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The Use of Patient-Reported Outcome Measures in Oncology: Perspectives of Oncologists

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ABSTRACT Objective: This survey study was designed with the aim of assessing the use and opinions about patient-reported outcome measures (PROM) by healthcare workers in oncology clinics in Türkiye. Material and Methods: A 10-question survey was distributed to medical and radiation oncologists through digital platforms, receiving 334 complete responses. Results: Of the participants, 87.4% worked in medical oncology and 12.6% in radiation oncology clinics, respectively. 56% of participants reported less than 5 years of experience. Among participants, 11.7% of medical oncologists and 25% of radiation oncologists reported using PROMs in daily practice ($p<0.05$). In oncology clinics, it was revealed that PROMs were mainly used in international clinical studies (27.8%), while it was used in national academic studies with less frequency (21.8%). The use of PROMs appeared to increase with professional experience ($p<0.05$). Among participants, 53.5% stated they had not used PROMs for any purpose. The two most important obstacles to the use of PROMs were lack of time (62.5%) and lack of assisting personnel (35.2%). 25% of participants stated they did not know anything about PROMs. Conclusion: The rate of PROMs use in oncology clinics in Türkiye is 13%, which is much behind the rest of the world, reflecting possible similar patterns in other low- and middle-income regions. This pioneering study underscores the need for strategic initiatives to embed PROs in cancer care, advocating for reforms in health systems.

Keywords: Patient-reported outcomes; patients reported outcome measures; oncology; survey

In recent years, cancer treatment has become more individualized with technological and pharmacological advancements. To comprehensively understand the needs of cancer patients and provide individualized patient-centered oncology care services, obtaining patient-reported outcomes (PROs) is important.[1,2] PROs are defined as a direct assessment of the health status of patients, health-related behavior, and experience of health services without interpretation by someone such as a physician, nurse, or caregiver.[3] Patient-reported outcome measures (PROMs) are instruments, generally comprising surveys that are used to report PROs.[4] The use of PROMs started in clinical research, and they are now an important part of follow-up for many chronic diseases.[5]

Cancer patients experience many symptoms related to the disease or side effects of the treatment in every stage of the disease.[6] However, healthcare providers often underestimate these symptoms or the severity of the symptoms.[7,8] Therefore, the application of patient-centered practices is recommended to monitor symptoms and improve the quality of life of patients and satisfaction with treatment.[9] Following the use of PROMs, cancer patients were found to have better control of symptoms, lower emergency service attendance, and higher overall survival.[10-12] Although interest in the routine use of PROMs for patient-centered cancer care has increased considerably, PROs have not been fully integrated into daily practice. The main obstacles preventing the transition

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APPENDIX 1: Evaluation of the Use of PROMs (Patient Reported Outcome Measures) in Oncology Clinics.

Patient-reported outcome measures (PROMs) aim to assess an individual's perception of their own health, including aspects like quality of life, side effects, and symptom severity, through surveys. The utilization of standardized scales like these is increasingly essential in all areas of healthcare to provide patient-centered optimal care. In this survey, the use of patient-reported outcome measurements (PROMs) in oncology clinics in Turkey will be evaluated. The survey consists of a total of 10 questions and takes approximately 2-3 minutes to complete. Your responses to the survey will be recorded anonymously.

For any questions related to the survey, please contact the responsible researcher, Dr. Eda Çalışkan Yıldırım, at the following phone number: 05545070442. If you agree to participate in the survey, please check the box below. This survey is created for academic purposes and is not conducted for any fee. We appreciate your participation.

o I agree to participate in the survey

What is your specialty?

a) Medical Oncology
b) Radiation Oncology

How much experience do you have in the relevant oncology field?

a) I am a resident/fellow
b) <5 years
c) 5-10 years
d) 11-15 years
e) >15 years

Which center do you work at?

a) Training and Research Hospital
b) University Hospital
c) Foundation University
d) Private Hospital
e) Public Hospital

How many oncology patients does your clinic serve on average per day?

a) <30
b) 30-60
c) 61-100
d) >100

Does your center use scales that assess patient-reported outcomes (PROMs) such as symptoms, side effects, in the evaluation of patients?

a) Yes
b) No

In what situations do you use PROM assessments most frequently? (You can select multiple options)

a) In daily practice
b) In international clinical trials
c) In national academic research
d) I do not use them

