



The use of electronic Patient Reported Outcomes in follow-up after palliative radiotherapy: A survey study in Belgium

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ARTICLE INFO

Keywords:

Palliative radiotherapy
Electronic patient reported outcome measures
ePROMs
Patient-centered care

ABSTRACT

Objective: Electronic Patient-Reported Outcome Measures (ePROMs) could be used to monitor patients' symptoms after treatment. However, ePROM implementation in clinical practice has been challenging, especially in (palliative) radiation oncology. The aim of this study was to explore the opinions of healthcare providers (HCP) active in radiation oncology in Belgium on the use of ePROMs for symptom follow-up after palliative radiotherapy.

Methods: An anonymous online survey was conducted with different HCP in radiation oncology in Belgium. Participants were recruited through several professional organizations with approximately 390 members actively working in the field of radiation oncology. The survey used was a self-developed questionnaire, based on existing literature on implementation of (e)PROMs in cancer care, our previous research on this topic as well as our personal experience in the field of oncology and palliative care.

Results: Of the 128 respondents, 26% had experience with ePROMs in clinical practice. Eighty-four percent considered ePROMs beneficial for patients' health and symptom knowledge, symptom self-management and active participation in care. ePROMs could help HCP to focus on detection of relevant symptoms and improve their management. Almost 75% were willing to implement and use ePROMs. Assigning ePROM introduction and follow-up to a dedicated person, such as a nurse navigator, was suggested to promote ePROM implementation and use in clinical practice.

Conclusion: Despite limited experience with ePROMs in clinical care for palliative radiotherapy patients, the majority of respondents is willing to implement and use ePROMs for this particular patient population.

Innovation: This is one of the first studies specifically focusing on experiences and opinions of HCP in radiation oncology on the use of ePROMs for symptom follow-up in palliative radiotherapy. HCP should be actively involved in implementation of ePROMs after palliative radiotherapy, to translate their vision of their ideals in practice.

1. Introduction

Palliation is a common indication for radiotherapy: many advanced cancer patients receive palliative radiotherapy for a multitude of symptoms and up to 40% of radiotherapy courses are delivered with palliative intent [1-4]. Generally, courses are short to maximize impact but minimize treatment-related symptoms. Despite preventive measures, treatment-related symptoms or persistent cancer-related

complaints may still occur or remain present after treatment [5]. Currently, there is limited guidance for follow-up strategies after a course of palliative radiotherapy. Suggestions for follow-up guidelines focus primarily on follow-up of re-treatment needs, rather than follow-up and treatment of therapy-induced symptoms [6].

A possibility to follow patients' symptoms after their palliative radiotherapy is using Patient-Reported Outcomes (PROs). PROs are defined, by the USA Food and Drug Administration, as "any report of the

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status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [7-10]. PRO measures (PROMs) are derived from the patient's self-assessment of a variety of health and wellbeing indices, such as symptoms, side-effects, functional outcomes or multidimensional constructs such as quality-of-life (QoL) [7]. PROM data collection can be through self-administration on paper or online (ePROMs), interviews or a combination of different approaches. Several studies have reported that paper-based PROMs and ePROMs are comparable and give equivalent scores [11,12]. However, ePROMs have several benefits over paper-based PROMs: reminders for completion can be sent out; ePROMs data can prompt automated feedback and self-management support to patient; data can be integrated in the patient's electronic medical records and ePROMs are associated with lower costs and shorter processing time compared to paper-based ones [13,14]. Additionally, patients increasingly express a preference for an electronic mode of administration [15,16].

PROMs are considered reliable, especially regarding concepts best measured from a patient's perspective [17-19]. Subjective patient perceptions can be particularly relevant as it has been shown that patient experiences do not always coincide with the clinician's understanding [20,21]. Palliative cancer patients have to cope with multiple symptoms and complex problems, especially when death is near. The collection of PROMs allows to determine the effectiveness of interventions by comparing the health status after the intervention to that before treatment, thereby supporting or opposing certain clinical activities [22].

PROM collection/symptom monitoring in oncology practice can have numerous advantages for patients, including improved communication with healthcare professionals, higher satisfaction and higher levels of health-related QoL, as well as economic benefits due to decreased emergency room visits and hospital readmissions [10]. However, in the advanced/palliative cancer setting, the importance of using (e)PROMs has been primarily proven for systemic therapy [23,24]: improving clinical effectiveness, treatment adherence, symptom reporting, quality of care and survival rates [19,24-28]. Far less research has been performed on ePROM use and implementation of ePROM in routine clinical care after palliative radiotherapy, especially regarding individual symptoms [22,29,30]. This could be because implementation of (e)PROMs after radiotherapy (in the palliative setting) is different than in systemic treatment: radiation courses are short with symptoms usually occurring after completion of treatment, compared to longer courses of systemic therapy where symptoms occur during treatment. Additionally, patients may have a different rapport with their radiation oncologist compared to their medical oncologist.

