last 12 months. Nearly 62% of the patients regretted their decision to start dialysis. Patients' self-reported knowledge of hospice (5%) and palliative care (7.9%) services was very limited, yet 46% preferred a treatment plan focused on comfort and symptom management rather than life extension.

**Conclusion.**—Pakistani patients reported a need for better informed dialysis decision making and EoL care and better access to palliative care services. These findings underscore the need for palliative care training of Pakistani physicians and in other developing countries to help address communication and EoL needs of their dialysis patients.

### Keywords

ESKD; dialysis decision making; shared decision making; end-of-life care; Palliative care in Pakistan

### Introduction

Pakistan is a developing country that lacks the critical infrastructure to support optimal care of patients with chronic kidney disease (CKD) and end-stage kidney disease (ESKD).<sup>1</sup> Only 0.9% of Pakistan's gross national product is spent on health care, compared with nearly 18% of the gross domestic product in the U.S.<sup>2</sup> Costs of dialysis and kidney transplantation are often paid by patients and families, who typically cannot afford health insurance.<sup>2</sup> The annual cost of hemodialysis in Pakistan is estimated to be \$4669, nearly four times the per capita income, of \$1260/year.<sup>2</sup> Peritoneal dialysis is even more expensive at \$12,450 annually and is not widely available.<sup>3</sup> The approximate cost of dialysis per year is around eight times per capita annual income in Pakistan.<sup>4</sup> Consequently, patients may only be able to pay for dialysis once or twice a week,<sup>3</sup> resulting in poor survival.<sup>5</sup> Furthermore, data from other underdeveloped countries such as India suggest that around 65% of patients are not able to receive dialysis or withdraw from dialysis because of financial constraints.<sup>6</sup> In addition, there is a lack of formal quality control to ensure safe dialysis.<sup>3</sup> Furthermore, only a handful of trained nephrologists practice in the country.<sup>7</sup> These specialists are located in major urban cities, making it necessary for patients and families to travel long distances for

specialist care.<sup>1</sup> Hence, routine CKD care, not including dialysis, is delivered mostly by general practitioners often not trained in CKD treatment.<sup>8</sup>

In Pakistan, ESKD is often a disease of the young. Although the country lacks a formal national registry for ESKD, studies suggest that the median age of Pakistani patients approaching ESKD is 44 years,<sup>2</sup> compared with 63 years in the U.S.,<sup>9</sup> probably because they lack routine medical care.<sup>10</sup> Given the lack of affordable access to dialysis, mortality rates are especially high.<sup>11</sup> Only 10% of patients with ESKD receive dialysis, and most of those die within three months of dialysis initiation.<sup>2</sup>

Despite high mortality rates, palliative care is not well established in Pakistan; it is available only in major cities such as Lahore and Karachi.<sup>12,13</sup> Hospice services are nearly nonexistent, and comfort care toward EoL is less commonly provided.<sup>12,14</sup> In addition, Pakistani physicians lack training in end-of-life (EoL) care and have a predilection toward performing cardiopulmonary resuscitation regardless of prognosis or patient wishes.<sup>15</sup> Therefore, studies exploring EoL care gaps and solutions in the country are critically needed.

In developed countries, research suggests the need for improved dialysis decision making and EoL care planning for patients receiving maintenance dialysis. In one U.S.-based study, only 53% of patients felt informed about their disease.<sup>16</sup> Only 10.6% recalled having prognostic discussions, whereas 80% wished to have such conversations.<sup>16</sup> In another U.S.-based study, only 1% of patients were informed about conservative management as a viable alternative to dialysis.<sup>17</sup> Decisions were frequently made by physicians alone, not by shared decision making, and many patients regretted their decision to initiate dialysis.<sup>16</sup> Moreover, only 35% of patients with ESKD had a living will in place.<sup>16</sup> However, little is known about patients' preferences for decision making and EoL care planning in a developing country like Pakistan.