If you do not use PROMs, why not? (You can select multiple options)

a) I do not know exactly what they are used for
b) Lack of time
c) I find the evidence for clinical benefit insufficient
d) They are not routinely recommended in guidelines
e) Lack of support staff

If you use PROMs, what do you primarily aim to assess with them? (You can select multiple options)

a) Symptom burden
b) Evaluation of nutritional status
c) Pain assessment
d) Side effect assessment
e) Quality of life assessment

Which of the following PROM scales do you frequently use? (You can select multiple options)

a) ESAS
b) EORTC-30 and cancer-specific modules
c) SF-36
d) FACT-G and cancer-specific modules
e) EQ-5D-5L

Would you prefer to use these scales routinely under ideal conditions?

a) Yes
b) No
c) Uncertain

to PROs in clinical practice involve inadequate information about PROMs among healthcare providers, a lack of time to apply and interpret PROMs, and a lack of technological support.[13]

Although the use of PROMs has increased significantly worldwide, there is insufficient data on the use of PROMs by oncologists in Türkiye. In this survey, we investigated the current status of the application of PROMs and the reasons for not using them in the field of oncology in Türkiye.

MATERIAL AND METHODS

In this study, we designed and conducted a national cross-sectional online survey. The survey form contained 10 questions and was created by the researchers using Google Forms (Google, USA) (Appendix 1). To determine whether the questions in the survey were understandable, a pilot study was conducted with 20 medical oncologists.

This survey was sent by e-mail to medical oncologists and radiation oncologists practicing in Türkiye and residents/fellows continuing their training in oncology. In total, 334 participants responded to the survey, with a calculated response rate of 17%.

The survey assessed the field of specialization (medical or radiation oncologist) and experience of the participants, the center they were affiliated with, the application of PROMs, the purpose of using PROMs, and the reasons for not using PROMs. The survey included a brief introduction and contained information on the mean duration to complete it. Completion and submission of the survey constituted informed consent to participate. Respondents were assured that their responses would be kept anonymous and only summarized data would be disclosed.

The study protocol was approved by the Non-Interventional Ethics Committee of Dokuz Eylül University (date: December 14, 2022, no: 2022/40-05) and followed the guidelines provided by the Declaration of Helsinki.

All data were statistically analyzed using SPSS version 25.0 (IBM Corp., Armonk, NY, USA). Descriptive statistics of categorical variables are reported as frequencies. Sub-analyses were performed on variables such as the field of specialization of participants, years in practice, and facility of practice. Proportions were compared by conducting the chi-square test. All results were considered to be statistically significant at $p<0.05$.

RESULTS

The survey was completed by 334 healthcare workers, including 292 medical oncologists and 42 radiation oncologists. The information on participants, including facility of practice, experience in oncology, and patient volumes (patient number per day), is summarized in Table 1.

Only 46% of participants stated that they used PROMs. Among them, 27% of the participants stated that they used PROMs for international clinical studies, 21% for national academic studies, and 13% for daily practice (Figure 1). Regarding the reasons for not using PROMs, 62.5% of participants stated a lack of time, while 35.2% of participants stated a lack of assisting personnel. Also, 24.3% of participants stated that they did not know the utility of PROMs (Figure 2). When the participants were asked the rea-

TABLE 1: Characteristics of the participants.

Characteristic	n (%)
Specialty	
Radiation oncology	42 (12.6)
Medical oncology	292 (87.4)
Facility of practice	
Academic	275 (82.3)
Non-academic	59 (17.7)
Hospital type	
Public	256 (76.6)
Private	78 (23.4)
Patient volume (patient number per day)	
<30	41 (12.3)
30-60	62 (18.6)
60-100	77 (23.1)
>100	154 (46.1)
Years in oncology practice	
<3 years (resident/fellow)	143 (42.8)
<5 years	44 (13.2)
5-10 years	60 (18)
11-15 years	39 (11.7)
>15 years	48 (14.4)