As (e)PROMs can provide crucial information about patient experiences during cancer trajectories, their use in clinical practice is becoming increasingly advocated [10]. However, their implementation and adoption in routine clinical practice has shown to be challenging [31]. Additionally, the evidence for the impact of (e)PROMs on routine clinical practices, such as prompting appropriate referrals, is reported to be weak or ambiguous. A greater understanding of how PROMs may be integrated and used in clinical care must be sought [32].

Previous research from our group revealed that both patients and HCP (radiation oncologists working in our hospital, general practitioners and home-care nurses) agree that ePROMs could improve systematic clinical follow-up after palliative radiotherapy, with self-management support being a key feature of such an ePROM intervention. Especially patients saw self-management of symptoms as a possibility to keep as much control about their live and care situation as possible [33].

In order to capture experiences and opinions of a broader group of HCP active in radiation oncology in Belgium on the use of (e)PROMs for palliative radiotherapy, we performed an online survey study. The goal of the study was to identify personal opinions on potential barriers and facilitators for (e)PROMs in this specific setting. In particular because these may differ from those of HCP active in general medical oncology.

2. Methods

2.1. Study design and setting

An anonymous online survey for professionals in radiation oncology in Belgium was conducted between March 2022 and July 2022.

2.2. Recruitment

Study participants were radiation oncologists (ROs), nurses, radiation therapy technologists (RTTs), clinical support managers (CSMs) and quality managers (QMs). There were no specific in- or exclusion criteria, as we wanted our study results to represent the active workforce.

Participants were recruited through several professional organizations with members active in the field of radiation oncology in Belgium: BeSTRO (the Belgian Organization of Radiation Oncology), VVRO (Vereniging Verpleegkundigen Radiotherapie en Oncologie, a Flemish association for nurses active in radiotherapy and oncology), VMBv (Vereniging van Medische Beeldvormers, a Flemish association for technologists working in radiology, radiotherapy and nuclear medicine) and Aftier (Association Francofone des Infirmières et Technologues Exerçant en Radiothérapie Belge, an association for French speaking nurses and RTT's active in radiotherapy in Belgium).

The professional associations that participated in this study have approximately 390 members actively working in the field of radiation oncology in 25 centers. Some individuals may have memberships to more than one organization. The exact number of professionals could not be determined, as the number of individuals that have a membership of more than one professional association could not be verified due to the anonymity of this study.

2.3. Survey

The online survey used in this study was a self-developed questionnaire on professionals' personal opinions about the relevance and feasibility of (e)PROMs for patient follow-up after palliative radiotherapy. The survey was self-administered in Dutch or French and took approximately 10 min to complete via the online survey platform SurveyMonkey. An English translation of the survey is available in Appendix A.

The survey was designed during multiple meetings by the research team based on the existing literature on implementation of (e)PROMs in cancer care, our previous research on this topic as well as our personal experience in the field of oncology and palliative care [8,27,29,33]. Questions about organizational or policy barriers were not included in this survey, as they are already well known from previous studies and we wanted to explore personal perspectives of different HCP active in the field of radiation oncology on ePROM use after palliative radiotherapy. Similarly, questions about specific PROM instruments were out of scope for this survey in order to avoid capturing feelings about a particular instrument instead of ePROMs as a concept. As self-management of symptoms was reported as an opportunity of (e)PROMs by both patients and HCPs in our previous study, we added several questions on this topic to our questionnaire to see if this was seen as a facilitator for ePROM use [33].

During the development phase, the survey was reviewed by a nurse, an RTT, a PhD student in palliative care and a resident in radiation oncology (all working in our department) to check whether the questions in the survey were suitable, clear and touched all relevant topics.

The survey started with a short introduction of the overall objective of the study, followed by 42 questions (primarily multiple choice) divided into four sections (Appendix A). Open-ended questions were kept to a minimum, but were offered for enabling additional input and feedback. The first section collected demographic and work-related information; the second section focused on current practice of follow-up after palliative radiotherapy in the respondents' own hospital; the

third section focused on the perceived relevance of (e)PROMs after palliative radiotherapy and in the last section data was collected on experience, implementation and use of (e)PROMs in palliative radiotherapy.

Questions focused primarily on the personal opinions and attitudes of HCP active in radiation oncology on ePROM use in daily clinical practice, as most barriers and facilitators on ePROMs for benchmarking purposes as well as implementation issues on an organizational and policy-based level are already known from previous studies.

