



Use of Electronic Patient Reported Outcomes in Clinical Nephrology Practice: A Qualitative Pilot Study

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Abstract

Background: Use of patient-reported outcome measures (PROM) in clinical practice can offer clinicians important information about the impact of illness on patients and their quality of life. Electronic reporting of patient-reported outcomes (ePROs) provide quick access of this information to the health care team. Although this type of information is acknowledged to be critical to not only improving the quality of care but also involving patients in care planning, little is known about how ePRO reports can be used in nephrology clinics to enhance person-centered care.

Objective: The purpose of this research was to examine how ePROs were used in home dialysis clinics.

Design: A pilot qualitative research design was employed.

Setting: The study was conducted in 2 home dialysis clinics over 6 months.

Patients: A total of 99 home dialysis patients and 12 nurses participated in the study.

Measurements: Patients completed 2 ePROs (the Edmonton Symptom Assessment System revised for renal patients and Kidney Disease Quality of Life-36) prior to their clinic appointment, and results were given to their health care providers. Nurses saw patients first, along with ePRO data. Patients and nurses consented to having their clinic interactions observed and audio recorded ($n = 169$).

Methods: Summative content analysis was used to synthesize the data.

Results: The ePRO data were used to discuss 24 specific issues (brought up a total of 456 times over 165 interactions), most frequently: itchiness ($n = 55$), appetite ($n = 51$), problems with sleeping ($n = 50$), tiredness ($n = 46$), and shortness of breath ($n = 45$) as well as overall patient health and the general effects of kidney disease on the patient's daily life. The issues that most often prompted a change in care plan, referral to another health care professional, or further assessment included itching ($n = 23$), depression ($n = 18$), tiredness ($n = 13$), sleeping ($n = 12$), anxiety ($n = 11$), and disease interfering with daily life ($n = 7$).

Limitations: Limitations include the duration of follow-up (6 months), the restriction to 2 home dialysis clinics, and the potential for the Hawthorne effect due to observation.

Conclusions: Use of these ePROs in the home dialysis clinics provided useful information that guided focused assessments and augmented standard assessments to support person-centered care. Further studies are warranted to identify whether this practice offers benefits over usual care.

Abrégé

Contexte: En pratique clinique, les mesures des résultats déclarés par les patients (PROM) fournissent aux cliniciens des renseignements importants sur les répercussions de la maladie pour les patients et leur qualité de vie. La déclaration électronique des PROM (ePRO) permet à l'équipe soignante d'avoir rapidement accès à ces informations. On reconnaît l'ePRO comme essentielle non seulement pour améliorer la qualité des soins, mais pour impliquer davantage les patients dans leur plan de soins. Néanmoins, on en sait peu sur la manière dont elle pourrait être utilisée dans les cliniques de néphrologie pour offrir des soins plus personnalisés.

Objectif: L'étude visait à observer la façon dont les ePRO sont employées dans les cliniques de dialyse à domicile.

Type d'étude: Une étude qualitative pilote a été réalisée.

Cadre: L'étude s'est tenue dans deux cliniques de dialyse à domicile sur une période de six mois.

Participants: Douze infirmières et 99 patients dialysés à domicile ont participé à l'étude.

Mesures: Les patients ont rempli deux ePRO (les questionnaires *Edmonton Symptom Assessment System revised for renal patients* et *Kidney Disease Quality of Life-36*) avant leur rendez-vous à la clinique et les résultats ont été transmis à leurs



fournisseurs de soins. Les infirmières ont en premier lieu rencontré les patients et consulté les données des ePRO. Les participants ont consenti à l'observation et à l'enregistrement audio des rencontres à la clinique (n = 169).

Méthodologie: Une analyse de contenu sommative a servi à synthétiser les données.

Résultats: Les données des ePRO ont été utilisées pour discuter de 24 enjeux spécifiques (soulevés un total de 456 fois au cours de 165 interactions), les plus fréquemment cités étant le prurit (n = 55), l'appétit (n = 51), les problèmes de sommeil (n = 50), la fatigue (n = 46) et l'essoufflement (n = 45). La santé générale du patient et les répercussions de la maladie sur sa qualité de vie ont également été abordées. Les enjeux ayant le plus souvent entraîné un changement au plan de soins, un aiguillage vers un autre professionnel de la santé ou un suivi plus poussé étaient le prurit (n = 23), la dépression (n = 18), la fatigue (n = 13), les problèmes de sommeil (n = 12), l'anxiété (n = 11) et les entraves à la vie quotidienne (n = 7).

Limites: Les résultats sont limités par la courte période de suivi (six mois), le faible échantillon (2 cliniques) et un potentiel effet d'Hawthorne dû à l'observation.

Conclusion: L'utilisation des ePRO dans les cliniques de dialyse à domicile a fourni des renseignements utiles qui ont guidé des évaluations ciblées et augmenté les interventions traditionnelles, pour appuyer une prestation de soins plus personnalisés. D'autres études sont nécessaires pour déterminer si cette pratique offre des avantages par rapport aux soins prodigués habituellement.

