The Power of Patient-Reported Outcomes in Oncology Practice

Waqas Ahmed Khan and Saad Salim Naviwala

Department of Medical Oncology, The Aga Khan University Hospital, Karachi, Pakistan.

Symptomatic management is essential in clinical care, particularly for patients with chronic debilitating diseases such as cancer. Yet, up to half the time, healthcare providers do not detect patients' symptoms, particularly between clinic visits.[1] The routine documentation of patients' complaints and treatment-related adverse events experienced by cancer patients is often insufficient and not easily accessible in medical records, especially in paper-based systems, during their hospital visits. Additionally, many patient factors, such as psychological aspects and overall patient well-being, are frequently overlooked and heavily depend on the interviewer's skill and expertise. This issue is particularly challenging in busy settings where time constraints do not align with the patient-load. Patients often find it difficult to understand the connection of certain experiences to the disease or treatment and consider them trivial, leading to underreporting of important findings.[2] This issue is worsened by literacy rates, physician oversights, the degree of education provided by the treating team, financial limitations, inefficient workflows, poor infrastructure, and a lack of multidisciplinary approaches.[3]

Patient-reported outcomes (PROs) have proven to be an extremely valuable tool in oncology, providing important insights into the patient's experiences and enhancing the quality of provided care. Over the last few years, PROs, along with health-related quality of life (HRQoL) measures, have become crucial in oncology trials as well as clinical practices and capture the patient's subjective experience of illness and treatment, leading to improved outcomes and patient satisfaction. PROs are generally defined as any report of the status of a patient's health condition that comes directly from the patient, without interpretation by any healthcare provider.[4] Without well-structured PROs, open-ended and unfocused questioning can lead to missing important clues that patients do not consider significant and physicians fail to ask about. Poorly addressed complaints such as pain, nausea or vomiting, diarrhoea, dehydration, and fatigue are a major cause of visits to the emergency room (ER).[5,6] The unrecognised signs and symptoms lead to inadequate management, missed treatments, ER visits, hospitalisations, poor quality of life, and dissatisfaction. Evidence suggests that systematically monitoring patients' symptoms through PROs fills this gap by increasing patient awareness and communication between patients and doctors. This leads to better symptomatic treatment, patient satisfaction and quality of life, and extending survival.[7-9]

The goal of integrating PROs into clinical practice is to standardise the capturing of adverse events in a structured way but in a more patient-centric manner that is easier to interpret and would pave the way for safe and timely delivery of treatment and improved compliance to therapy. Patients can manage their care more effectively with the improved use of supportive treatments avoiding unnecessary hospital visits. The effectiveness of PROs depends on the quality of the data collected, which is in turn, dependent on the active participation of patients or their caregivers and their awareness of the importance of their contributions.[10] With structured documentation of symptoms, functional status, and emotional wellbeing of a patient through direct feedback, treatment plans are modified at an individual level. Effective communication of the patient's needs and preferences leads to a sense of ownership among them. From a physician's perspective, PROs reduce the time spent on questioning and documentation of side effects, allow patients to navigate issues more effectively, and provide a basis for decisions. This has a tangible effect on the wellbeing of patients because it provides direction that might not have been obvious from clinical assessments alone. Eventually, the integration of PROs might influence policy-making to support improved resource allocation and performance assessment in the health sector. Additionally, integrating PROs can facilitate global research collaboration, especially with the use of electronic recording of PROs, and their incorporation into clinical trials.

Even in low- and middle-income countries (LMICs) such as Pakistan, where health resources are limited, PROs can effectively fill the gap between patients' expectations and physicians' perceptions. Even in the absence of integrated electronic systems, paper-based evaluations can improve communication between patients and physicians, leading to a better understanding of the patient's health status and quality of life. However, paper records have many limitations as data collection and sharing are not very efficient on paper, and there is too much reliance on human resources, making real-time access

---

Correspondence to: Dr. Waqas Ahmed Khan, Department of Medical Oncology, The Aga Khan University Hospital, Karachi, Pakistan
E-mail: wak991@yahoo.com

....
Received: May 27, 2024; Revised: August 23, 2024;
Accepted: August 26, 2024
DOI: https://doi.org/10.29271/jcpsp.2024.09.1007

difficult. In addition, paper is prone to damage. Electronic patient-reported outcomes (ePROs) address these challenges by automating data collection and analysis, enabling real-time and easy access, and reducing administrative tasks allowing seamless integration into clinical workflows. Educating healthcare staff on structuring the questionnaires in a clinically relevant and culturally appropriate manner, ideally available in the local language (e.g. Urdu for the Pakistani population) can aid greatly not only in assessing their validity, reliability, and reproducibility but also enhance the patient participation. Moreover, involving the local communities, as well as policymakers in a concerted and collaborative effort can tremendously benefit PRO initiatives. By incorporating PROs in current cancer support groups and preserving strong feedback loops, we can guarantee that patient voice will remain an integral part of the health system.

In summary, the success of integrated PRO measures may contribute to enhancing the quality of care and supports a shift towards an integrated approach that incorporates patient experience aspects in conjunction with clinical outcomes.

REFERENCES

1. Pakhomov SV, Jacobsen SJ, Chute CG, Roger VL. Agreement between patient-reported symptoms and their documentation in the medical record. *Am J Manag Care* 2008; **14(8)**:530-9.
2. Rosendal M, Jarbol DE, Pedersen AF, Andersen RS. Multiple perspectives on symptom interpretation in primary care research. *BMC Fam Pract* 2013; **14(1)**:167. doi: 10.1186/1471-2296-14-167.
3. Altin SV, Stock S. The impact of health literacy, patient-centered communication and shared decision-making on patients’ satisfaction with care received in German primary care practices. *BMC Health Serv Res* 2016; **16(1)**:450. doi: 10.1186/s12913-016-1693-y.
4. Howell D, Molloy S, Wilkinson K, Green E, Orchard K, Wang K, *et al.* Patient-reported outcomes in routine cancer clinical practice: a scoping review of use, impact on health outcomes, and implementation factors. *Ann Oncol* 2015; **26(9)**:1846-58. doi: 10.1093/annonc/mdv181.
5. Mayer DK, Travers D, Wyss A, Leak A, Waller A. Why do patients with cancer visit emergency departments? Results of a 2008 population study in North Carolina. *J Clin Oncol* 2011; **29(19)**:2683-8. doi: 10.1200/JCO.2010.34.2816.
6. Panattoni L, Fedorenko C, Greenwood-Hickman MA, Kreizenbeck K, Walker JR, Martins R, *et al.* Characterizing potentially preventable cancer- and chronic disease-related emergency department use in the year after treatment initiation: A regional study. *J Oncol Pract* 2018; **14(3)**:e176-e85. doi: 10.1200/JOP.2017.028191.
7. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, *et al.* Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *JAMA* 2017; **318(2)**:197-8. doi: 10.1001/jama.2017.7156.
8. Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown JM, *et al.* Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomized controlled trial. *J Clin Oncol* 2004; **22(4)**: 714-24. doi: 10.1200/JCO.2004.06.078.
9. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, *et al.* What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol* 2014; **32(14)**: 1480-501. doi: 10.1200/JCO.2013.53.5948.
10. Gensheimer SG, Wu AW, Snyder CF. Oh, the places we'll go: Patient-reported outcomes and electronic health records. *Patient* 2018; **11(6)**:591-8. doi: 10.1007/s40271-018-0321-9.

••••••••••