2.4. Data collection

Participants were invited to take part in the study via a survey link shared by the different professional organizations. The BeSTRO announced the study through their online newsletter; the other organizations sent an email to their members. The professional organizations sent a reminder approximately two months after the initial invitation.

Based on the available literature on emailed and anonymous survey response, we expected a 25% response rate, meaning approximately 98 out of 390 answers [34].

2.5. Data analysis

Participant responses were recorded anonymously and retrieved electronically using the online survey platform SurveyMonkey. As IP addresses could not be reviewed to ensure anonymity, members of the professional associations not actively working in a radiation oncology department were specifically asked not to participate and participants were requested not to submit multiple entries. Questions could be skipped and the survey could be turned in, even if not all questions were answered, to increase the response rate.

Descriptive statistics were used to summarize responses to each question. All analyses were conducted using Microsoft Excel or by using the SurveyMonkey analysis tool.

2.6. Ethical approval

Approval for this study was obtained from the Ethics Committee Research UZ/KU Leuven Belgium (B3222021000603). Completion of the survey was considered as the informed consent.

3. Results

3.1. Demographic and work-related characteristics of the participants

In total, 128 individuals responded to the survey: 46 ROs, 42 nurses, 19 RTTs, 2 CSMs, 16 QM and 3 other professions (Fig. 1). Ninety-seven

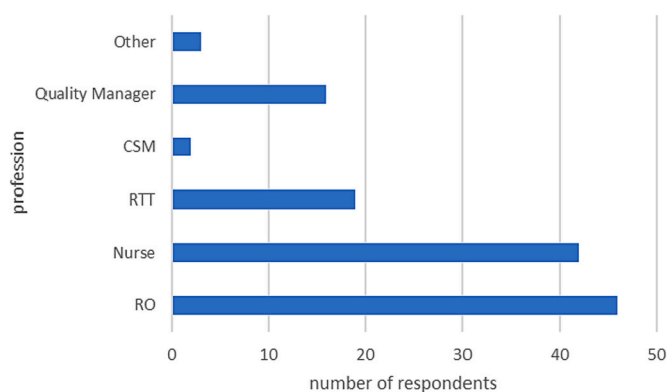


Fig. 1. Profession of respondents. All respondents answered this question. RO: Radiation Oncologist; RTT: Radiation Therapists; CSM: clinical support manager.

individuals started the Dutch questionnaire, 76 of which completed all questions; 31 persons started the French questionnaire, 20 completed all questions.

Eighty-one percent of respondents (103/127) finished their training, with no major difference between the French and Dutch speaking respondents. On average participants had 11 years of clinical experience (range: 0–42 years; median 8 years). Of the French-speaking respondents 48% (15/31) was in a managerial position, compared to 16% of the Dutch-speaking (16/97). The majority was employed in an academic hospital (Fig. 2), this was mainly because 60% of Dutch-speaking respondents was employed in an academic hospital (57/95); with 65% of the French-speaking respondents working in a regional hospital (20/31). An overview is shown in Fig. 2.

3.2. Follow-up after palliative radiotherapy

A consultation regarding the symptoms after palliative radiotherapy was considered to be (very) important by 89% ($N = 92/103$) and was sometimes ($N = 29/103$; 28%), often ($N = 35/103$; 34%) or always ($N = 16/103$; 16%) organized during follow-up. The vast majority found a concluding consultation after palliative radiotherapy (very) important ($N = 83/103$; 85%), but in reality, these consultations were ‘seldom’ or ‘never’ organized according to 28 out of 103 respondents (27%). There was not much difference in the opinions of the different HCP on this subject. One respondent, a nurse, commented that patients treated with a fractionated schedule were usually seen during their treatment, but not always on the day of the last fraction. Planning a consultation for patients treated with a single fraction of radiotherapy was challenging and these patients were often only seen at their own request. Another nurse noted that they had the impression that patients often had questions at the end of their treatment, without anyone to discuss these with, because a consultation was rarely planned on the last day of treatment.

Regarding the symptoms, both patients’ self-management facilitation ($N = 96/109$; 88%) and facilitation of adequate support by HCP ($N = 92/101$; 91%) were considered (very) important. Unfortunately, neither was considered available to all patients: self-management facilitation was ‘always’ or ‘often’ available according to 31 out of 109 respondents (28%); adequate support according to $N = 40/101$ respondents (40%). On the other hand, the majority of respondents (strongly) agreed that medical support was accessible to patients, either in hospital ($N = 61/101$; 60%) or in the primary care setting ($N = 74/100$; 74%). ROs were more positive about the accessibility of care than the other HCP.