Keywords

patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), quality of life, person-centered care, qualitative, content analysis

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What was known before

Although use of patient-reported outcomes (PROs) in clinical practice can offer clinicians important information about the impact of illness on patients and their quality of life, little is known about how these reports can be used in nephrology clinics to enhance person-centered care.

What this adds

The clinicians used the ePRO (electronic reporting of patient-reported outcomes) data to initiate discussion and clarify symptoms through focused assessments. Their actions in response to the ePRO data included referral, further assessment, waiting to monitor, and teaching.

Background

Given the overwhelming and international demand for clinicians to offer more person-centered care, new strategies are required so that aspects of patient experience are better understood and addressed. Patient-reported outcome measures (PROMs) provide an avenue for patients to share information about the impact of dialysis on their life and their quality of life with clinicians. Patient-reported outcome measures are self-report, standardized instruments

used to appraise outcomes related to their quality of life (ie, well-being, symptoms, overall health, functional status, as well as other aspects of psychological, social, and spiritual well-being¹ of health care recipients [patients and informal caregivers]). Electronic reporting of patient-reported outcomes (ePROs) offers clinicians quick access to results. Although this type of information is acknowledged as critical to not only improving the quality of care, but also involving patients in care planning, there are significant knowledge gaps about how PROM reports are used in nephrology care settings to augment person-centered care.² By person-centered care, we mean care that supports a meaningful life,³ bearing in mind the person's "history, values, beliefs, priorities, preferences, current situation, future aspirations, and how they make sense of what is happening to them."⁴ The objective of this study was to examine how ePROs were used in clinical nephrology practice.

Recently, PROMs were voted as the number 1 area of interest to nephrologists in the United States.⁵ Similarly, chronic kidney patients have identified quality of life as the health outcome that they most value.⁶ Such PROMs as quality of life self-assessment tools are being integrated internationally into routine care. For example, in the United States, the Centers for Medicare and Medicaid Services have mandated routine assessment of quality of life using PROMs for all end-stage kidney disease patients as a

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prerequisite for coverage.⁷ However, very little is known about how PROM data are being used in clinical practice to inform kidney care.²

Over 20 years ago, Mingardi⁸ wrote that use of quality of life assessment needs to be “mandatory” to provide a more comprehensive view of dialysis patients. Yet, it has only been marginally considered since that time. In one study by Keogh et al,⁹ the researchers surveyed 140 kidney patients who completed the Renal Quality of Life Profile and found that nurses most often addressed issues related to holidays, sex life, tiredness, mobility, and depression. In the second study, Smith and Wise¹⁰ undertook a retrospective audit of implementation of the Patient Outcome Scale-symptom with 54 dialysis patients about end-of-life issues. Nurses’ actions included following up with completion of the Depression and Anxiety Symptom Scale, referral to a social worker or palliative care services, or review of a care plan. In 1992, Kurtin et al¹¹ provided SF-36 responses from 24 dialysis patients to 2 nephrologists. They developed principles for use in decision-making including encouraging, but not requiring, (1) patients to complete the PROM and (2) clinicians to review the PROM and discuss with team members. In another study, Tong et al¹² examined nephrologists’ perspectives on defining and implementing patient-centered outcomes with hemodialysis patients, but this study did not focus on use or integration of PROMs.

The majority of evidence-based research on the use of PROM feedback in nephrology care has been with nurses,^{9,10,13,14} social workers,¹⁵⁻¹⁷ and less often with interdisciplinary staff teams.¹⁸⁻²⁰ There is growing empirical research addressing routine integration of PROM data at individual²¹⁻³³ and aggregate³⁴⁻³⁶ levels of kidney care, as well as with electronic means.^{31,37-41} Other than Trillingsgaard et al’s³¹ observation of 9 patient–clinician consultations using PROMs, no other researchers have observed interactions in real-time clinical practice of the use of PROMs. In this article, we present research that highlights how clinicians use PROMs. Given the global attention toward person-centered nephrology care, consideration of pragmatic utilization of ePROs in patient interactions is both required and timely.

Methods

Study Design

A longitudinal qualitative research design was used with summative content analysis of 169 recorded interactions between home dialysis patients and health care providers. The research questions were as follows:

Research Question 1: To what extent was ePRO data used in clinical encounters?

Research Question 2: What actions were taken in response to ePRO data?

Participants

Using purposive, convenience sampling, letters were mailed to all home dialysis patients in 2 outpatient clinics from 2 cities who participated in the pilot phase of the study.^{14,39} If interested, they were invited to attend their next regularly scheduled clinic 15 minutes early to complete ePROs prior to their appointment. Inclusion criteria included being on home dialysis (peritoneal or hemodialysis) and over 19 years of age. Exclusion criteria included an inability to read or converse in English, acute medical crisis, or moderate to severe cognitive impairment. Ninety-nine patients volunteered over 6 months, for a total of 169 clinician recorded encounters. All nurses working in the clinic were included (with no exclusion criteria) and invited to participate given that they saw patients prior to the social worker, dietitian, and nephrologist. Nurses learned of the study through presentations at the clinic. All 12 nurses participated. Recordings were only conducted when both the patient and nurse consented.

