



# The Importance of Patient-reported Outcome Measures in Dialysis Care: Perspectives of Kidney Healthcare Providers in Türkiye

## Diyaliz Bakımında Hasta Bildirimli Sonuç Ölçütlerinin Önemi: Türkiye'deki Böbrek Sağlığı Hizmet Sunucularının Görüşleri

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### ABSTRACT

**Objective:** Patient-reported outcome measures (PROMs) are essential for monitoring patient health and personalized treatments. The effective use of PROMs in clinical practice can improve outcomes by increasing patient engagement. Educating both clinicians and patients on PROMs and conducting regular monitoring is crucial. This study aims to investigate the significance of PROMs for kidney healthcare providers (KHPs).

**Methods:** An online survey was prepared to assess KHPs' attitudes toward dialysis modalities and PROMs. The survey was distributed across Türkiye between March 25 and June 15, 2023. Data were analyzed using the Shapiro-Wilk test and Pearson's chi-squared test.

**Results:** A total of 102 doctors and 42 nurses (82 females, 62 males, mean age  $45 \pm 8.6$  years) participated. Among respondents, 57.7% believed that interaction between dialysis patients in the center significantly helped patients manage their disease. Additionally, 66% agreed that coming to the clinic three times a week is burdensome for most patients. Furthermore, 75.1% of KHPs encouraged patients to consider home dialysis due to its flexibility. KHPs believed that peritoneal dialysis (70.1%)

### ÖZ

**Amaç:** Hasta bildirimli sonuç ölçütleri (PROM), hastaların sağlık durumlarını izlemek ve tedavilerini kişiselleştirmek için önemli araçlardır. PROM'ların klinik uygulamada etkin kullanımı, hasta katılımını artırarak tedavi sonuçlarını iyileştirebilir. PROM'lar konusunda hem klinisyenlerin hem de hastaların eğitimi ve düzenli izleme yapılması büyük önem taşımaktadır. Bu çalışma, böbrek sağlığı hizmet sunucuları (BSHS) için PROM'ların önemini araştırmayı amaçlamaktadır.

**Yöntemler:** BSHS'lerin diyaliz modaliteleri ve PROM'lara yönelik tutumlarını değerlendirmek amacıyla bir çevrim içi anket hazırlandı. Anket, 25 Mart-15 Haziran 2023 tarihleri arasında Türkiye genelinde dağıtıldı. Veriler Shapiro-Wilk testi ve Pearson'in ki-kare testi ile analiz edildi.

**Bulgular:** Ankete 102 doktor ve 42 hemşire (82 kadın, 62 erkek, ortalama yaş  $45 \pm 8,6$  yıl) katıldı. Katılımcıların %57,7'si, merkezdeki diyaliz hastaları arasındaki etkileşimin, hastaların hastalıklarını yönetmelerine önemli ölçüde katkı sağladığını düşündü. Ayrıca, %66'sı hastaların haftada üç kez kliniğe gelmeyi külfetli bulduğunu belirtti. Katılımcıların %75,1'i ise hastalara zaman esnekliği

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## ABSTRACT

and home hemodialysis (79.8%) provide a better quality of life compared to center hemodialysis. Educational videos were the most preferred educational method for dialysis modalities (58.3%), followed by applied continuing education (48.2%) and dialysis rotations (41.7%).

**Conclusion:** Integrating PROMs into clinical practice and linking them with actionable interventions can enhance patient well-being and health outcomes. It is crucial to educate KHPs on PROMs and encourage consistent use by clinicians to optimize treatment outcomes.

**Keywords:** Dialysis modalities, kidney healthcare providers, PROMs

## ÖZ

sunduğu için ev diyalizini düşünmelerini önerdi. BSHS'lerin %70,1'i periton diyalizinin, %79,8'i ise ev hemodiyalizinin, merkezdeki hemodiyalize kıyasla hastalar için daha iyi bir yaşam kalitesi sunduguna inanıyordu. Diyaliz modalitelerine yönelik eğitimde en çok tercih edilen yöntem eğitim videolarıydı (%58,3); bunu uygulamalı sürekli eğitim (%48,2) ve diyaliz rotasyonları (%41,7) izledi.