While treatment of symptoms after palliative radiotherapy was (strongly) agreed upon to be something that both HCP in hospital and in primary care setting should be able to provide ($N = 87/101$; 86%); only 22% ($N = 22/101$) respondents believed primary care providers, especially General Practitioners (GPs) had enough knowledge on (palliative) radiotherapy to do so, with 42% ($N = 43/101$) fearing that the knowledge of (palliative) radiotherapy was insufficient. ROs were more positive about the knowledge of GPs than the other HCP. The knowledge of non-radiotherapy HCP in hospital on radiation-induced symptoms and their treatment was thought to be sufficient by 25% ($N = 25/101$); insufficient by 50% ($N = 50/101$); the other 25% ($N = 26/101$) of respondents had no opinion on this subject. There were no major opinion differences between the different respondents regarding these questions.

3.3. (e)PROMs in (palliative) radiotherapy

The majority of the respondents ($N = 74/128$; 58%) had knowledge of the use of (e)PROMs in radiotherapy. Only 26% (33/126) had personal experience in routine clinical practice using (e)PROMs, all of them being Dutch speaking respondents. The respondents who had experience with (e)PROMs in the setting of palliative radiotherapy was even more limited to 16% (20/126).

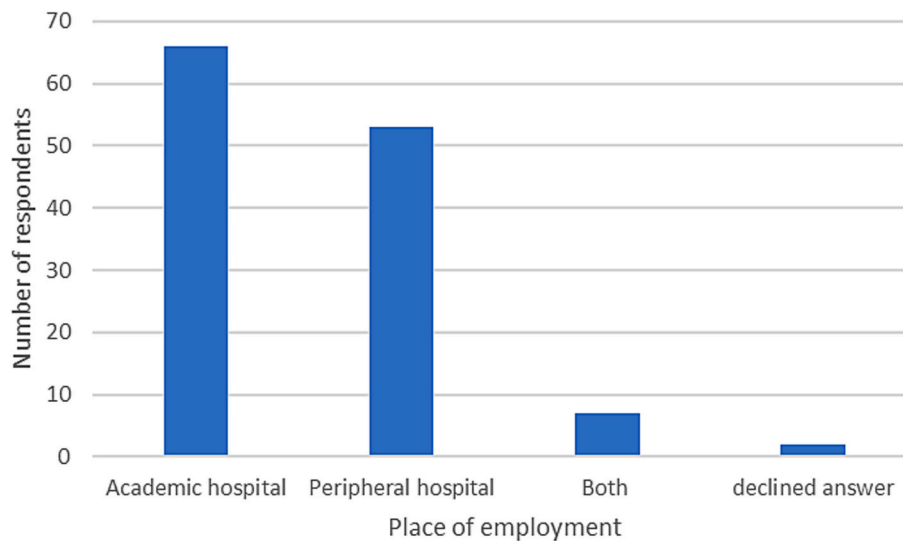


Fig. 2. Place of employment of the respondents. 126 respondents answered this question.

3.3.1. The effect of (e)PROMs on patients

Despite limited ePROM experience, (e)PROMs in palliative radiotherapy were generally viewed as something that would have a positive effect on the care of palliative patients. There was (strong) agreement that (e)PROMs increased the knowledge of patients regarding their symptoms and health ($N = 81/97$; 84%); improved patients' participation in their health care ($N = 75/97$; 77%); improved patients' self-management ($N = 63/97$; 65%) and improved patient-healthcare provider communication ($N = 84/97$; 87). Eighty-two percent (80/97) of respondents (strongly) agreed with the statement that (e)PROMs use would be of added value for patients treated with palliative radiotherapy. The different HCP agreed on this subject.

3.3.2. The effect of (e)PROMs on health care workers

There was a (strong) agreement with the statements that (e)PROMs after palliative radiotherapy improved the knowledge of health care workers on their patients ($N = 76/97$; 78%) and their involvement with their patients ($N = 73/97$; 75%). Additionally, 75% (73/97) of respondents (strongly) agreed that using (e)PROMs increased the communication between different health care workers and 72% ($N = 69/96$) (strongly) agreed that (e)PROMs improve multidisciplinary care. Overall, using (e)PROMs was considered useful for HCP by 78% ($N = 74/95$).

3.3.3. The effect of (e)PROMs on symptom monitoring

Eighty-eight percent ($N = 85/96$) of respondents (strongly) agreed that (e)PROMs could help focus on relevant symptoms; 73% ($N = 71/97$) (strongly) agreed that they could help in the early detection of symptoms and complaints and 77% ($N = 74/96$) that (e)PROMs could help treating and managing symptoms better. Only 23% ($N = 22/97$) of respondents (strongly) agreed with the statements that (e)PROMs are helpful in the ascertain and discussion of difficult themes, with 32% ($N = 31/97$) answering 'neutral' to this question. Different HCP agreed on this subject. However, one correspondent, a radiation oncologist, noted that they had experience with (e)PROMs facilitating a discussion on a difficult theme and allowing for an in-depth conversation regarding further treatment he or she felt would not have taken place if (e)PROMs had not been used.