Measures

Prior to the study, the health authority required that all patients complete the Edmonton Symptom Assessment System revised for renal patients (ESAS-r: Renal, asking about 10 symptoms and 1 question on well-being)^{42,43} preceding each clinic appointment every 3 months. Participants in this study continued to do so, but now completed the measure electronically on tablet computers in the waiting rooms (see http://palliative.org/NewPC/_pdfs/tools/ESASr%20Renal.pdf for example of ESAS-r: Renal; in our study, the clinic did not include the open-ended question or visual diagram). In addition, staff completed the Home Dialysis Multidisciplinary Clinic Assessment (HDMCA) at the time of the appointment. For the purposes of the study, a new app for tablets was created using FileMaker Go using iOS 7. The Kidney Disease Quality of Life-36 (KDQOL™-36)⁴⁴ was also completed using a tablet. The KDQOL-36™ is the short form of a longer instrument that includes the SF-12 as the core measure with additional domains addressing the burden of kidney disease, symptoms/problems of kidney disease, and effects of kidney disease scales from the KDQOL-SF™v1.3⁴⁴ (see https://www.rand.org/health-care/surveys_tools/kdqol.html). It was available online with Medical Education Institute’s *KDQOL Complete*.⁴⁵ Online scoring in real time, along with reports of domains and responses to 12 symptoms, were printed for clinicians before the visit with the patient. Patient participants were offered copies of their reports, along with KDQOL patient education materials tailored to their responses.

Data Collection

A research assistant (RA) or the lead author (K.S.-M.) joined patients and nurses in private clinic rooms to

observe use of ePRO data. All interactions were audio recorded and patients were aware of the purpose of the study. The health authority approved audio recording but not transcription of clinical interactions. The RAs were female nurses or allied health professionals, some of whom were completing masters or PhD degrees. None of them had prior relationships with either clinic nurses or patients.

Research assistants completed a checklist to record all the items from the ESAS-r: Renal and KDQOL™-36 that were discussed during the clinician interaction, who initiated discussion, and how often the clinicians referenced the ePRO data (see supplementary file). All RAs attended training sessions with the lead author (K.S-M.) on use of the checklist. The RAs role-played mock clinician–patient interactions to pilot test use of the checklist. The checklist was modified slightly after use in clinics for 2 weeks.

Data Analysis

Summative content analysis was employed for this study. Although conventional content analysis infers meaning through counting and comparisons, summative content analysis explores content for interpretation of the underlying context.⁴⁶ This method relies on credibility, and content experts are needed to validate the use of any particular content, in this case the ePRO data. The 3 coauthors on this article are registered nurses (RNs), and 2 have extensive clinical and research experience in nephrology.

An RA or lead author (K.S-M.) listened to all recordings to double-check accuracy of each checklist. One research team member (K.T.) listened to all the recordings and documented the occurrences in which the nurses appeared to use the ePRO data in their clinical assessment. The first 35 recordings were reviewed independently by the lead author (K.S-M.) and a team meeting was held to calibrate coding and ensure discrepancies in interpretation and analysis were resolved. Categories were formed by collapsing codes in which contextual usage of the content ran through all the data. Team meetings were held throughout the analysis process and after final coding was completed to discuss findings and reach consensus on the findings.

Ethical Approval

Ethical approval was from the University of Alberta Health Research Ethics Board (Approval #PRO 00040538) and the Vancouver Island Health Authority (Approval #H2013-065). All patient and clinician participants provided a signed informed consent, verbally confirmed at the start of the study and prior to all ongoing recorded interactions. Consent for publication of collated unidentified data was also approved by all participants.

Results

A total of 99 patient participants and 12 nurse participants participated in the study. The patients included 14 receiving home hemodialysis and 85 on home peritoneal dialysis. The clinic nurses who participated were all female and had a mean age of 46 ± 8 . Their experience working in nephrology nursing included 27% for 1 to 10 years, 46% for 11 to 20 years, and 27% for 21 to 30 years. Additional demographics of patient and nurse participants are published elsewhere.⁴⁰

A total of 165 of 169 recordings of patient–nurse interactions were used in our analysis. Recordings ranged from approximately 20 to 90 minutes in length. Four recordings were removed from the analysis; 2 appointments were interrupted by another health care professional resulting in an incomplete nursing assessment, and in 2 cases, the data were not used because of concerns related to cognitive ability of the patient and inability to consent. The 165 clinical encounters included 99 unique patients and 66 with repeat encounters, approximately 3 months apart, using both the ESAS-r: Renal and the KDQOL-36. However, in 19 of the interactions, RNs did not have the KDQOL-36 on-hand as it was not completed in time for the assessment. In one interaction, the RN was unable to find or receive the ESAS-r: Renal before assessment.