**Sonuç:** PROM'ların klinik uygulamaya entegrasyonu ve bunların eyleme geçirilebilir müdahalelerle ilişkilendirilmesi, hastaların refahını ve sağlık sonuçlarını iyileştirebilir. BSHS'lerin PROM'lar konusunda eğitilmesi ve klinisyenlerin PROM'ları tutarlı bir şekilde kullanmaya teşvik edilmesi büyük önem taşımaktadır.

**Anahtar Kelimeler:** Diyaliz modaliteleri, böbrek sağlığı hizmet sunucuları, PROMs

## Introduction

Chronic kidney disease (CKD) is a major global health issue, affecting millions and placing a significant burden on healthcare systems (1). As CKD progresses to end-stage kidney disease (ESKD), kidney replacement therapy—including dialysis or transplantation—is required for survival (2). Hemodialysis and peritoneal dialysis are the primary modalities, crucial for managing ESKD (3). However, dialysis often brings physical, emotional, and social challenges that negatively affect patients' quality of life (4).

Patient-reported outcome measures (PROMs) are essential tools for capturing patients' subjective experiences, including symptoms, functional status, and quality of life (5,6). With the growing focus on patient-centered care, PROMs have gained recognition in nephrology for guiding shared decision-making (7). Their systematic use enables healthcare providers to personalize treatment, improve outcomes, and enhance patient satisfaction (8), while also fostering better communication and patient engagement in care (9).

Despite the potential benefits of PROMs in kidney healthcare, their systematic integration into clinical practice remains limited, and there is a need for further research to explore the attitudes, perceptions, and practices of kidney healthcare providers (KHPs) regarding the use of PROMs (10). Understanding KHPs' perspectives on PROMs is essential for identifying barriers to their implementation and developing strategies to overcome these barriers effectively (11). In this context, it is crucial to consider the unique healthcare landscape of Türkiye, including the distribution of healthcare resources, cultural factors influencing patient-provider interactions, and the accessibility of different dialysis modalities. By examining the perspectives of KHPs in Türkiye, this study aims to contribute to the broader understanding of PROMs utilization in kidney healthcare and inform strategies for promoting patient-centered care and improving outcomes for individuals with CKD.

## Methods

### Study Design

This study used a cross-sectional design to investigate the significance of PROMs among KHPs in Türkiye. Data were collected through an online survey administered via Google Forms, a secure and widely-used online questionnaire platform. The survey consisted of 16 questions developed by the research team, grounded in a review of current literature, established PROMs frameworks, and expert opinions from nephrology and dialysis care professionals. The questionnaire included multiple-choice, Likert scale, and ranking items aimed at assessing participants' demographics, preferences regarding dialysis modalities, perceived challenges and facilitators for home dialysis, and attitudes toward PROMs. A Turkish version of the complete questionnaire is provided as Supplementary File 1.

### Ethics Committee Information

Ethics approval was obtained from Bezmialem Vakıf University with the Ethics Committee (decision no: 2023/59, date: 22.03.2023).

### Study Population

Nephrologists, pediatricians, dialysis-certified internal medicine physicians, and dialysis-certified practitioners in Türkiye were identified as the groups to be included in the study. Recruitment efforts were conducted through professional networks, healthcare organizations, and relevant associations specializing in nephrology and dialysis care. Of all participants, 56.9% were female and 43.1% were male. The professional distribution of participants is presented in Table 1.

### Data Collection

The survey was administered electronically using a secure online platform. Data collection occurred between March 25 and June 15, 2023. Participants were provided with a link to the survey along with instructions for completion.

