Editorial

For reprint orders, please contact: info@becaris.com

Journal of **Comparative Effectiveness Research**

Implementation of electronic patient-reported outcomes for symptom monitoring during cancer treatment: the importance of getting it right

Ethan Basch*[,1], Kathryn Hudson[2] & Gabrielle Rocque[3]

[1]Division of Oncology, University of North Carolina, Chapel Hill, NC 27599, USA

[2]Texas Oncology, Dallas, TX 75246, USA

[3]Division of Hematology & Oncology, University of Alabama at Birmingham, Birmingham, AL 38294, USA

*Author for correspondence: ebasch@med.unc.edu

> "Since the advent of PROs, the question has remained: which components of a PRO program drive improved patient outcomes?"

First draft submitted: 16 October 2023; Accepted for publication: 26 October 2023; Published online: 14 November 2023

Keywords: digital monitoring • ePROs • patient-reported outcomes • PROs • remote monitoring • symptom monitoring

A substantial body of published evidence demonstrates that symptom monitoring via electronic patient-reported outcomes (PROs) during systemic treatment for cancers, if integrated with navigation programs or nurse symptom management, results in improvements in symptom control, quality of life, physical function, emergency visits, hospitalizations, treatment tolerability, patient satisfaction and in some cases lengthened overall survival [1–6].

In a publication by Yan and colleagues in the October issue of the *Journal of Comparative Effectiveness Research*, the authors describe an early experience with a real-world implementation of patient-reported outcomes across the province of Alberta, Canada between 2016 and 2019 [7]. Their experience notably contrasts with the prior literature on the benefits of PROs captured during routine care, finding negative results. The authors are to be applauded both for this large undertaking in PRO implementation, as well as for publishing their negative findings and thus providing key insights into the mechanisms by which PROs can drive quality care delivery, and potential pitfalls to avoid.

Since the advent of PROs, the question has remained: which components of a PRO program drive improved patient outcomes? This study helps answer that question. In the Alberta implementation approach reported by Yan *et al.*, breast, colorectal and lung cancer patients completed paper symptom surveys in clinic waiting rooms before oncology ambulatory visits. These paper surveys were then manually entered into the electronic medical record by a member of the care team with the intention for the patient's clinician to review the content. Most, but not all, patients had had systemic therapy or surgery prior to the index date. The authors reported that there was no clear strategy for clinician review, and it was unknown how and when clinicians responded to the PRO surveys. When outcomes of this program were analyzed, no improvement in hospitalizations or survival was found.

The Alberta approach highlights the critical importance of using electronic rather than paper collection of PROs, ease of use, functionality, and clinical integration in a PRO program [8]. In their process, they used paper surveys that were then uploaded into a separate software program from the electronic medical record. A paper process introduces multiple potential sources of error, including missing paper forms, errors in transcription, delays in data entry, and data not entered due to unclear responsibility for entry. Electronic PROs, however, are directly and immediately incorporated into the electronic medical record, increasing reliability and the likelihood of clinician review. They can be seen quickly by multiple members of the care team, improving coordination of care. When incorporated into the EMR, ideally clinicians can trend symptoms over time, which may alert them to any worsening symptoms.

PROs are only as valuable as the response that patients receive from them. It is crucial that a robust workflow is in place for the care team to respond in real time to concerning symptoms. In the Alberta study, there was no clear process in place to address distressing symptoms, and it was not known if the PRO data were considered by clinicians or used to guide clinical care. In studies that show a benefit of PROs, symptoms with concerning levels of severity or worsening trigger an alert that is reviewed and acted upon by the care team (nurse/navigator), before their next office visit.

Cadence is also imperative. Although symptoms reported solely on the day of office visits have been shown to improve patient outcomes [6], PROs collected frequently in-between visits (e.g., weekly) allow the medical team to be proactive in responding to symptoms, giving the greatest chance to intervene to prevent a hospitalization or ER visit. Symptoms can be trended and truly monitored over time [9].

Another key barrier to implementation resulting from lack of an electronic platform is the inability to adequately provide audit-and-feedback, a key implementation strategy. Ongoing monitoring should ideally include a dashboard showing the proportion of patients approached to enroll in the PRO system, the proportion of enrolled patients who comply with self-reporting at each expected time point, and the rate of nurse/navigator responses to alert notifications. Identified challenges should be addressed by a central value-based care or quality improvement team to provide adjustments or support as warranted. Successful implementation requires commitment and investment by practice leadership with engagement of clinicians and staff, similar to any change in care processes toward value-based oncology.

Patient selection and intervention timing are also key to produce a benefit in ePRO programs. In the Alberta patient population, patients were not required to be on systemic cancer treatment, which is the patient population for which benefits have most commonly been shown. Therefore, at least some of the included patients likely had curable localized disease who never received systemic or prolonged treatment. In addition, the authors acknowledged that patients were included in the analysis if they reported as few as one PRO survey up to 120 days after their diagnosis. Symptoms typically follow a longitudinal trajectory in which the symptom burden peaks in the time around treatment initiation as patients begin a new therapy. At this time, patients may have symptoms from disease, as well as from treatment side effects that they have not yet learned to manage. Early PRO monitoring in the first 2 months supports the ability to identify toxicities, educate and empower patients on symptom management, and make dose adjustments based on toxicity. The exclusion of clinical outcomes occurring during that 120-day period in Alberta (due to methodological constraints) likely missed potentially meaningful events.