Use of ePRO Data in Clinical Encounters

The ePRO data were clearly used to discuss 24 unique issues (brought up a total of 456 times over 165 interactions), as well as overall patient health and the general effects of kidney disease on the patient's daily life. In some instances, RNs asked generally about well-being, but did not probe further with specific items from the KDQOL-36. The most frequently discussed issues as prompted by the ePRO data were itchiness ($n = 55/456$), appetite ($n = 51/456$), problems with sleeping ($n = 50/456$), tiredness ($n = 46/456$), and shortness of breath ($n = 45/456$) (see Table 1).

Most often, in 103 of 165 interactions, RNs used the ePRO data to initiate discussion and clarify symptoms through focused assessments. In 40/165 interactions, the RN audibly reviewed the ePRO data before beginning the general assessment, but otherwise integrated elements of ESAS-r: Renal and/or KDQOL-36 assessments into what appeared to be their regular practice and assessment. In 32/165 interactions, the RN used the ePRO data to quickly prioritize assessments or redirect conversation to those assessments. Registered nurses generally used the HDMCA form to conduct patient assessments, and in 31 of the 165 interactions, we noted no clear use of ePRO data with sole reliance on the HDMCA. In 4 of these recordings, the patients reported 1 minor, or no, health concerns.

Table 1. RN Use of the Quality of Life Health Assessments.

KDQOL™-36 and ESAS-r: Renal items	Frequency of items assessed using KDQOL™-36 or ESAS-r: Renal (n = 456) N (%)	On HDMCA
Itching	55 (12.1)	x
Appetite	51 (11.2)	x
Problems with sleeping	50 (11.0)	x
Tiredness	46 (10.1)	
Shortness of breath	45 (9.9)	x
Pain	33 (7.2)	x
Depression/downhearted or blue	29 (6.4)	
Nausea/upset stomach	28 (6.1)	x
Feeling of well-being	24 (5.3)	
Anxiety	21 (4.6)	
Energy	16 (3.5)	
Drowsiness	14 (3.1)	
Dx interferes with life	9 (2.0)	x
Chest pain	6 (1.3)	x
Cramps	6 (1.3)	
Problems with access site or catheter	5 (1.1)	x
Travel	4 (0.9)	
Frustration in dealing with dx	3 (0.7)	
Dry skin	3 (0.7)	
Overall health	3 (0.7)	
Stress/worries cause by dx	2 (0.4)	
Ability to work around the house	1 (0.2)	
Sex life	1 (0.2)	
Personal appearance	1 (0.2)	
Moderate activities	0	
Climbing stairs	0	
Accomplishing less (due to physical health)	0	
Didn't work as carefully	0	
Pain interfering with work	0	
Interference with social activities	0	
Time spent dealing with dx	0	
Burden to family	0	
Muscle soreness	0	
Faintness/dizziness	0	
Washed out/drained	0	
Numbness in hands/feet	0	
Fluid restriction	0	
Dietary restriction	0	
Dependence on health care professionals	0	

Note. RN = registered nurse; KDQOL™-36 = Kidney Disease and Quality of Life-36 Survey; ESAS-r: Renal = Edmonton Symptom Assessment System revised for renal patients; HDMCA = Home Dialysis Multidisciplinary Clinic Assessment.

There were marked differences in the use of the ESAS-r: Renal and KDQOL-36 data, with the ESAS-r: Renal data used in the majority of assessments. There were 38/165 interactions in which the KDQOL was not reviewed by the RN, nor used to support the clinical assessment of dialysis patients. Some items from the KDQOL-36 were not explicitly addressed during assessments, including climbing stairs, accomplishing less, did not work as carefully, pain interfering with work, and dependence on health care professionals.

Dietary restrictions were discussed, but clearly as part of the HDMCA. Sex life and personal appearance were only discussed once each and brought up by the patient in each instance.

Actions Taken in Response to ePRO Data

Use of the ePRO data by nurses in care decisions and the 466 total responses varied (nurses may have had multiple

Table 2. RN Response to the Quality of Life Health Assessments.

Response or recommendation	Frequency of responses to KDQOL™-36 or ESAS-r: Renal items (n = 466), n (%)
No change indicated	202 (43.3)
No change warranted	149 (32.0)
Referral to social work	22 (4.7)
Physician follow-up	18 (3.9)
RN follow-up	12 (2.6)
Teaching/take home materials	10 (2.1)
Wait and monitor	10 (2.1)
Medication change	8 (1.7)
Encouraged use of moisturizer	7 (1.5)
Validation/consolation	7 (1.5)
Change to dialysis (cyclor)	5 (1.1)
Attributed to older age	3 (0.6)
Encouraged transfusion	3 (0.6)
Referral to dietitian	2 (0.4)
Change to dressing	2 (0.4)
Encouraged increase exercise	2 (0.4)
Self-limit machine	2 (0.4)
Change exchange time	1 (0.2)
Change exchange volume	1 (0.2)

Note. RN = registered nurse; KDQOL™-36 = Kidney Disease and Quality of Life-36 Survey; ESAS-r: Renal = Edmonton Symptom Assessment System revised for renal patients.

responses to 1 of the 456 issues). In 62/165 interactions, no change to the patient's care plan was indicated in response to 202 issues discussed as triggered by ePRO data (see Table 2). This does not include the 31 interactions in which the ePRO data did not appear to be used at all.