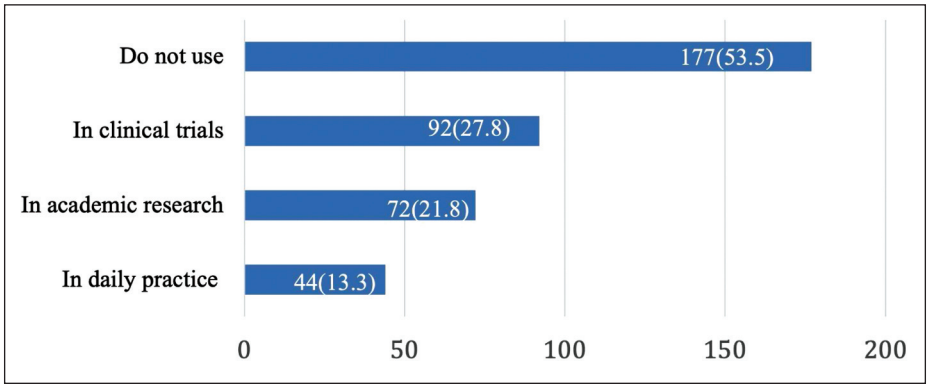

FIGURE 1: The use of patient-reported outcome measures.

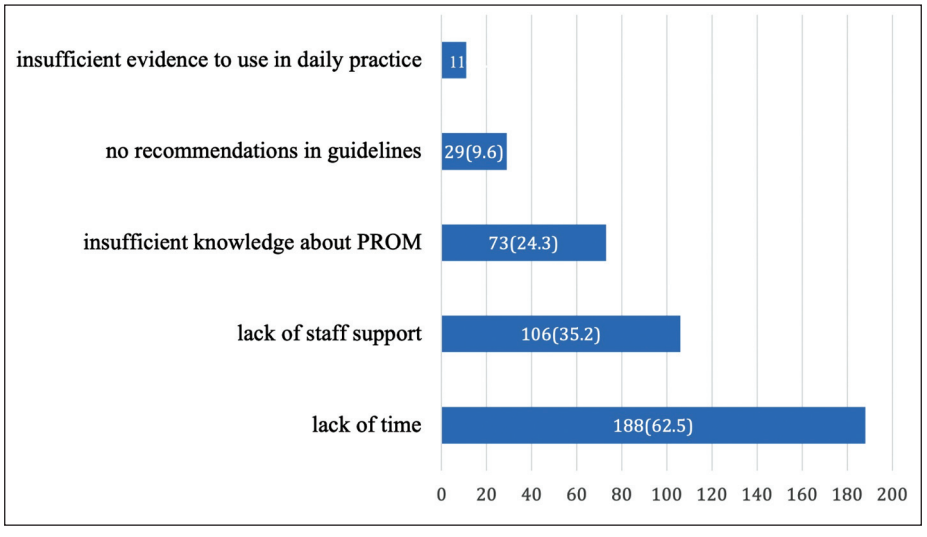

FIGURE 2: The reasons for not using patient-reported outcome measures.

sons for using PROMs, 60.2% of them stated that they used it to assess side effects and 50.6% used it to evaluate quality of life.

The use of PROMs to assess nutritional status, pain, and symptom burden was reported less frequently. The most commonly used scales to examine Turkish validity and reliability include the European Organization for Research and Treatment of Cancer-30 (EORTC-30) and cancer-specific subtypes (46.5%). The Edmonton Symptom Assessment Scale and The Functional Assessment of Cancer Therapy-General scales are used less frequently than the EORTC scale.

To the question, "Would you use PROMs in your daily practice under ideal circumstances", 70% of the participants answered "yes", 5% of the participants answered "no", and 25% of the participants remained "undecided".

By comparing the rates of use of PROMs in daily practice between radiation oncologists and medical oncologists, we found that 25% of radiation oncologists and 11.7% of medical oncologists used PROMs ($p<0.05$). When the correlation between professional experience and use of PROMs was assessed, participants working for more than 10 years in the field of oncology used PROMs significantly more than participants working for less than 10 years in the field (20.6% vs. 10.6%; $p<0.05$). However, no correlation was found between participants who did not have adequate information about PROMs and the duration of professional experience. Additionally, no difference in the lack of knowledge about PROMs

was found between participants working in academic and non-academic facilities.

No difference in the use of PROMs in daily practice was found between the academic and non-academic centers. The rate of use of PROMs for national research was higher in academic institutions than in non-academic institutions (24% vs. 10.2%; $p<0.05$). No significant correlation was found between the number of patients treated in the clinics and the application of PROMs.

DISCUSSION

Patient-centered oncological care has become the standard approach around the world. PROMs are instruments used to assess the health status of patients and are indispensable for patient-centered care activities.[14] In this study, we investigated the use of PROMs and the perception regarding them among healthcare professionals in oncology clinics across Türkiye. The results of the survey showed several key findings that provided deeper insights into the implementation of PROMs and its implications in the Turkish healthcare system.