Pakistani dialysis patients differ from those in Western countries in culture and religion. Pakistani culture, in general, does not emphasize individual autonomy to the same degree as in the West. Rather, medical paternalism is prevalent in Pakistan, and decisions are often made by families or physicians on behalf of the patient.<sup>18</sup> Furthermore, in Islamic faith, death is considered as a transition point to an everlasting life and disease/illness a way to purify sins.<sup>19</sup> Because of the lack of infrastructure for CKD care, limited access to specialist care, scarcity of palliative care trained specialists, and differences in cultural and religious practices toward decision making and EoL, we hypothesized that Pakistani patients will report lack of informed decision making, less knowledge about palliative care/hospice, and unmet EoL planning needs. To test these hypotheses, we administered a 43-item questionnaire to Pakistani patients undergoing dialysis to gather their perspectives about dialysis decision making, EoL care attitudes, and knowledge of palliative care and hospice.

## Methods and Statistical Analyses

The survey was adapted from the study of Canadian dialysis patients by Davison.<sup>20</sup> The questions were translated into Urdu, the national language of Pakistan, by two authors (F. S.

and M. S.) who are native Urdu speakers and physicians, in consultation with a language expert. Minor changes were made to the content of the survey to ensure conceptual equivalence and avoid misinterpretation by study participants. Linguistic validity was ensured by backtranslation.<sup>21</sup> Face validity was evaluated by five physicians, including a renal palliative care physician (F. S.) and a psychiatrist as well as a psychologist and nurses on the dialysis team. We piloted the survey with 50 Pakistani patients. We had initially included a question about advance directives, but this was eliminated because advance directives are not a part of the Pakistani medical culture. The study was approved by the Institutional Review Board of Army Medical College, Rawalpindi, Pakistan.

The survey was distributed by three authors (M. S., K. R., R. N.) to dialysis patients from seven dialysis units, located in three cities of Punjab (Rawalpindi, Sialkot, and Lahore) and one city of the Sindh province (Hyderabad) from March to June 2015. All adult patients (at least 18 years or older) receiving maintenance dialysis were eligible to participate in the study. In each dialysis unit, staff were present to facilitate the survey process, and each patient was approached personally by one of the three authors, who remained available to provide assistance. The study background was explained, verbal consent was obtained, and all questions were answered. Survey questions were administered verbally to participants who were illiterate or visually impaired. Patients lacking capacity were excluded from the study. We used a convenience sampling method and did not calculate any formal sample size. Descriptive statistics were used to describe patients' characteristics and preferences.

## Results

A total of 578 maintenance dialysis patients were approached, and 522 patients (response rate 90%) completed the survey. Table 1 shows patients' clinical status and personal characteristics. More than half of the respondents were males with a mean age of 49.6 years, and 93% were Muslims. Nearly all patients were on hemodialysis. Table 2 summarizes patients' self-knowledge about their illness and hospice/palliative care services. Only 13% reported that they felt uninformed about their medical condition, but 45% were hopeful that their condition would improve in the future. Only a very small percentage of patients reported knowing what hospice (5%) and palliative care (7.9%) are.

Table 3 summarizes patients' preferences about knowing their prognosis, quality of life, and advance care planning (ACP). Most patients considered it important to have more information about their medical condition (68%), prognosis (54%), and management options such as alternative ways to manage physical symptoms or withdrawing from dialysis (61%). About two-thirds wanted their families to be actively involved in the decision making regarding their management plan. Similarly, about half of the patients wanted their nephrologists to discuss quality of life and to attend to their spiritual, social, and psychological concerns.

