

A Step in the Right Direction The Promise of PROMs in Routine Hemodialysis Care

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CJASN 15: 1228–1230, 2020. doi: <https://doi.org/10.2215/CJN.12350720>

A good physician treats the disease, the great physician treats the *patient* who has the disease.

—Sir William Osler

Patients with kidney failure experience a high symptom burden that negatively affects their quality of life and experience. Despite the contribution of symptoms to poor outcomes, symptoms remain under-recognized and undertreated. One strategy to address this problem is systematic solicitation of patient reports of their symptoms (1). We were, therefore, excited to read in *CJASN* the results of an implementation study by Evans *et al.* (2) of systematic deployment of a patient-reported outcome measure (PROM) to improve symptom assessment and management. Their findings reinforce the feasibility of using PROMs in clinical practice, while providing important lessons to guide future work to realize their potential.

PROMs are standardized, validated questionnaires completed by patients to measure their perception of their functional well-being and health status (3). PROMs provide two benefits. First, many symptoms are not easily detected *via* biomedical laboratory data. Patient report of the presence and severity is the best way to determine a symptom's effect on the patient's experience. Second, the best PROMs enhance provider and patient communication, fostering a patient-centered approach.

Evans *et al.* (2) implemented the “Your Symptoms Matter” project in eight hemodialysis centers in Ontario, Canada, using the Edmonton Symptom Assessment System Revised: Renal (ESAS-r:Renal) administered to patients every 4–6 weeks. The project was evaluated using patient and provider surveys prior to and after implementation, along with semistructured interviews midimplementation with nine patients or caregivers and 48 providers and staff. A chart audit of at least 20 charts per symptom per site was completed 12 months after implementation. The authors conclude that implementation of ESAS-r:Renal PROM is feasible yet had little impact on symptom management, patient-provider communication, or interdisciplinary communication.

We view the study of Evans *et al.* (2) as an important step in the right direction toward usefully deploying patient-centered interventions. The Ontario teams

successfully created a process for regularly collecting PROM data and feeding the results into clinical care. Using the National Health Service Sustainability Model to guide implementation, the authors enlisted organizational and individual clinic buy-in, created a workflow for distributing and collecting surveys, and developed educational resources to ensure providers had tools to manage symptoms identified. This careful planning led to near-100% survey completion by eligible patients, bringing to light many symptoms not previously focused on by patients or providers. Chart audits showed that documentation was more likely the higher the severity rating of the symptom. Patients reported more valuable conversations about severe symptoms, and providers said the information helped them prioritize which symptoms to address with patients. However, the reported changes mostly affected symptom assessment, rather than symptom management.

The study of Evans *et al.* (2) joins many other PROMs studies that have affected care processes but failed to demonstrate an effect on care outcomes (4). Should we now conclude that it is time to drop the PROM tool from the tool kit for improving patient quality of life? Or should we double down on further work to learn how to use this tool effectively?

We favor renewed focus on the latter. Identifying a distressing symptom is the first step in initiating a chain of steps with the ultimate goal of improving patients' health-related quality of life. As shown in Figure 1, there are several intervening steps between a patient's report of a symptom and the distal outcome of improved quality of life. Many frameworks for implementing PROMs have focused on the development and implementation of the measures themselves, which we label step 0 or precursors (3,5,6). This critical precursor step also includes laying the groundwork for change through actions such as recruiting a champion, getting leadership buy-in, and adapting to local conditions (7,8), all of which Evans *et al.* (2) seem to have done well.

The findings of Evans *et al.* (2) point in the direction of subsequent steps in the implementation chain needing further attention. For instance, they found that providers felt less confident to manage symptoms after the intervention despite the creation of education and training sessions. This suggests the need to bolster clinician capacity to evaluate and execute a symptom