Only 13.3% of clinical practitioners were found to use PROMs in Türkiye. Few studies have assessed the use of PROMs and the perception of healthcare professionals on this matter in the field of oncology. The most comprehensive study was conducted by Cheung et al., who examined the experience and perspectives of health professionals in different continents. In that study, 66.6% of participants used PROMs in daily practice, and 25% of them stated that they applied it to more than 80% of patients. Additionally, nearly 73% of participants practiced in high-income countries. No difference in the rate of use of PROMs was recorded between participants in high-income and low/moderate-income countries.[15] Nguyen et al. investigated health professionals responsible for the care of head and neck cancer patients in Australia and found that 14% of the professionals used PROMs.[16] This stark contrast between the utilization rates observed in this study and those reported in other parts of the world highlights a significant gap in the incorporation of patient-reported perspectives into cancer treatment in Türkiye. This finding raises important questions about the factors contributing to this disparity, and further research is needed to identify these factors.

In our study, the primary reasons for not using PROMs among participants included a lack of time and a lack of assisting personnel. In the study by Cheung et al. 46% of health professionals reported a lack of time and 66.4% reported a lack of assisting personnel as system-related barriers to the use of PROMs. Although the rate of use of PROMs does not differ according to the income level of countries, the obstacles to their use differ between countries. In high-income countries, the most frequent barrier is technological support, while in low-income countries the most frequent barrier is low literacy level and patient compliance problems.[15] The insufficient knowledge of healthcare professionals regarding the implementation and interpretation of PROMs is also an important barrier to its usage. In this study, nearly 24% and 10% of participants stated that they did not have adequate information and recommended guidelines about PROMs. The first guideline related to PROs was published by the European Society of Medical Oncology in 2022 and provides key recommendations for routine use of PROMs during the care of patients with cancer.[17] Participants with less experience in oncology were found to implement PROMs at lower rates compared to more experienced participants. Although it was expected that less experienced participants would have a lower rate of insufficient knowledge about PRO compared to more experienced participants, no such difference was found. Cheung et al. reported that nearly 70% of participants had at least 10 years of experience, which may be a reason for the high rates of use of PROMs in their study.[15]

The findings of this study further emphasized the benefits of PROMs, as most of the participants expressed their willingness to use PROMs under ideal conditions. This positive outlook suggests that given the right resources and support, healthcare professionals recognize the value of PROMs in improving patient-centered care and treatment outcomes.

The information obtained in this study was limited as the survey conducted included only 10 ques-

tions. This was the most important drawback of our study. If the reasons for not implementing PROMs in clinical practice could be evaluated in different categories, such as patient-related, system-related, or healthcare professional-related reasons, it could have helped us present more targeted solutions. Another limitation was that only medical oncology and radiation oncology physicians participated in the study; the inclusion of other health professionals responsible for the care of cancer patients would have provided more information. The strength of our study is that not many studies have evaluated the use of PROM among oncologists, and thus, our findings provide novel information.

CONCLUSION

This study provided a significant first step in understanding the implementation of PROMs and the perspective regarding their use among healthcare workers in oncology clinics in Türkiye. The low adoption rate of PROMs highlights an opportunity for healthcare authorities to promote the integration of PROs into routine cancer care practices. By addressing the identified barriers and offering tailored support, healthcare organizations can bridge the gap between current practices and the growing global interest in PROs, thus facilitating more patient-centered and evidence-based cancer care in Türkiye.

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: *Eda Çalışkan Yıldırım, Mehmet Uzun;* ***Design:*** *Eda Çalışkan Yıldırım;* ***Control/Supervision:*** *Eda Çalışkan Yıldırım, İlhan Öztop, Tuğba Yavuzşen;* ***Data Collection and/or Processing:*** *Eda Çalışkan Yıldırım, Mehmet Uzun;* ***Analysis and/or Interpretation:*** *Eda Çalışkan Yıldırım, Tuğba Yavuzşen;* ***Literature Review:*** *Eda Çalışkan Yıldırım;* ***Writing the Article:*** *Eda Çalışkan Yıldırım;* ***Critical Review:*** *Eda Çalışkan Yıldırım, Mehmet Uzun, İlhan Öztop, Tuğba Yavuzşen;* ***References and Fundings:*** *Eda Çalışkan Yıldırım, Mehmet Uzun, İlhan Öztop, Tuğba Yavuzşen.*