## Consent

Ethics committee approval included a waiver of written informed consent; participation was voluntary and completion of the anonymous online survey implied consent. The questionnaire included a variety of question types designed to gather comprehensive insights from participants. Demographic questions, such as gender, profession, and years of experience, were used to characterize the participant profile. Closed-ended Likert scale questions (e.g., ranging from “strongly disagree” to “strongly agree”) were employed to assess healthcare providers’ attitudes toward PROMs and dialysis modalities. Additionally, multiple-choice questions were used to explore preferences regarding educational methods and perceived patient needs. These questions aimed to collect data on participants’ clinical experiences, perceptions of PROMs, preferences for dialysis options, and their views on effective educational strategies, ultimately supporting subgroup analysis and broader interpretation.

## Statistical Analysis

Descriptive statistics were used to summarize the demographic characteristics of the study participants and the distribution of responses to survey questions. Continuous variables were reported as means with standard deviations, while categorical variables were summarized using frequencies and percentages. The Shapiro-Wilk test was employed to assess the normality of data distribution, and Pearson’s chi-squared test was utilized to analyze associations between categorical variables. Statistical significance was set at  $p<0.05$ .

The full survey questionnaire used in this study is provided as Supplementary File 1 (available online).

## Results

A total of 102 physicians and 42 nurses completed the survey (82 females, 62 males; mean age:  $45\pm8.6$  years). Participants work in the Marmara Region (54.2%), Central Anatolia Region (16%), Aegean Region (9.7%), Mediterranean Region (8.3%), Southeastern Anatolia Region (5.6%), Black Sea Region (3.5%), and Eastern Anatolia Region (2.8%). The respondents included 87 nephrologists (60.4%), 42 nurses (29.2%), 12 pediatric nephrologists (8.3%), 2 dialysis-certified internal medicine physicians (1.4%), and 1 dialysis-certified general practitioner (0.7%).

**Table 1.** Profession distribution of participants

Profession	Number of participants	Percentage (%)
Nephrologist	87	60.4
Pediatric nephrologist	12	8.3
Dialysis-certified internist	2	1.4
Dialysis-certified general practitioner	1	0.7
Nurse	42	29.2
<b>Total</b>	<b>144</b>	<b>100.0</b>

Participants’ years of experience in the nephrology were as follows: 10-20 years (43.1%), more than 20 years (25%), less than 5 years (16.7%), 5-10 years (15.3%).

Figure 1 presents responses to four key statements regarding dialysis modalities and patient experience. The interaction between dialysis patients at the center was seen as a positive influence on disease management by most providers, with 39.6% agreeing and 18.1% strongly agreeing. In contrast, opinions were mixed on whether in-center dialysis is less stressful than home dialysis, with 25% disagreeing and 31.3% responding as “unsure”. A strong majority (75.1%) of respondents encouraged home dialysis, citing the flexibility it offers; 43.8% agreed and 31.3% strongly agreed. Regarding patient mobility, 36.8% agreed and 20.1% strongly agreed that being able to travel is extremely important for dialysis patients.

Figure 2 illustrates KHPs’ preferences for the most effective educational methods regarding dialysis modalities. Education videos were most preferred (58.3%), followed by applied continuing education (48.2%) and dialysis rotations (41.7%). Online continuing education was also favored (41.7%), reflecting a need for flexible learning methods. Conference speeches (31.9%) were moderately preferred, while journal articles (8.3%) and brochures (8.3%) were least favored. Only 2.0% reported no need for further education on dialysis modalities.

## Discussion

The findings of this study reveal that KHPs in Türkiye acknowledge the importance of PROMs in improving kidney healthcare. By focusing on patient-reported experiences, KHPs can deliver more individualized care and foster better communication and engagement with patients (12,13).

A notable finding was that 45.8% of KHPs expressed a preference for home dialysis over in-center dialysis. This preference is largely attributed to the flexibility home dialysis offers, which improves treatment adherence, quality of life, and patient autonomy (14). Facilities that support home dialysis typically offer structured training programs, including simulation-based sessions, home visits by specialized nurses, and 24/7 remote support lines to ensure patient safety and compliance (15,16).