Table 4 presents patients' perspectives on EoL care and discussion. More patients relied on family/friends (40%) for support on emotional and social issues, rather than on their doctors or nurses (29% and 18%). Only 4% of patients counted on religious leaders/Imams for emotional support. Almost one-half (47%) of the respondents wanted their families to make

medical decisions if they ever became incompetent to make decisions for themselves, whereas 27% preferred their physician to make decisions on their behalf. Most patients (80%) reported dependence on their physicians (nephrologist or family physician) for medical information. About half (54%) reported that they had agreed to start dialysis because it was their physicians' wish, whereas less than one-third (28%) affirmed that it was their own choice. More than half (62%) of the patients in our survey regretted their decision to start dialysis.

Almost two-thirds were comfortable discussing EoL care with their nephrologist and family members. However, most (81%) reported never having a discussion about life expectancy with their physician, and 42% did not report any discussion about choices concerning EoL care during the past 12 months. More patients preferred a treatment plan focusing on improving quality of life (47%) rather than prolonging life (19%), but one-third (34%) were still unsure. More than half of our survey participants (56%) wanted full resuscitation in case of cardiopulmonary arrest, and only 17% had completed a living will. Approximately one-third preferred their nephrologist to discuss EoL issues (37%) compared with 22% who wished to have this discussion with their family physician. Most patients wanted to discuss EoL care issues only when the need arises (56%). Preferred place of death for most patients was home (68%), rather than the hospital (12%).

## Discussion

To our knowledge, this is the first study to report on ESKD treatment decisions and EoL care preferences in a predominantly Muslim cohort of middle-aged Pakistani patients receiving maintenance dialysis. Most reported not understanding the disease trajectory; nearly a half wished to know about their prognosis. Only one-fourth of the patients reported dialysis to have been their own choice, whereas 50% preferred conservative management as a treatment option and 62% regretted their decision to initiate dialysis. Only a small proportion of patients knew about palliative care and hospice services.

Understanding context is important to interpreting these results. ESKD care in Pakistan suffers from the lack of a well-developed health care infrastructure. The country has only 80 nephrologists serving a population of 160 millions, according to a study from 2006;<sup>7</sup> hence nephrologists are in very high demand. Studies from other low-income countries show that most patients with ESKD (53% in India and 84% in Africa) discontinue dialysis and die.<sup>22,23</sup> In Pakistan, more than half of the patients needing dialysis refuse because they cannot afford treatment, or their quality of life is expected to be poor, and/or they fear needles.<sup>24</sup> Nonetheless, despite limitations in the quality and affordability of available care for ESKD in low-income countries like Pakistan, these patients have a right to participate in informed decision making about treatment and to be offered patient-centered EoL care.

In our study, 82% of the patients reported that they were completely/somewhat informed about their medical condition compared with 53.4% of Western patients who reported being completely/somewhat informed.<sup>17,25</sup> Despite the belief of Pakistani patients that they have disease knowledge, only 12% of the Pakistani patients suspected that their condition could worsen during the period of 12 months, whereas 45% thought that it would improve. This

large discrepancy between patients' perceived disease knowledge and the actual trajectory of ESKD suggests poor disease knowledge that might be attributed to physicians' failure to engage in informed decision making. It is also possible that families withhold medical information from patients to protect them, a common cultural way to express affection.<sup>26</sup>

Evidence of medical paternalism was prevalent in this sample as more than half of the respondents reported that their decision to start dialysis was made by their nephrologists, whereas only 28% reported making their own choice. This paternalistic approach to care has been reported in previous Pakistani studies.<sup>27</sup> Others have argued that paternalism is universal in medical culture worldwide; it is certainly not exclusive to Pakistan.<sup>16,20</sup>

A high proportion of the patients wished to know their prognosis, a critical component of the informed decision making, but only a few recalled having such discussions. This finding is similar to a previous Pakistani study on patients with cancer where three of five wished to know their prognosis.<sup>28</sup> Potential barriers to prognostic discussions could include medical paternalism, a belief that only God knows the exact prognosis, a lack of physician training in delivering bad news, physicians' fear of disrupting the physician-patient relationship, physicians wish to maintain hope, and their own fear of death.<sup>26,29-31</sup> Prognostic discussions help patients determine their EoL care goals, plan for their future, and strengthen their sense of hope rather than diminishing it.<sup>32</sup> Patients who recall a discussion regarding their prognosis are more satisfied with their care and more ready to discuss cardiopulmonary resuscitation status.<sup>33</sup> In the absence of such discussions, they are likely to overestimate their prognosis.<sup>34</sup> Further qualitative studies in the context of Pakistani society, religion, and medical culture are needed to comprehensively understand barriers to prognostic discussions.