REFERENCES

1. Alemayehu D, Cappelleri JC. Conceptual and analytical considerations toward the use of patient-reported outcomes in personalized medicine. Am Health Drug Benefits. 2012;5(5):310-317. [PubMed] [PMC]
2. Lutz AT, Griza A, Machado GM, Loose U, Dahmer A, Herbert JS. Patient reported outcomes in the daily practice in clinical oncology: a systematic review. Crit Rev Oncol Hematol. 2022 May;173:103658. [Crossref] [PubMed]
3. U.S. Department of Health and Human Services FDA Center for Drug Evaluation and Research; U.S. Department of Health and Human Services FDA Center for Biologics Evaluation and Research; U.S. Department of Health and Human Services FDA Center for Devices and Radiological Health. Guidance for industry: patient-reported outcome measures: use in medical product development to support labeling claims: draft guidance. Health Qual Life Outcomes. 2006 Oct;4:79. [Crossref] [PubMed] [PMC]
4. Weldring T, Smith SM. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). Health Serv Insights. 2013 Aug;6:61-68. [Crossref] [PubMed] [PMC]
5. Mercieca-Bebber R, King MT, Calvert MJ, Stockler MR, Friedlander M. The importance of patient-reported outcomes in clinical trials and strategies for future optimization. Patient Relat Outcome Meas. 2018 Nov;9:353-367. [Crossref] [PubMed] [PMC]
6. Di Maio M, Basch E, Bryce J, Perrone F. Patient-reported outcomes in the evaluation of toxicity of anticancer treatments. Nat Rev Clin Oncol. 2016;13(5):319-325. [Crossref] [PubMed]
7. Basch E, Iasonos A, McDonough T, et al. Patient versus clinician symptom reporting using the National Cancer Institute Common Terminology Criteria for Adverse Events: results of a questionnaire-based study. Lancet Oncol. 2006;7(11):903-909. [Crossref] [PubMed]
8. Di Maio M, Gallo C, Leighl NB, et al. Symptomatic toxicities experienced during anticancer treatment: agreement between patient and physician reporting in three randomized trials. J Clin Oncol. 2015;33(8):910-915. [Crossref] [PubMed]
9. Warrington L, Absolom K, Conner M, et al. Electronic systems for patients to report and manage side effects of cancer treatment: systematic review. J Med Internet Res. 2019;21(1):e10875. [Crossref] [PubMed] [PMC]
10. Basch E, Deal AM, Kris MG, Scher HI, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. J Clin Oncol. 2016;34(6):557-565. Erratum in: J Clin Oncol. 2016;34(18):2198. Erratum in: J Clin Oncol. 2019;37(6):528. [Crossref] [PubMed] [PMC]
11. 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. 2020;16(9):e958-e965. [Crossref] [PubMed]

12. 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. 2017;318(2):197-198. [Crossref] [PubMed] [PMC]

13. Graupner C, Kimman ML, Mul S, et al. Patient outcomes, patient experiences and process indicators associated with the routine use of patient-reported outcome measures (PROMs) in cancer care: a systematic review. Support Care Cancer. 2021;29(2):573-593. [Crossref] [PubMed] [PMC]

14. Lloyd H, Wheat H, Horrell J, et al. Patient-reported measures for person-centered coordinated care: a comparative domain map and web-based compendium for supporting policy development and implementation. J Med Internet Res. 2018;20(2):e54. [Crossref] [PubMed] [PMC]

15. Cheung YT, Chan A, Charalambous A, et al. The use of patient-reported outcomes in routine cancer care: preliminary insights from a multinational scoping survey of oncology practitioners. Support Care Cancer. 2022;30(2):1427-1439. [Crossref] [PubMed] [PMC]

16. Nguyen H, Butow P, Dhillon H, et al. Using patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs) in routine head and neck cancer care: what do health professionals perceive as barriers and facilitators? J Med Imaging Radiat Oncol. 2020;64(5):704-710. [Crossref] [PubMed]

17. Di Maio M, Basch E, Denis F, et al; ESMO Guidelines Committee. Electronic address: clinicalguidelines@esmo.org. The role of patient-reported outcome measures in the continuum of cancer clinical care: ESMO Clinical Practice Guideline. Ann Oncol. 2022;33(9):878-892. [Crossref] [PubMed]