However, the availability and scope of home dialysis training for KHPs vary widely. While no comprehensive national education program currently exists, findings from our survey indicate that only a minority of KHPs (18.7%) reported receiving structured training specifically on home dialysis modalities. According to the 2023 report of the Turkish Society of Nephrology, only 22 centers in Türkiye currently provide home hemodialysis services, and these programs are highly variable in terms of staffing, patient load, and training capacity (17). This suggests that less than 10% of dialysis centers in Türkiye offer active home hemodialysis programs.

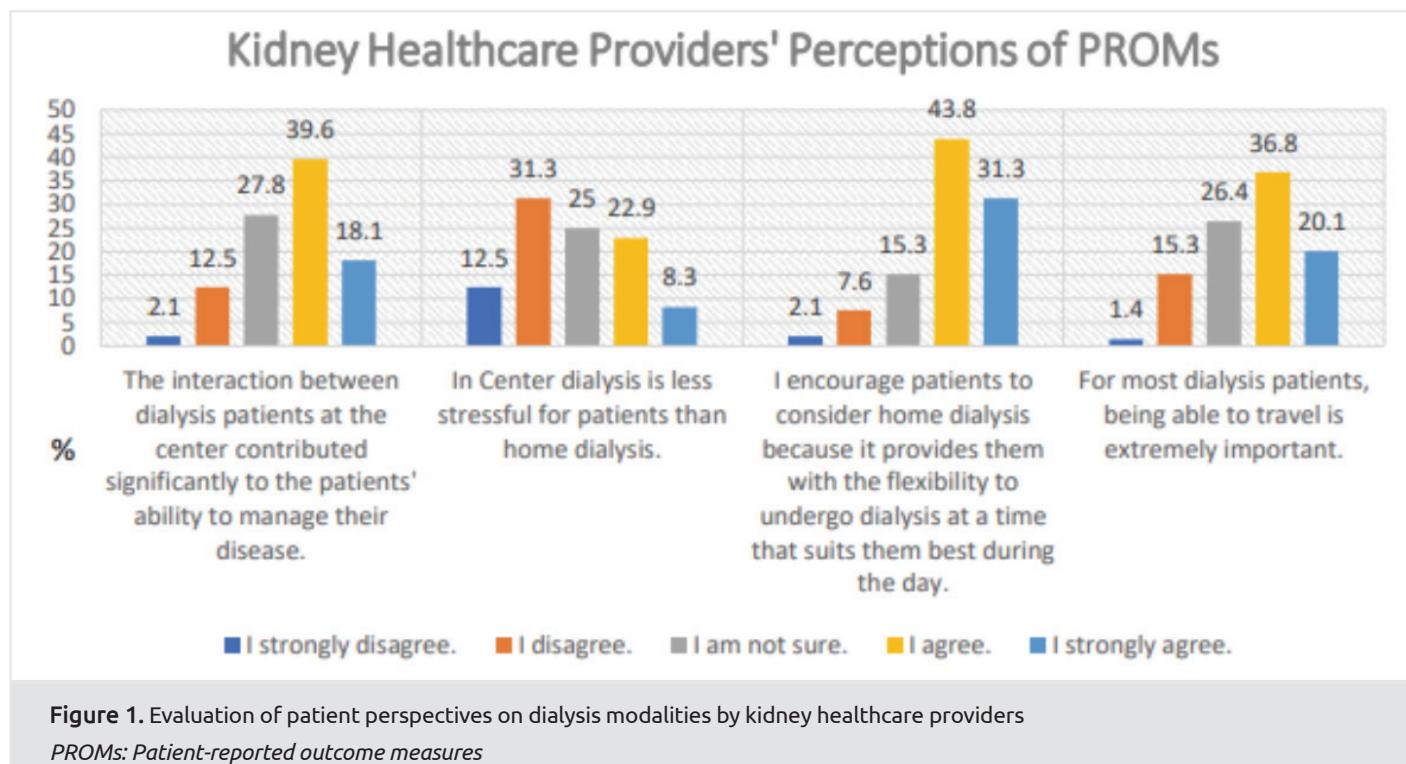
These findings highlight the need for broader national policy and interdisciplinary training initiatives to expand home dialysis accessibility. Integrating PROMs with structured clinical training