About two-thirds of patients in our sample regretted their decision to start dialysis. Decisional regret about starting dialysis was much higher in our cohort of Pakistani dialysis patients than in similar studies conducted in Western countries (reported range of 7%–61%).<sup>16,20,35,36</sup> According to a Dutch study, regret is more likely to be experienced by younger patients and those who are influenced by either their physician or their family members to start dialysis.<sup>37</sup> Some have suggested that a lack of autonomy in decision making about dialysis initiation and lack of prognostic awareness may underlie this decisional regret.<sup>38</sup> In the future, it will be critical to study why such a high percentage of Pakistani dialysis patients regretted their decision to initiate dialysis, and is this regret attributable to lack of informed decision making, clinical symptoms, poor quality of life, or the financial impact of dialysis on families?

It is notable that 46% of the patients in this study preferred conservative kidney management with therapies aimed at relieving symptoms rather than prolonging life. This suggests the need for initiatives and research to incorporate palliative care principles into ESKD care, including discussion of conservative kidney management with Pakistani patients. In this context, an important question to address is whether conservative kidney management is the right treatment approach for patients who cannot afford dialysis.<sup>39</sup> Presently, such patients receive conservative kidney management by default, rather than by choice. In the care of patients with ESKD, an enhanced primary care focus on symptom management and relief of

suffering might offer patients a source of dignity in the face of hopelessness and poverty. In Pakistan, the field of palliative care is very young, as demonstrated by the very low prevalence of knowledge about palliative care and hospice (8% and 5%) among our sample of patients with ESKD. In a Canadian study of 584 patients, 22% knew about palliative care and 18% about hospice.<sup>20</sup> In a similar American study, 23% and 82% knew about palliative care and hospice, respectively.<sup>16</sup> Whether Pakistani ESKD patients can afford dialysis or not, all need easy access to hospice and palliative care services, so their symptoms can be managed and ACP can become a routine part of their treatment. In 2014, the World Health Organization emphasized the need to improve EoL care of sicker patients with chronic conditions like ESKD who live in low-income to middle-income countries and to increase the availability of palliative care services.<sup>40</sup> The report endorsed palliative care as a human right for patients living in countries with fewer resources. Patients who cannot access needed health care when they face life-limiting illness need palliative care the most. Future initiatives to establish primary care-based palliative care programs for Pakistani patients with ESKD are needed urgently.<sup>12</sup>

In our survey, 63% of patients considered it important to prepare and plan for death, but only 18% were able to discuss these issues with their doctors. These findings are consistent with those reported in U.S. and Canadian patients,<sup>16,20</sup> but the Pakistani health care system can make some fundamental changes to improve EoL care. It lacks a system for ACP, and most physicians are unaware of practices to honor patients' dignity near the end of their lives.<sup>15,41</sup> Moreover, EoL discussion in a relatively young patient requires expertise, which is not routinely taught in Pakistani medical schools.<sup>42</sup>

Our study has several strengths and limitations. To our knowledge, it is the first study conducted in Pakistan to investigate dialysis patients' experiences with dialysis decision making and EoL attitudes. It highlights major shortcomings in dialysis decision making and opportunities for improvement in EoL care through physician training programs and policy changes to increase the availability of palliative care. Limitations of the study include the use of a convenience sampling methodology, lack of a formal assessment of the reading level of survey questions, and inability to capture data on the percentage of patients who were self-pay vs. paid by other resources. Furthermore, a selection bias based on income was unavoidable because only patients able to afford dialysis were included in the study. In addition, patients with low educational levels may have misunderstood some of the questions, despite the presence of a survey facilitator. Finally, we did not assess health literacy or use a validated scale to assess kidney disease knowledge.