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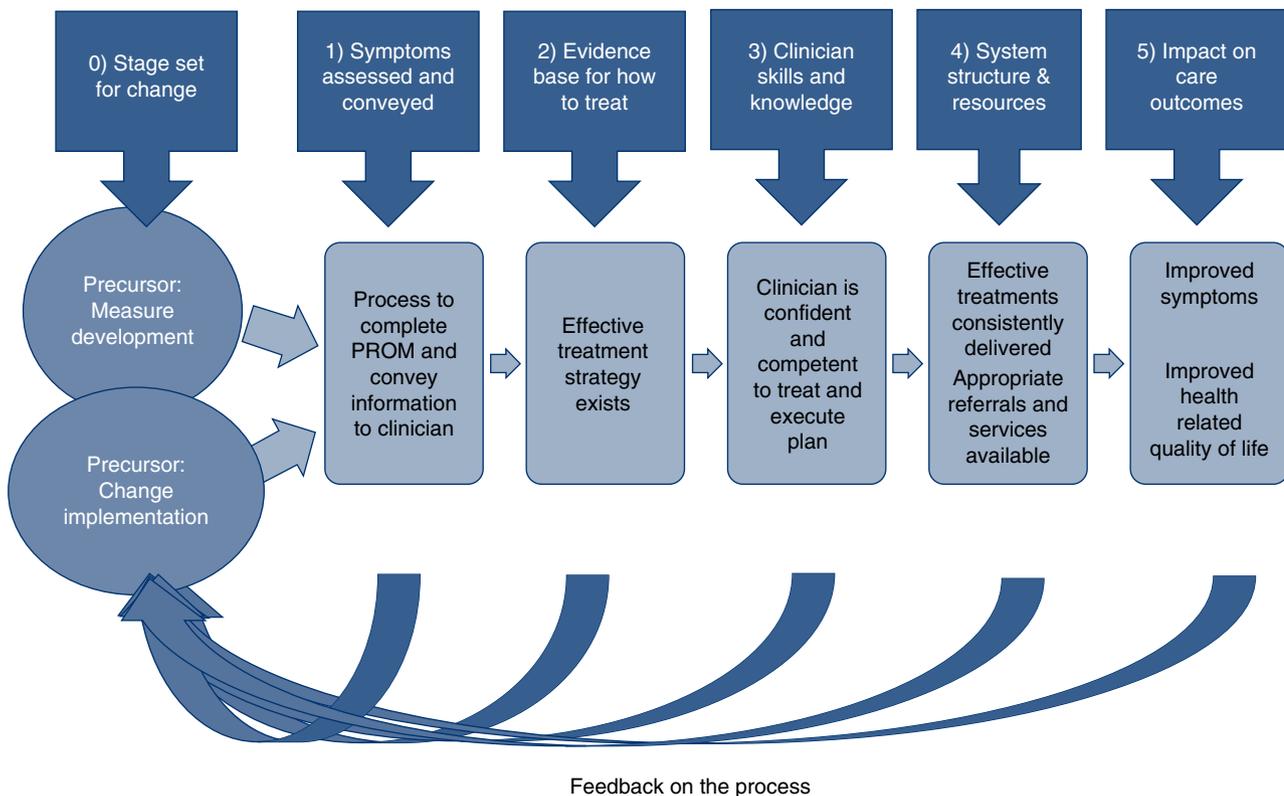


Figure 1. | Model for implementation steps linking patient-reported outcome measures (PROMs) to clinical outcomes. This model has been adapted from classic structure-process-outcome models to show the process of symptom assessment as an initial step because this was the starting point for the project by Evans *et al.* (2).

management plan (step 3). One respondent noted the frustrating long wait for an appointment after referral, suggesting the need to improve infrastructure and resources to ensure treatments are consistently delivered (step 4). Making such improvements is best done through an iterative process that feeds evaluation results back into revisions to the implementation plan. Future efforts to implement PROMs should test interventions aimed at these next steps along the implementation chain.

One missed opportunity in the study of Evans *et al.* (2) was getting feedback from patients who did not complete any or few questionnaires. Of the eight patients selected by staff to participate in interviews, all had completed numerous ESAS-r:Renal surveys (range, 5–8). This group of willing completers may have a very different view from those who completed none or just one. The viewpoint of these skeptics or nonparticipating patients would have enriched the findings.

Another significant issue is how to best involve patients in the evaluation and management plan. Individualized PROMs allow patients to explicitly prioritize what symptoms are addressed with the provider. These tools have a higher chance of identifying clinically relevant symptoms that will meaningfully affect the patient experience (9). An ongoing study is evaluating the use of a technology-assisted intervention in which patients can individualize treatment of symptoms using a stepped collaborative care that includes pharmacotherapy and psychotherapy options (10).