3.3.4. Implementation and use of (e)PROMs in palliative radiotherapy

Seventy-five percent ($N = 71/95$) of responders (strongly) agreed that the implementation of (e)PROMs would result in an additional workload. For this question there was agreement between all

respondents. Only 11% ($N = 11/96$) (strongly) agreed that using (e)PROMs after successful implementation would alleviate their workload, with 47% ($N = 45/96$) strongly disagreeing with this statement. Especially ROs feared an increase in workload, where nurses were more positive and thought (e)PROMs could potentially alleviate the work. Despite fears for an increased workload, 66% ($N = 63/96$) were motivated to implement (e)PROMs and 75% ($N = 72/96$) were motivated to use (e)PROMs in routine clinical practice, without large disagreements between the different HCP. Eighty-two percent ($N = 78/95$) would be willing to review (e)PROMs before a clinical consultation, with alerts for significant symptoms being regarded a facilitator for use by 61% ($N = 59/96$) and 83% ($N = 79/95$) willing to follow-up on alerts. The majority of respondents felt that it should be the RO or a nurse-specialist who should introduce (e)PROMs to the patient and be responsible for (e)PROMs follow-up. However, ROs were more enthusiastic about nurses following (e)PROM results than nurses themselves. One nurse even commented that the workload for nurses was high enough and that allocating additional tasks to them should stop. On the other hand, another nurse noted that having an RO introduce (e)PROMs to patients could increase the threshold for consultations. They felt that a nurse-specialist introducing (e)PROMs would make patients feel more safe to ask questions about the (e)PROMs and the issues addressed in them to the nurses and RTTs on the treatment machine.

Several individuals noted that assigning the responsibility for (e)PROM introduction and follow-up to a specific person would increase the success of (e)PROMs in routine clinical practice. The most ideal profile for this job was considered a nurse-specialist from the radiation oncology department or a nurse navigator, that follows the patient throughout their entire disease trajectory. The latter was suggested as they generally follow patients for longer periods of time, during different phases in their medical journey, and therefore know their patients well.

There was serious doubt if (e)PROMs in clinical practice were feasible for palliative patients: only 21% ($N = 20/96$) of respondents (strongly) agreed with the statement that (e)PROMs are feasible in this patient population, 31% ($N = 30/96$) disagreed. ROs were more positive about feasibility than the other respondents. Two people, both nurses, suggested allowing by-proxy completion of (e)PROMs in order to increase feasibility. Combining (e)PROM completion with a teleconsultation, in order to discuss patient's general health and motivate patients to complete their (e)PROMs, was brought up by three respondents. However, all respondents making suggestions to increase (e)PROM success, commented that their suggestions wouldn't be possible

in the current work environment.

4. Discussion and conclusion

4.1. Discussion

This survey study aimed to gather information on the personal experiences and opinions of (Belgian) HCP in radiation oncology regarding (e)PROMs for symptom follow-up after palliative radiotherapy. While there is data on experiences and attitudes of HCP on (e)PROMs in advanced cancer, this is one of the first studies that focusses specifically on palliative radiotherapy. With ePROMs for symptom follow-up after palliative radiotherapy currently not often used in routine clinical care, we believe this study provides valuable information to be used during ePROM implementation in this setting.

The vast majority of respondents were non-users or few-users of (e)PROMs in routine clinical care after palliative radiotherapy, which is similar to data on (e)PROM use from other studies in (non-palliative) radiotherapy [35]. However, the respondents acknowledged the importance of (e)PROMs and were generally eager to implement and use them, despite the potential increased workload associated with their use. A recent study by Cheung et al. on (e)PROMs in medical oncology showed similar results: in their study, the majority of oncology practitioners acknowledged the importance of PROMs in clinical practice and were positive about their use, with the bulk of respondents low-frequency or never-users [36]. However, the enthusiasm from our responders to implement (e)PROMs is important, as engagement of all stakeholders has been shown to be a necessity for successful implementation and use of (e)PROMs [37].

The importance of (e)PROM integration within existing systems and practices, without creating additional demands on staff to initially implement PROMs, analyze/use the data collected and support patients in PROMs completion, is well known [32,33,35,36,38,39]. While we did not specifically ask about all these implementation barriers in our survey, the lack of staff support and need for an integration of (e)PROMs in the clinical workflow was reported by several respondents spontaneously, demonstrating that this is an ongoing concern.