Our study has several clinical and policy implications at a global level. The worldwide incidence of EKD is rising<sup>43</sup> with CKD ranked as the 18th highest cause of death.<sup>44</sup> In developing countries, dialysis outcomes are poor and prognosis limited—making informed decision making as one of the most critical components of ESKD care.<sup>3,22</sup> In such countries, particularly those with a self-pay model of ESKD care, informed dialysis decision making requires not only a balanced description of treatment choices, including transplantation, and the sharing of clear information about prognosis, anticipated quality of life during treatment, and withdrawal of dialysis but also information on the consequences of suboptimal dialysis and financial burden. Patients, in the present study, wished more information on prognosis,

disease knowledge, and other EoL issues. They also wanted more family involvement in their care. Therefore, families should be a part of such discussions, because caregiving burden can be a key factor in informed decision making.<sup>45,46</sup> To achieve these goals (Table 5), culturally and religiously adapted patient decision aids may be useful in supporting the joint decision-making process.<sup>47</sup> In conjunction with informed decision making, implementation of a faith-based system to document EoL wishes can empower patients to state their preferences.<sup>48</sup> Many developing countries such as Pakistan are benefitting from a new wave of private medical schools,<sup>49</sup> and culturally adapted training in palliative care should be a part of the medical school curriculum in under-resourced countries. In the absence of a widespread availability of palliative care specialists in Pakistan, nurses, social workers, practitioners of alternative medicine (hakims etc.), general practitioners, and specialists should receive training in primary palliative care skills to address EoL needs of the patients undergoing dialysis and also manage patients receiving conservative management.<sup>50</sup> The concept of *izzat ki zindgi and izzat ki moat*, that is, *a dignified life and a dignified death* is culturally embraced in Pakistan. Such slogans could be a part of the media campaign to promote better EoL care. Such initiatives would align well with the World Health Organizations' mission to integrate palliative care into the management of chronic illnesses such as kidney failure.<sup>40</sup>

In summary, Pakistani patients undergoing dialysis report a lack of informed shared decision making and wish to have EoL discussions with their providers. Establishment of palliative care services and physician training in the philosophy and methods of palliative care can help patients with ESKD within developing countries achieve their medical communication and EoL needs.

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**Key Message**

In the face of immense financial burdens, lack of proper health infrastructure to provide chronic dialysis, and high mortality, there is an urgent need to improve informed decision making and end-of-life care in Pakistan. Training of Pakistani physicians in primary palliative care skills may offer a solution.

**Table 1**

## Patients' Characteristics and Religiosity

Characteristics	n (%)
Age (yrs); mean (SD)	49.61 ( $\pm$ 13.94)
Up to 30	62 (12)
31–40	70 (13)
40–50	127 (24)
51–60	160 (31)
Older than 60	103 (20)
Sex (male)	56.5
Type of treatment	
Hemodialysis	515 (98.7)
Peritoneal dialysis	5 (1)
Months on dialysis; mean	38.3
Marital status	
Married	342 (65.6)
Unmarried, divorced, and/or widowed	179 (34.4)
Education	
Uneducated	64 (12.3)
Fifth grade	122 (23.4)
10th grade	143 (27.4)
12th grade	103 (19.7)
Professional college/university	90 (17.2)
Religion	
Islam	483 (92.5)
Christianity	18 (3.4)
Hinduism	9 (1.7)
Sikhism	6 (1.1)
Other	3 (0.6)
Religious sect	
Sunni	323 (62.1)
Shia	54 (10.4)
Barelvi	37 (7.1)
Deobandi	40 (7.7)
Ahle-Hadees	33 (6.3)
Others	20 (3.8)
Extent to which you consider yourself religious minded?	
Not religious minded	82 (15.7)
Somewhat religious minded	129 (24.7)
Religious minded	203 (38.9)
Extremely religious minded	101 (19.3)
Life decisions based on religion	