The responses RNs most often took after considering the ePRO data included referring or recommending follow-up with another health care professional in the home dialysis clinic (ie, the nephrologist, social worker or dietitian; n = 42/466), assessing further (ie, physically assessing wounds or exit sites, requesting follow-up blood work; n = 12/466), recommending waiting and monitoring of a symptom based on recent care plan change (n = 10/466), and teaching (ie, strategies to stop itching, appropriate medication use, the logistics of traveling with dialysis and reasons for different bag exchange rates/volumes; n = 10/466). Remaining responses included suggesting changes to dialysis (ie, cyclor, use self-limiting option or timing/volume of bag exchange; n = 9/466), recommendation for changes to medication (n = 8/466), offering clear emotional support and validation in response to expressed sadness or frustration (n = 7/466), and recommending the use of over the counter moisturizer to combat itching (n = 7/466) (Table 2). Recommendations for more exercise, follow-up for a blood product transfusion, discontinuing the use of chlorhexidine, and developing a routine to improve sleep were each made once in response to assessments triggered by the ePRO scores. Interestingly, in 3/466 instances, concerns around general well-being, tiredness,

and sex life were attributed to old age with no further recommendations made.

The issues that most often prompted a change in care plan, referral to another health care professional or further assessment included itching (n = 23/466), depression (n = 18/466), tiredness (n = 13/466), sleeping (n = 12/466), anxiety (n = 11/466), and disease interfering with daily life (n = 7/466). Other issues addressed or noted for follow-up 4 times or less included frustration, shortness of breath, travel, appetite, pain, feeling of well-being, frustration in dealing with disease, problems with access site, travel, drowsiness, nausea, dry skin, and overall health and energy.

Discussion

Use of the ePROs in these 2 clinics facilitated identification of a number of patient symptoms which nurses then used for follow-up. The symptoms that occurred are similar to those reported in other studies⁴⁷⁻⁴⁹ and it may be that some of them might not have been reported had the ePRO not been used at the point-of-care. Itching was the most discussed issue, as well as the symptom with the most action taken. The ratio was 2:1—approximately every 2 times it was discussed (n = 55), clinicians followed-up (n = 23). In alignment, dialysis patients have previously reported that itching was the second most important research priority, specifically the causes, prevention, and treatment strategies of itching.⁶

Appetite was the next top issue (n = 51), but it was very rarely addressed nor followed-up. This may be because

nurses assumed dieticians may initiate such conversations, yet we did not note referrals to this end. Similarly, shortness of breath ($n = 45$) was very frequently discussed with few care decisions or responses. However, problems with sleeping ($n = 50$) and tiredness ($n = 46$) were in the top issues with a change in care plan, referral or further assessment ($n = 12$ and $n = 13$, respectively). This may be because there are better strategies available to manage these symptoms. Nevertheless, the ePRO reports were not used during clinician interactions to the extent that we had anticipated. It may be that once use is engrained in usual practice, they may be used more frequently.⁵⁰ Nevertheless, change process is time-consuming and requires commitment⁵¹ that may not have been present for the purposes of the study. We do not yet know whether there are substantive benefits to use of ePROs over regular communications and patient assessments, a question that is being raised and investigated not only within the renal context but globally.^{2,52-54} A clinical trial comparing usual care to that incorporating ePROs routinely into practice would help us address this question.

Routine integration of ePRO data in real-time point-of-care offers valuable data to inform person-centered care, as well as care efficiencies.^{31,37-41} Yet, this is a complex intervention that requires attention to workflow.⁴⁰ In this study, the KDQOL™-36, a nonrequired PROM, was rarely discussed and incorporated into practice. Why? It may be that a shorter measure would be more useful. This would require further exploration. Notably, only 5 of the 36 KDQOL items are comparable to items on the ESAS-r: Renal, and the KDQOL-36 provides broader assessment of quality of life beyond physical symptoms. Contextually, the ESAS-r: Renal had been recently introduced into routine care practices, and the HDMCA form was used in every single recorded patient encounter. The ESAS-r: Renal was completed by the patient alone and not by a clinician, whereas the HDMCA was the clinician's assessment form completed during a clinical encounter. It is important to note that the top 3 symptoms (itching, appetite, sleeping) that were primarily discussed and attended to in real-time were the PROM items that were also on the HDMCA. Thus, there was a triangulation of data toward these symptoms with patients providing their own self-assessment, as well as clinicians' assessment of these symptoms. Future research and knowledge translation are needed to collaborate with clinicians to explore how patients' priorities that are identified in PROMs which are *not* identified on required clinician worksheets or forms may be discussed and responded to in clinical encounters.