One of the suggestions in this survey was dedicating a nurse navigator or care coordinator for the implementation and follow-up of (e)PROMs. Employing a nurse navigator for (e)PROM follow-up seems a good idea and has been suggested in other studies as well [31,35,40]. Continuous support from a nurse navigator could provide patients with better continuity of care, especially as radiotherapy plays only a small part in the care of palliative patients. As our respondents questioned the knowledge of other HCP on radiotherapy, Any nurse navigator would require knowledge on radiotherapy side-effects and their management to perform this role.

With current limitations in staff and resources, a step-by-step implementation, linking (e)PROMs to referral pathways and other tools to support clinical decision-making, and piloting the protocol on a manageable sample of patients using small cycles of change may be the way forward [36,41]. A recent trial assessing the effect of patient-reported symptom monitoring on HRQOL in lung cancer patients, observed that a reactive approach (patient receives alert) and an active approach (health-care provider receives alert) are equally effective on HRQOL [42]. Because of time demands placed on HCP, a more patient-centered approach, focusing on self-monitoring and self-care can facilitate sustainable implementation of symptom monitoring within daily clinical practice.

Respondents in our survey worried about the ability of palliative patients to use (e)PROMs. Providing patients with different options such as a website, mobile- and tablet-based applications as well as wearable computing devices to collect (e)PROMs may increase responses throughout the evaluation period. Additionally, several studies have shown that palliative patients are both willing and capable to play an active role in their care and use an online/digital system. In one trial of

Basch et al., specifically aimed at patients with advanced or metastasized cancer, ePROM use was high and 89% of patients would even recommend the system to other patients [43]. In this study feedback from nurses and oncologists caring for these patients demonstrated favorable perceptions of clinical utility and impact on quality and value of care [43].

In this survey we did not ask any questions on the selection of particular (e)PROMs for clinical practice. There are many questionnaires available, but most are designed for research purposes and may not be practical in clinical routine. While this study provides a good initial overview of HCP's opinions and views on (e)PROMs in palliative radiotherapy, further mixed-method research during implementation of (e)PROMs in this specific patient cohort is necessary to identify the exact needs of both HCP and patients for successful clinical implementation.

The set-up of our study allowed us to ask a multitude of questions to people in different professions in several radiation oncology departments in Belgium. While this gave us a good general overview of the views on (e)PROMs in palliative radiotherapy, the heterogeneous sample might not fully reflect the characteristics of the radiation oncology workforce in all participating sites. We also realize that only motivated individuals with a strong opinion on (e)PROMs in palliative radiotherapy completed the questionnaire, which may have introduced a bias. Based on the individual feedback comments in the questionnaire, we believe that both positive and negative opinions on (e)PROMs were expressed. Another limitation of this study includes the option to 'skip' questionnaire questions, resulting in not all questions being answered by all respondents. While making our survey anonymous has probably resulted in straightforward answering, it prevented us to contact individuals with strong opinions for an in depth interview or further exploration.

4.2. Innovation

This is one of the first studies specifically focusing on personal experiences and opinions of HCP in radiation oncology regarding (e)PROMs for symptom follow-up after palliative radiotherapy. In order to successfully implement (e)PROMs for palliative cancer patients, all HCP caring for these patients need to be convinced of (e)PROM usefulness and usability. Our study shows that HCP in radiation oncology are well aware of (e)PROM benefits and are willing to participate in (e)PROM implementation and use after palliative radiotherapy. Despite their willingness to do so, (e)PROMs are not often used in clinical practice in this setting. Currently, (e)PROMs after palliative radiotherapy are mostly used in research or for benchmarking purposes, not for follow-up and symptom management of individual patients [29,35].

The results of this study could be used in further implementation endeavors of (e)PROMs in clinical care for palliative oncology patients treated with radiotherapy.

4.3. Conclusion

Patients with cancer experience their disease as well as treatment-related symptoms as important for their QoL. For palliative patients, for which preservation of QoL becomes more and more important during their disease trajectory, recognition and treatment of their symptoms is of utmost importance. Adequately capturing the patient's health experience is critical and has become achievable for patients at home through the use of (e)PROMs. The use of (e)PROMs for symptom follow-up after palliative radiotherapy is still in the very early stage of implementation. We described several factors important in the care for palliative radiotherapy patients, as well as HCP related implementation barriers for (e)PROMs in this setting.

The results of our survey show that there is a willingness to implement and use (e)PROMs in routine clinical practice after palliative radiotherapy. However, implementation remains difficult, due to personnel shortage, lack of education and the way our health care

system is currently organized, resulting in few of our respondents having experience with (e)PROMs in routine clinical practice. A dedicated person or even team to educate, guide and support both HCP and patients in the implementation and use of (e)PROMs after palliative radiotherapy could be very useful. Actively involving HCP working in radiation oncology before and during implementation of (e)PROMs, will result in more successful implementation of (e)PROMs in clinical care.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Ethics approval

This study was approved by the research ethics committee of UZ/ KU Leuven.