Characteristics	<i>n</i> (%)
Not at all	31 (5.9)
Infrequently	118 (22.6)
Most of the times	198 (37.9)
Always	169 (32.4)

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**Table 2**

## Patients' Self-Knowledge About Illness and Hospice/Palliative Care

Questions	n (%)
How informed are you with regard to your medical condition?	
Uninformed	70 (13.4)
Somewhat informed	308 (59)
Informed	123 (23.6)
How do you see your health in next 12 months?	
Worsening	64 (12.3)
No change	144 (27.6)
Improving	235 (45)
Not sure	74 (14.2)
Do you know what palliative care is?	
Yes	41 (7.9)
No	348 (66.8)
Not sure	129 (24.8)
Do you know what hospice is?	
Yes	26 (5)
No	361 (69.3)
Not sure	118 (22.6)

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**Table 3**

**Patients' Preferences About Prognosis, Quality of Life, and ACP**

Question	Unimportant/Somewhat Unimportant	Unsure	Important/Extremely Important
How important is it for you to be informed about your prognosis?	128 (24.5)	110 (21.1)	284 (54.4)
How important is detailed information about your medical condition?	98 (18.8)	71 (13.6)	353 (67.6)
How important is it for you to prepare and plan ahead in case of death?	103 (19.7)	88 (16.9)	331 (63.4)
How important is it to you to have access to information on alternative ways to manage your physical symptoms (e.g., traditional medicine, new treatments, holistic care, etc.)	92 (17.7)	114 (21.8)	316 (60.6)
How important is it to you for your family to be actively involved in medical decision making?	88 (16.9)	106 (20.3)	328 (62.9)
How important is it for you to be informed about treatment options such as withdrawing dialysis?	115 (22)	103 (19.7)	304 (58.2)
How important is it for you to have your physical symptoms (e.g., pain, nausea) treated by the nephrology staff?	97 (18.5)	91 (17.4)	334 (64)
How important is it for your quality of life responses to affect your future care?	105 (20.1)	105 (20.1)	312 (59.7)
How important is it for you to discuss your quality of life regularly with our nephrology staff?	117 (22.5)	91 (17.4)	314 (60.1)
How important is it for you to have your social, psychological, or spiritual concerns attended to by nephrology staff?	156 (29.9)	98 (18.8)	267 (51.2)

ACP = advance care planning.

**Table 4**

**Patients' Perspective on EoL and ACP**

Questions	n (%)
Who do you rely on your social and emotional support during your illness and treatment?	
Family/friends	211 (40.4)
Doctor	152 (29.1)
Nurse	93 (17.8)
Spiritual advisor/religious scholar	21 (4)
Nobody	34 (6.5)
If you are physically or mentally unable to make decisions for yourself, who would you choose to make medical decisions about you?	
Family/friends	247 (47.4)
Doctor	138 (26.5)
Nurse	73 (14)
Spiritual advisor/religious scholar	30 (5.8)
Nobody	28 (5.4)
How do you normally get information that will help you make a personal decision your health/well-being?	
Specialist (e.g., kidney doctor)?	249 (47.7)
Family physician	169 (32.4)
Family/friends	36 (6.9)
Paper resources	3 (6)
Internet	36 (6.9)
Media/television	4 (8)
Other	12 (2.3)
Do you regret your decision of starting dialysis?	
Yes	327 (62.6)
No	186 (35.6)
If you are currently receiving dialysis, why did you choose dialysis over conservative care (no dialysis)?	
Your doctor's wish	283 (54.2)
Your own personal wish to	148 (28.4)
Your family's wish	84 (16.1)
How comfortable are you in discussing EoL care issues with your family members?	