Limitations of this study include the duration of follow-up (6 months), the restriction to 2 home dialysis clinics, and the potential for the Hawthorne effect due to observation. Further training on symptom management may increase the number of actions taken in response to the questionnaires. The HDMCA form routinely used in the clinic had overlap with the ePRO data. Thus, it was not

always apparent if use of the data in the clinical encounter and responses were triggered by ePRO data, or in combination with the HDMCA. We further recognize that some actions taken in response to the ePRO data changes may have been made after the assessment that would not have been captured on the audio files. Future research could address use of ePROs by other health professionals including nephrologists. A clinical trial could help determine whether use of ePROs is more effective or efficient than usual clinical practice.

Conclusion

Although use of PROs in clinical practice can offer clinicians important information about the impact of illness on patients and their quality of life, little has been known about how these reports can be used in nephrology clinics to enhance person-centered care. The findings from this study support the proposition that the use of ePRO data provided useful information that guided focused assessments and augmented standard assessments to support person-centered care. The clinicians used the ePRO data to initiate discussion and clarify symptoms through focused assessments. Their actions in response to the ePRO data included referral, further assessment, waiting to monitor, and teaching. Further studies are warranted to identify whether routine integration of ePROs offers benefits over usual care.

Ethics Approval and Consent to Participate

Ethical approval was from the University of Alberta Health Research Ethics Board (Approval #PRO 00040538) and the Vancouver Island Health Authority (Approval #H2013-065). All patient and clinician participants provided a signed informed consent, verbally confirmed at the start of the study and prior to all ongoing recorded interactions.

Consent for Publication

Consent for publication of collated unidentified data was approved by all participants. All coauthors reviewed and approved the final manuscript for publication.

Availability of Data and Materials

Ethics Committee approvals were not obtained for sharing of datasets outside of the research team.

Authors' Note

Elements of this work were presented at the Canadian Society of Nephrology, Annual General Meeting on May 2, 2019, in the "Spotlight on New Investigators." This New Investigator Lectureship Award was presented in a TED Talk entitled, *The known and unknown: Patient-reported outcomes in kidney care*.

Declaration of Conflicting Interests

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Supplemental Material

Supplemental material for this article is available online.