This study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments.

CRedit authorship contribution statement

Eva Oldenburger: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. **Sofie Isebaert:** Conceptualization, Methodology, Writing – review & editing. **Anne-marie Coolbrandt:** Conceptualization, Methodology, Writing – review & editing. **Chantal Van Audenhove:** Conceptualization, Methodology, Writing – review & editing. **Karin Haustermans:** Conceptualization, Methodology, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We would like to thank all professional organizations active in radiation oncology in Belgium for distributing our survey to their members. We would especially like to thank Aude Vaandering for her enthusiasm to distribute the survey in the Walloon region.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2023.100243>.

References

- Wu SY, Singer L, Boretta L, Garcia MA, Fogh SE, Braunstein SE. Palliative radiotherapy near the end of life. *BMC Palliat Care* 2019;18:29. <https://doi.org/10.1186/s12904-019-0415-8>.
- Spencer K, Morris E, Dugdale E, Newsham A, Sebag-Montefiore D, Turner R, et al. 30 day mortality in adult palliative radiotherapy - a retrospective population based study of 14,972 treatment episodes. *Radiother Oncol* 2015. <https://doi.org/10.1016/j.radonc.2015.03.023>.
- Janjan NA. An emerging respect for palliative Care in Radiation Oncology. *J Palliat Med* 1998;1:83–8. <https://doi.org/10.1089/jpm.1998.1.83>.
- Murphy JD, Nelson LM, Chang DT, Mell LK, Le QT. Patterns of care in palliative radiotherapy: a population-based study. *J Oncol Pract* 2013;9. <https://doi.org/10.1200/JOP.2012.000835>.
- Spencer K, Parrish R, Barton R, Henry A. Palliative radiotherapy. *BMJ* 2018;360:k821. <https://doi.org/10.1136/bmj.k821>.
- Lin VQ, Riviere P, Murphy JD, Bruggeman AR. Retrospective review of follow-up strategies for patients receiving palliative radiotherapy. *J Pain Symptom Manage* 2023;66:238–41. <https://doi.org/10.1016/j.jpainsymman.2023.06.002>.
- Weldring T, Smith SMS. Article commentary: Patient-reported outcomes (PROs) and patient-reported outcome measures (PROMs). *Heal Serv Insights* 2013;6. <https://doi.org/10.4137/hsi.s11093>. HSI.S11093.
- 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;26:1846–58. <https://doi.org/10.1093/annonc/mdv181>.
- Food US. Drug administration: guidance for industry: patient-reported outcome measures—use in medical product development to support labeling claims. *Food Drug Adm Cent Drug Eval Res* 2009;6:301–443.
- Caminiti C, Maglietta G, Diodati F, Puntoni M, Marcomini B, Lazzarelli S, et al. The effects of patient-reported outcome screening on the survival of people with cancer: a systematic review and meta-analysis. *Cancers (Basel)* 2022;14:1–12. <https://doi.org/10.3390/cancers14215470>.
- Gwaltney CJ, Shields AL, Shiffman S. Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: a meta-analytic review. *Value Health* 2008. <https://doi.org/10.1111/j.1524-4733.2007.00231.x>.
- Muehlhausen W, Doll H, Quadri N, Fordham B, O'Donohoe P, Dogar N, et al. Equivalence of electronic and paper administration of patient-reported outcome measures: A systematic review and meta-analysis of studies conducted between 2007 and 2013. *Health Qual Life Outcomes* 2015. <https://doi.org/10.1186/s12955-015-0362-x>.
- Meirte J, Hellemans N, Anthonissen M, Denteneer L, Maertens K, Moortgat P, et al. Benefits and disadvantages of electronic patient-reported outcome measures: systematic review. *JMIR Perioper Med* 2020;3:e45588. <https://doi.org/10.2196/15588>.
- Sandhu S, King Z, Wong M, Bissell S, Sperling J, Gray M, et al. Implementation of electronic patient-reported outcomes in routine cancer care at an academic center: identifying opportunities and challenges. *JCO Oncol Pract* 2020;16:e1255–63. <https://doi.org/10.1200/op.20.00357>.
- Dumais KM, Dias N, Khurana L, Gary ST, Witherspoon B, Evans CJ, et al. Preferences for use and design of electronic patient-reported outcomes in patients with chronic obstructive pulmonary disease. *Patient - Patient-Centered Outcomes Res* 2019;126(12):621–9. <https://doi.org/10.1007/S40271-019-00376-9>.
- 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. <https://doi.org/10.1186/S40697-014-0022-9>.
- Fromme EK, Eilers KM, Mori M, Hsieh YC, Beer TM. How accurate is clinician reporting of chemotherapy adverse effects? A comparison with patient-reported symptoms from the Quality-of-Life Questionnaire C30. *J Clin Oncol* 2004;22:3485–90. <https://doi.org/10.1200/JCO.2004.03.025>.
- Basch E, Iasonos A, McDonough TA, Barz A, Culkin A, Kris MG, 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;7:903–9. [https://doi.org/10.1016/S1470-2045\(06\)70910-X](https://doi.org/10.1016/S1470-2045(06)70910-X).
- 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;32:1480–501. <https://doi.org/10.1200/JCO.2013.53.5948>.
- Di Maio M, Gallo C, Leighl NB, Piccirillo MC, Daniele G, Nuzzo F, et al. Symptomatic toxicities experienced during anticancer treatment: agreement between patient and physician reporting in three randomized trials. *J Clin Oncol* 2015;33:910–5. <https://doi.org/10.1200/JCO.2014.57.9334>.
- Yang LY, Manhas DS, Howard AF, Olson RA. Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication. *Support Care Cancer* 2018;26:41–60. <https://doi.org/10.1007/s00520-017-3865-7>.
- Consolo L, Castellini G, Cilluffo S, Basile I, Lusignani M. Electronic patient-reported outcomes (e-PROMs) in palliative cancer care: a scoping review. *J Patient-Reported Outcomes* 2022;6:1–18. <https://doi.org/10.1186/s41687-022-00509-z>.
- 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;13:319–25. <https://doi.org/10.1038/nrclinonc.2015.222>.
- 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 - J Am Med Assoc* 2017;318:197–8. <https://doi.org/10.1001/jama.2017.7156>.
- Bennett AV, Jensen RE, Basch E. Electronic patient-reported outcome systems in oncology clinical practice. *CA Cancer J Clin* 2012;62:337–47. <https://doi.org/10.3322/caac.21150>.
- Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;3:e001570. <https://doi.org/10.1136/bmjopen-2012-001570>.
- Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. *J Clin Oncol* 2016;34. <https://doi.org/10.1200/JCO.2015.63.0830>.
- Girgis A, Durcinoska I, Levesque JV, Gerges M, Sandell T, Arnold A, et al. eHealth system for collecting and utilizing patient reported outcome measures for personalized treatment and care (PROMPT-Care) among cancer patients: mixed methods approach to evaluate feasibility and acceptability. *J Med Internet Res* 2017;19:1–13. <https://doi.org/10.2196/JMIR.8360>.
- Oldenburger E, Oldenburger F, Coolbrandt A, Isebaert S, Neyens I, Sevenants A, et al. The use of patient reported outcome measures (PROMs) in palliative