Finally, we urgently need a better arsenal of proven treatments for common symptoms in kidney disease. Recognizing the gap between symptom burden and effective treatments, the Kidney Health Initiative has created work groups for insomnia, muscle cramps, and fatigue—common symptoms prioritized by patients with kidney disease (1). As future research provides better pharmacologic and non-pharmacologic strategies, we will be better positioned to demonstrate effectiveness in patient care through a model of implementation with steps that link PROMs to patient-centered outcomes. When symptom management is prioritized and incentivized on par with other biomedical metrics like dialysis adequacy, we will be closer to achieving Osler’s vision of care for the whole person.

Disclosures

D.E. Lupu reports salary support *via* charitable contributions to George Washington University for work as senior advisor with the Coalition for Supportive Care of Kidney Patients. J.O. Schell reports receiving grants from Palliative Care Research Cooperative and royalty from UpToDate, outside the submitted work.

Funding

None.

Acknowledgments

The content of this article reflects the personal experience and views of the author and should not be considered medical advice or recommendations. The content does not reflect the views or

opinions of the American Society of Nephrology (ASN) or CJASN. Responsibility for the information and views expressed herein lies entirely with the author(s).

References

1. Flythe JE, Hilliard T, Lumby E, Castillo G, Orazi J, Abdel-Rahman EM, Pai AB, Rivara MB, St Peter WL, Weisbord SD, Wilkie CM, Mehrotra R; Kidney Health Initiative Prioritizing Symptoms of ESRD Patients for Developing Therapeutic Interventions Stakeholder Meeting Participants: Fostering innovation in symptom management among hemodialysis patients: Paths forward for insomnia, muscle cramps, and fatigue. *Clin J Am Soc Nephrol* 14: 150–160, 2019
2. Evans JM, Glazer A, Lum R, Heale E, MacKinnon M, Blake PG, Walsh M: Implementing a patient-reported outcome measure for hemodialysis patients in routine clinical care: Perspectives of patients and providers on ESAS-r:Renal. *Clin J Am Soc Nephrol* 15: 1299–1309, 2020
3. Porter I, Gonçalves-Bradley D, Ricci-Cabello I, Gibbons C, Gangannagaripalli J, Fitzpatrick R, Black N, Greenhalgh J, Valderas JM: Framework and guidance for implementing patient-reported outcomes in clinical practice: Evidence, challenges and opportunities. *J Comp Eff Res* 5: 507–519, 2016
4. Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, Revicki DA, Symonds T, Parada A, Alonso J: The impact of measuring patient-reported outcomes in clinical practice: A systematic review of the literature. *Qual Life Res* 17: 179–193, 2008
5. van der Wees PJ, Verkerk EW, Verbiest MEA, Zuidgeest M, Bakker C, Braspenning J, de Boer D, Terwee CB, Vajda I, Beurskens A, van Dulmen SA: Development of a framework with tools to support the selection and implementation of patient-reported outcome measures. *J Patient Rep Outcomes* 3: 75, 2019
6. Calvert M, Kyte D, Price G, Valderas JM, Hjollund NH: Maximising the impact of patient reported outcome assessment for patients and society. *BMJ* 364: k5267, 2019
7. Harvey G, Kitson A: PARIHS revisited: From heuristic to integrated framework for the successful implementation of knowledge into practice. *Implement Sci* 11: 33, 2016
8. Foster A, Croot L, Brazier J, Harris J, O’Cathain A: The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: A systematic review of reviews. *J Patient Rep Outcomes* 2: 46, 2018
9. Finkelstein FO, Finkelstein SH: Time to rethink our approach to patient-reported outcome measures for ESRD. *Clin J Am Soc Nephrol* 12: 1885–1888, 2017
10. Roumelioti M-E, Steel JL, Yabes J, Vowles KE, Vodovotz Y, Beach S, Rollman B, Weisbord SD, Unruh ML, Jhamb M: Rationale and design of technology assisted stepped collaborative care intervention to improve patient-centered outcomes in hemodialysis patients (TACcare trial). *Contemp Clin Trials* 73: 81–91, 2018

Published online ahead of print. Publication date available at www.cjasn.org.

See related article, “Implementing a Patient-Reported Outcome Measure for Hemodialysis Patients in Routine Clinical Care: Perspectives of Patients and Providers on ESAS-r:Renal,” on pages 1299–1309.