References

- Fayers PM, Machin D. *Quality of Life: The Assessment, Analysis and Reporting of Patient-Reported Outcomes*. Oxford: John Wiley; 2016.
- Schick-Makaroff K, Thummapol O, Thompson S, et al. Strategies for incorporating patient-reported outcomes in the care of people with chronic kidney disease (PRO kidney): a protocol for a realist synthesis. *Syst Rev*. 2019;8(1):20. doi:10.1186/s13643-018-0911-6.
- HakanssonEklund J, Holmstrom IK, Kumlin T, et al. "Same same or different?" a review of reviews of person-centered and patient-centered care. *Patient Educ Couns*. 2019;102(1):3-11. doi:10.1016/j.pec.2018.08.029.
- Hewitt-Taylor J. *Developing Person-Centred Practice: A Practical Approach to Quality Healthcare*. London, England: Red Globe Press; 2015.
- AJKDblog. #NephMadness 2018 Champion: Patient-Reported Outcomes. <https://ajkdblog.org/2018/0406/nephmadness-2018-champion-patient-reported-outcomes/>. Published April 6, 2018. Accessed April 25, 2019.
- Manns B, Hemmelgarn B, Lillie E, et al. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol*. 2014;9(10):1813-1821.
- Centers for Medicare & Medicaid Services (CMS). Clinical Performance Measures (CPM) Project. <https://www.cms.gov/Medicare/End-Stage-Renal-Disease/CPMProject/index.html>. Published 2013. Accessed April 25, 2019.
- Mingardi G. From the development to the clinical application of a questionnaire on the quality of life in dialysis. The experience of the Italian collaborative DIA-QOL (Dialysis-Quality of Life) Group. *Nephrol Dial Transplant*. 1998;13(suppl 1):70-75.
- Keogh AM, Carfray A, Andrews S, et al. Assessing quality of life in routine clinical practice: a pilot study. *J Ren Care*. 2000;26(2):27-30.
- Smith V, Wise K. Evaluating nurses' action outcomes and exploring their perspectives of implementing the POS-S (Renal) assessment tool for haemodialysis patients. *Ren Soc Australasia J*. 2017;13(1):14-21.
- Kurtin PS, Davies AR, Meyer KB, DeGiacomo JM, Kantz ME. Patient-based health status measures in outpatient dialysis. *Med Care*. 1992;30(5 suppl):MS136-MS149. doi:10.1097/00005650-199205001-00012.
- Tong A, Winkelmayr WC, Wheeler DC, et al. Nephrologists' perspectives on defining and applying patient-centered outcomes in hemodialysis. *Clin J Am Soc Nephrol*. 2017;12(3):454-466. doi:10.2215/CJN.08370816.
- Buck N, Roy C, Atcherson E. Life with dialysis: structured interviews provide feedback. *J Nephrol Nurs*. 1986;3(2):78-81.
- Schick-Makaroff K, Molzahn A. Brief communication: patient satisfaction with the use of tablet computers: a pilot study in two outpatient home dialysis clinics. *Can J Kidney Health Dis*. 2014;1:22. doi:10.1186/s40697-014-0022-9.
- Callahan MB, LeSage L, Johnstone S. A model for patient participation in quality of life measurement to improve rehabilitation outcomes. *Nephrol News Issues*. 1999;13(1):33-37.
- Callahan MB. Using quality of life measurement to enhance interdisciplinary collaboration. *Adv Ren Replace Ther*. 2001;8(2):148-151.
- Dec E. Impact of locus of control on clinical outcomes in renal dialysis. *Adv Chronic Kidney Dis*. 2006;13(1):76-85. doi:10.1053/j.ackd.2005.10.009.
- Gustafson S, Burrows-Hudson S. Adding patient feedback on quality of life to the outcomes assessment picture. *Nephrol News Issues*. 1997;11(8):22-23.
- Meyer KB, Espindle DM, DeGiacomo JM, Jenuleson CS, Kurtin PS, Davies AR. Monitoring dialysis patients' health status. *Am J Kidney Dis*. 1994;24(2):267-279. doi:10.1016/s0272-6386(12)80192-2.
- Neul SK. Quality of life intervention planning: pilot study in youth with kidney failure who are on dialysis. *Nephrol Nurs J*. 2015;42(5):487-96; quiz 497.
- Aiyegbusi OL, Kyte D, Cockwell P, Anderson N, Calvert M. A patient-centred approach to measuring quality in kidney care: patient-reported outcome measures and patient-reported experience measures. *Curr Opin Nephrol Hypertens*. 2017;26(6):442-449. doi:10.1097/MNH.0000000000000357.
- Aiyegbusi OL, Kyte D, Cockwell P, et al. Using Patient-Reported Outcome Measures (PROMs) to promote quality of care and safety in the management of patients with Advanced Chronic Kidney disease (PRO-trACK project): a mixed-methods project protocol. *BMJ Open*. 2017;7(6):e016687. doi:10.1136/bmjopen-2017-016687.
- Aawar N, Moore R, Riley S, Salek S. Interpretation of Renal Quality of Life Profile scores in routine clinical practice: an aid to treatment decision-making. *Qual Life Res*. 2016;25(7):1697-1702. doi:10.1007/s11136-015-1191-4.
- Bamford J, Wirz L. Piloting psychology annual reviews as a method of measuring psychological distress and quality of life in paediatric renal transplant patients. *Biomed Res Int*. 2016;2016:1685362. doi:10.1155/2016/1685362.
- Bunani AD, Sedgewick JM, Lehbi AM. The association between social support and psychosocial factors upon mortality and quality of life. *Nephrol*. 2012(suppl 2):80.
- Bunani AD, Allehbi AM. The association between social support and psychosocial factors upon mortality and quality of life. *Hemodial Int*. 2013;17(1):178.
- Bunani AD, Bunani ED. The association between social support and psychosocial factors upon mortality and quality of life. *Pediatr Nephrol*. 2013;28(8):1509.
- Hils S, Schmid A, Bogatyreva L, et al. Telemedical supported aftercare as an innovative project-study improves the quality of life after living kidney transplantation-a single center experience. *Am J Transplant*. 2014;14(suppl 3):843-844.