Questions	n (%)
Very comfortable/somewhat comfortable	347 (66.5)
Unsure	91 (17.4)
Very uncomfortable/somewhat uncomfortable	83 (15.9)
How comfortable are you in discussing EoL care issues with the nephrology staff?	
Very comfortable/somewhat comfortable	331 (63.5)
Unsure	116 (22.2)
Very uncomfortable/somewhat uncomfortable	74 (11.3)
Have you thought about what might happen with your illness in the future?	
Yes	169 (32.4)
No	341 (65.3)
Has your doctor talked to you about how much time do you have to live?	
Yes	95 (18.2)
No	420 (80.5)
Have you written your will?	
Yes	89 (17)
No	422 (80.8)
If you have completed an advance directive, what did you request to be done in the case that your heart stopped beating?	
Resuscitate (full code)	209 (40)
Do not resuscitate (no code)	152 (29.1)
Do not know	160 (30.7)
There are a number of things doctors can do to try to revive someone whose heart has stopped beating, which usually includes a machine to help breathing. Thinking of your current condition, what would you want your doctor to do if your heart stopped beating?	
Restart my heart, if possible, including using a breathing machine	291 (55.7)
Allow me to die—do not try to restart my heart or use a breathing machine	148 (28.4)
Do not know	82 (15.7)
If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means prolonging pain and discomfort, or would you want a plan of care that focuses on revealing pain and discomfort?	
Relieve pain or discomfort and improve quality of life as much as possible	244 (46.7)
Do not know	178 (34.1)
Live as long as possible	99 (19)
Where would you prefer to die?	
At home	68

Questions	n (%)
Hospital	11.9
At another place	19.7
During the past 12 months, have you had a discussion with any of the following people about your choices concerning your EoL care?	
I have not had a discussion about these matters during the last 12 months	220 (42.1)
Family member	199 (38.1)
Friend	41 (7.9)
Family doctor	14 (2.7)
Kidney doctor (nephrologist)	12 (2.3)
Nurse/staff member from dialysis unit	24 (4.6)
Social worker	11 (2.1)
Which members of the health care team would you like to talk with about EoL issues?	
Kidney doctor (Nephrologist)	194 (37.2)
Family doctor/primary care physician	116 (22.2)
Nurse	64 (12.3)
Social worker	10 (1.9)
Other	31 (5.9)
Nobody	100 (19.2)
When would you like to have these EoL conversations?	
When you become seriously ill or when the need arises (as defined by your medical team)	292 (55.9)
When you specifically request it	69 (13.2)
Before you are started on dialysis	63 (12.1)
After you start dialysis but before becoming ill	90 (17.2)
How often would you like to have your EoL care plan reviewed?	
Whenever the need arises	258 (49.4)
Whenever I ask for this plan to be reviewed	197 (37.7)
On a regular basis (i.e., annually, semiannually)	63 (12.1)
Where would you like to have EoL care discussions?	
In a clinic	104 (19.9)
Private room	300 (57.5)
While on dialysis	118 (22.6)

EoL = end of life; ACP = advance care planning.

**Table 5**

## Potential Challenges and Strategies to Improve EoL Care in Pakistan

Challenges		Strategies	
1	Lack of workforce trained in palliative care	1	Provision of primary palliative care skills by general practitioners and specialists
2	Lack of culturally adapted palliative care curriculum	2	Involvement of social workers, nurses, hakims (alternative medicine specialists), and faith communities in promoting better EoL care
3	Lack of communication skills training programs	3	Cost-effective education in communication skills for health care workers and for others involved in EoL care by using videos and roles plays, etc.
4	Lack of focus on death with dignity in the medical culture	4	Adaptation of EoL curriculum to the local culture
		5	Media campaigns to raise awareness about death with dignity

EoL = end of life.