Collectively, the Alberta implementation can be contrasted with the prior province-wide implementation of ePROs in a different Canadian province, Ontario, which found significant reductions in hospitalization rates and improved overall survival in patients using PROs [4,5]. In Ontario, an electronic system was used for collecting the PROs, and reports were shared with clinicians in real time. The contrasting outcomes in Ontario and Alberta demonstrate the importance of the implementation approach for PROs. Defining the population for a PRO program up front, initiating PRO monitoring during systemic treatment, and assuring ongoing regular PRO reporting by patients via the use of a patient-friendly electronic system are critical. Published guidance is available on best practices for software function, survey selection, timing of surveys, staff deployment and training, patient engagement, and continuous monitoring and adjustment in keeping with the tenets of quality improvement [10–12]. For software functions specifically, best practices generally involve using a system through which patients can self-report symptoms on a regular basis (e.g., weekly) via an electronic survey using a computer, smart device, or automated telephone system. Significant or worsening patent-reported symptoms should trigger real-time alert notifications to the care team (generally to a nurse and/or navigator), enabling the team to react and manage concerning symptoms promptly. In addition, reports of longitudinal symptom trajectories should be viewed by the nurse and/or oncologist at clinic visits to guide discussions and care. These components remain core tenets of PRO intervention success and adaptations must be carefully considered to not diminish intervention benefit [13].

Despite the negative results found in this study, it is important not to misinterpret this manuscript as an indictment against PROs, and rather to view it an opportunity to continuously learn how better to implement complex, multifaceted interventions. As noted above, the Alberta implementation originated in 2016. Yan and colleagues were pioneers in implementing PROs. They demonstrated how programs start with the best practices available at the time and how to leverage support from leadership and frontline personnel. They also share that best practices evolve, as the authors note ongoing efforts to update the approach used in the province, having learned from their analysis. For the collective good of patients and our health systems, we must challenge other authors to

publish these early adopted experiences and share their continuous quality improvement efforts. Only with sharing these early results will we avoid implementation pitfalls and have an impetus for adapting and updating programs.

Financial disclosure

The authors have no financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

Competing interest disclosure

E Basch has received advisor payments from Navigating Cancer, Resilience, Sivan, Verily, and AstraZeneca. K Hudson is employed by Texas Oncology, and has received advisor payments from Daiichi Sankyo. Gabrielle Rocque has received advisor payments from Pfizer, Flatiron Health, Gilead Sciences. Research funding from CareVive Systems, Genentech. The authors have no other competing interests or relevant affiliations with any organization or entity with the subject matter or materials discussed in the manuscript apart from those disclosed.

Writing disclosure

No writing assistance was utilized in the production of this manuscript.

References

1. Basch E, Schrag D, Henson S *et al.* Effect of electronic symptom monitoring on patient-reported outcomes among patients with metastatic cancer: a randomized clinical trial. *JAMA* 327(24), 2413–2422 (2022).
2. Denis F, Basch E, Septans AL *et al.* Two-year survival comparing web-based symptom monitoring vs routine surveillance following treatment for lung cancer. *JAMA* 321(3), 306–307 (2019).
3. Mir O, Ferrua M, Fourcade A *et al.* Digital remote monitoring plus usual care versus usual care in patients treated with oral anticancer agents: the randomized phase 3 CAPRI trial. *Nat. Med.* 28(6), 1224–1231 (2022).
4. Barbera L, Sutradhar R, Seow H *et al.* The impact of routine Edmonton Symptom Assessment System (ESAS) use on overall survival in cancer patients: results of a population-based retrospective matched cohort analysis. *Cancer Med.* 9(19), 7107–7115 (2020).
5. Barbera L, Sutradhar R, Seow H *et al.* Impact of standardized Edmonton Symptom Assessment System use on emergency department visits and hospitalization: results of a population-based retrospective matched cohort analysis. *JCO Oncol. Pract.* 16(9), e958–e965 (2020).
6. Basch E, Deal AM, Dueck AC *et al.* Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *JAMA* 318(2), 197–198 (2017).
7. Yan JT, Boyne DJ, Lo E, Farah E, O'Sullivan DE, Cheung WY. Real-world impact of patient-reported outcome measurement on overall survival, healthcare use and treatment discontinuation in cancer patients. *J. Comp. Eff. Res.* 12(10), e230061 (2023).
8. Patt D, Wilfong L, Hudson KE *et al.* Implementation of electronic patient-reported outcomes for symptom monitoring in a large multisite community oncology practice: dancing the Texas two-step through a pandemic. *JCO Clin. Cancer Inform.* 5, 615–621 (2021).
9. Caston NE, Franks JA, Balas N *et al.* Evaluating nurses' time to response by severity and cancer stage in a remote symptom monitoring program for patients with breast cancer. *JCO Clin. Cancer Inform.* 7, e2300015 (2023).
10. Basch E, Rocque G, Mody G, Mullangi S, Patt D. Tenets for implementing electronic patient-reported outcomes for remote symptom monitoring during cancer treatment. *JCO Clin. Cancer Inform.* 7, e2200187 (2023).
11. PROTEUS Consortium. The PROTEUS Guide to Implementing Patient-Reported Outcomes in Clinical Practice covers design, implementation, and management of PRO systems in clinical care (2023). https://theproteusconsortium.org/wp-content/uploads/2023/04/PROTEUS-Practice-Guide.pdf
12. Basch E, Barbera L, Kerrigan CL, Velikova G. Implementation of patient-reported outcomes in routine medical care. *Am. Soc. Clin. Oncol. Educ. Book.* 38, 122–134 (2018).
13. Rocque GB, Dent DN, Ingram SA *et al.* Adaptation of remote symptom monitoring using electronic patient-reported outcomes for implementation in real-world settings. *JCO Oncol. Pract.* 18(12), e1943–e1952 (2022).