29. Iannuzzella F, Stefani A, Corradini M, et al. Evaluation of a telemonitoring system based on a mobile medical app in a cohort of peritoneal dialysis patients: a pilot study. *Nephrol Dial Transplant*. 2016;31(suppl 1):i241.
30. Pisarski P, Hils S, Schmid A, et al. Telemedicine as an innovative project-study in adherence improvement after living kidney transplantation at the transplantation-center Freiburg. *Transpl Int*. 2013;26:73.
31. Trillingsgaard C, Nielsen BK, Hjöllund NH, et al. Use of patient-reported outcomes in outpatient settings as a means of patient involvement and self-management support—a qualitative study of the patient perspective. *Eur J Pers Cent Healthc*. 2016;4(2):359-367.
32. Weisbord SD, Mor MK, Green JA, et al. Comparison of symptom management strategies for pain, erectile dysfunction, and depression in patients receiving chronic hemodialysis: a cluster randomized effectiveness trial. *Clin J Am Soc Nephrol*. 2013;8(1):90-99. doi:10.2215/CJN.04450512.
33. Wuerth D, Finkelstein SH, Ciarcia J, Peterson R, Kliger AS, Finkelstein FO. Identification and treatment of depression in a cohort of patients maintained on chronic peritoneal dialysis. *Am J Kidney Dis*. 2001;37(5):1011-1017. doi:10.1016/s0272-6386(05)80018-6.
34. Dad T, Tighiouart H, Fenton JJ, et al. Evaluation of non-response to the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) survey. *BMC Health Serv Res*. 2018;18(1):790. doi:10.1186/s12913-018-3618-4.
35. Finkelstein FO, Finkelstein SH. Time to rethink our approach to patient-reported outcome measures for ESRD. *Clin J Am Soc Nephrol*. 2017;12(11):1885-1888. doi:10.2215/CJN.04850517.
36. Iskander C, McQuillan R, Nesrallah G, Rabbat C, Mendelssohn DC. Attitudes and opinions of Canadian nephrologists toward continuous quality improvement options. *Can J Kidney Health Dis*. 2017;4:1-8. doi:10.1177/2054358117725295.
37. Aiyegbusi OL, Kyte D, Cockwell P, et al. Development and usability testing of an electronic patient-reported outcome measure (ePROM) system for patients with advanced chronic kidney disease. *Comput Biol Med*. 2018;101:120-127. doi:10.1016/j.compbiomed.2018.08.012.
38. Ong S, Porter E, Jassal S, Logan A, Miller J. My KidneyCare Centre Kiosk: description of an electronic self-management tool for patients with chronic kidney disease. *CANNT J*. 2012;22(2):15-16.
39. Schick-Makaroff K, Molzahn A. Strategies to use tablet computers for collection of electronic patient-reported outcomes. *Health Qual Life Outcomes*. 2015;13:2. doi:10.1186/s12955-014-0205-1.
40. Schick-Makaroff K, Molzahn AE. Evaluation of real-time use of electronic patient-reported outcome data by nurses with patients in home dialysis clinics. *BMC Health Serv Res*. 2017;17(1):439. doi:10.1186/s12913-017-2377-y.
41. Wong D, Cao S, Ford H, et al. Exploring the use of tablet computer-based electronic data capture system to assess patient reported measures among patients with chronic kidney disease: a pilot study. *BMC Nephrol*. 2017;18(1):356. doi:10.1186/s12882-017-0771-7.
42. Davison SN, Jhangri GS, Johnson JA. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: a simple assessment of symptom burden. *Kidney Int*. 2006;69(9):1621-1625. doi:10.1038/sj.ki.5000184.
43. Davison SN, Jhangri GS, Johnson JA. Longitudinal validation of a modified Edmonton symptom assessment system (ESAS) in haemodialysis patients. *Nephrol Dial Transplant*. 2006;21(11):3189-3195. doi:10.1093/ndt/gfl380.
44. Hays RD, Kallich JD, Mapes DL, Coons SJ, Carter WB. Development of the Kidney Disease Quality of Life (KDQOL) instrument. *Qual Life Res*. 1994;3(5):329-338.
45. Kidney Disease Quality of Life (KDQOL) Complete. <http://www.kdqol-complete.org>. Published 2019. Accessed April 26, 2019.
46. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288. doi:10.1177/1049732305276687.
47. Schick-Makaroff K, Molzahn A, Kalfoss M. Symptoms, coping, and quality of life of people with CKD. *Nephrol Nurs J*. 2018;45(4):339-346355.
48. Murtagh FE, Addington-Hale J, Higginson JJ. The prevalence of symptoms in ESRD: a systematic review. *Adv Chronic Kidney Dis*. 2007;14(1):82-99.
49. Molzahn A, Schick-Makaroff K. Supportive care of people with chronic kidney disease. In: Bodin S, ed. *Contemporary Nephrology Nursing*. 3rd ed. Pitman, NJ: American Nephrology Nurses' Association; 2017:625-635.
50. Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why. *Qual Life Res*. 2009;18(1):115-123. doi:10.1007/s11136-008-9430-6.
51. Greenhalgh J, Dalkin S, Gibbons E, et al. How do aggregated patient-reported outcome measures data stimulate health care improvement? a realist synthesis. *J Health Serv Res Policy*. 2018;23(1):57-65. doi:10.1177/1355819617740925.
52. Feng Y, Parkin D, Devlin NJ. Assessing the performance of the EQ-VAS in the NHS PROMs programme. *Qual Life Res*. 2014;23(3):977-989. doi:10.1007/s11136-013-0537-z.
53. Calvert M, Kyte D, Price G, Valderas JM, Hjöllund NH. Maximising the impact of patient reported outcome assessment for patients and society. *BMJ*. 2019;364:k5267. doi:10.1136/bmj.k5267.
54. Rowland C, Walsh L, Harrop R, Roy B, Skevington S. What do U.K. orthopedic surgery patients think about PROMs? Evaluating the evaluation and explaining missing data [published online ahead of print June 3, 2019]. *Qual Health Res*. 2019. doi:10.1177/1049732319848698.