and individualized care planning may help drive the transition toward more patient-centered and resource-efficient renal care models (18,19).

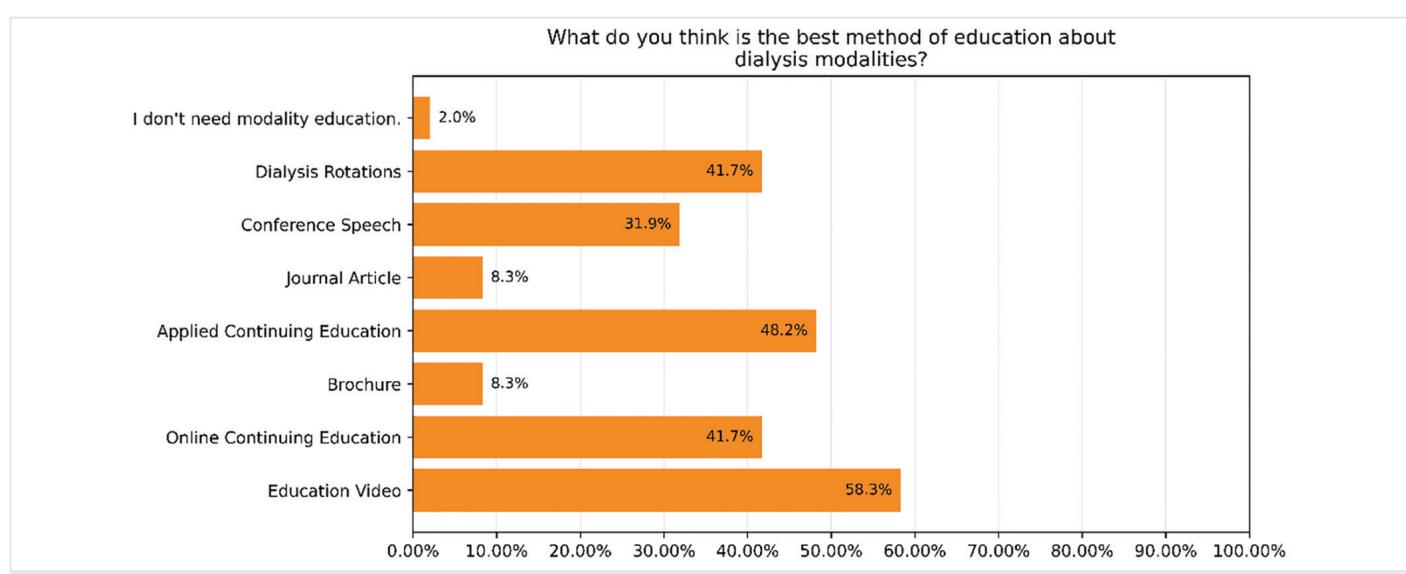
The study highlights a significant trend among healthcare professionals: most support referring patients to the dialysis modality they believe will provide the best clinical outcomes, even when patients are unsure about this. This raises important questions about patient-centered treatment and shared decision making in healthcare. It suggests that some healthcare providers prioritize perceived treatment effectiveness over patients' preferences. However, this approach also raises concerns about respecting patients' autonomy and involving them in decisions

about their care. It has been reported that a significant proportion of kidney healthcare professionals prioritize what they perceive as the most effective treatment option, potentially overlooking patient preferences. This underscores the balance between clinical effectiveness and patient-centered care, highlighting that decisions made without consideration of patient preferences may affect the alignment between clinical effectiveness and patient preference (12,13).

Peer support among patients receiving dialysis has been shown to improve emotional well-being and self-management. Patients in centers that encourage peer interaction often report lower anxiety and depression levels. Promoting such support systems



**Figure 1.** Evaluation of patient perspectives on dialysis modalities by kidney healthcare providers  
PROMs: Patient-reported outcome measures



**Figure 2.** Dialysis modality training preferences of kidney healthcare providers

in dialysis centers could lead to improved emotional and clinical outcomes (14,15).

Many patients undergoing hemodialysis find the thrice-weekly schedule burdensome, impacting work-life balance and overall well-being. Flexible care models, such as home dialysis and telehealth, may reduce this burden. Some KHPs reported using video consultations and remote monitoring during the coronavirus disease 2019 pandemic, demonstrating the potential of these modalities in maintaining continuity of care. Shared decision-making also plays a role in enhancing treatment satisfaction and adherence (16,17).

Training for KHPs is critical to ensure high standards of care. Simulation-based education has proven particularly effective in developing technical and decision-making skills. Studies have shown that such training reduces errors and improves clinical preparedness (18,19). These hands-on approaches also promote interprofessional collaboration and empathy, both essential for patient-centered nephrology practice.

Workshops using case-based learning and role-play enhance communication skills and empathy. These formats enable providers to better understand patient perspectives and deliver more individualized care (20). However, integrating PROMs into clinical nephrology still faces challenges such as resource constraints and limited training. Overcoming these barriers will require support from policymakers, healthcare institutions, and advocacy groups.

Emotional well-being is a critical yet often overlooked aspect of dialysis care. Long-term dialysis patients frequently experience anxiety, depression, and social isolation. Greater control through home dialysis and strong peer/provider support can mitigate these effects. Regular emotional assessment via PROMs may help identify needs early and support holistic care (6).

### Study Limitations

This study has several limitations. First, the sample may not be fully representative, as it consisted of voluntary participants. The perspectives of non-responders or those holding differing views may be underrepresented. Second, the use of an online survey may introduce bias, particularly social desirability bias. Third, the cross-sectional design limits the ability to assess changes in attitudes over time. Lastly, while the study explores preferences for home dialysis, it does not include specific data on the availability or readiness of centers to support such modalities, which could impact the feasibility of broader implementation.

### Conclusion

This study highlights the value of PROMs in kidney care from the perspective of KHPs in Türkiye. PROMs enhance communication, guide shared decision-making, and support more personalized treatment. While home dialysis modalities are generally favored for their flexibility and quality-of-life benefits, the integration of PROMs and patient-centered care practices

remains limited. Expanding education and structured training for KHPs, combined with system-level support, is essential to improve implementation. Future efforts should focus on addressing practical and systemic barriers to PROMs integration and supporting initiatives that prioritize patient perspectives and needs.

### Ethics

**Ethics Committee Approval:** Ethics approval was obtained from Bezmialem Vakif University with the Ethics Committee (decision no: 2023/59, date: 22.03.2023).

**Informed Consent:** Written informed consent was waived by the ethics committee; participation was voluntary and completion of the anonymous online survey implied consent.

### Footnotes

### Authorship Contributions

Concept: E.K., M.G., R.K., Design: E.K., M.G., Ö.C.E., R.K., Data Collection or Processing: E.K., C.S., Analysis or Interpretation: E.K., M.G., Ö.C.E., C.S., A.Y.T., Literature Search: E.K., M.G., A.Y.T., R.K., Writing: E.K., Ö.C.E., R.K.

**Conflict of Interest:** No conflict of interest was declared by the authors.

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**Supplementary link:** <https://d2v96xpocvxx.cloudfront.net/b37683d5-c547-4565-8c20-fa38c0b1ec76/content-images/df899c12-1eba-48e2-97d1-4319acc0aaf7.pdf>