- radiotherapy: a topical review. *Radiother Oncol* 2020;149:94–103. <https://doi.org/10.1016/j.radonc.2020.04.045>.
- [30] Fabian A, Domschikowski J, Letsch A, Schmalz C, Freitag-Wolf S, Dunst J, et al. Use and reporting of patient-reported outcomes in trials of palliative radiotherapy: a systematic review. *JAMA Netw Open* 2022;5:E2231930. <https://doi.org/10.1001/jamanetworkopen.2022.31930>.
- [31] Hyland CJ, Mou D, Virji AZ, Sokas CM, Bokhour B, Pusic AL, et al. How to make PROMs work: qualitative insights from leaders at United States hospitals with successful PROMs programs. *Qual Life Res* 2023;32:2259–69. <https://doi.org/10.1007/s11136-023-03388-z>.
- [32] Nic Giolla Easpaig B, Tran Y, Bierbaum M, Arnolda G, Delaney GP, Liauw W, et al. What are the attitudes of health professionals regarding patient reported outcome measures (PROMs) in oncology practice? A mixed-method synthesis of the qualitative evidence. *BMC Health Serv Res* 2020;20:1–24. <https://doi.org/10.1186/s12913-020-4939-7>.
- [33] Oldenburger E, Neyens I, Coolbrandt A, Isebaert S, Sevenants A, Van Audenhove C, et al. Using ePROMs for follow-up after palliative radiotherapy: an exploratory study with patients and health care providers. *Patient Educ Couns* 2021. <https://doi.org/10.1016/j.pec.2021.11.022>.
- [34] Fincham JE. Response rates and responsiveness for surveys, standards, and the journal. *Am J Pharm Educ* 2008;72:43. <https://doi.org/10.5688/AJ720243>.
- [35] Oliver LA, Hutton DP, Hall T, Cain M, Bates M, Cree A, et al. Amplifying the patient voice: a survey of practitioners' use of patient-reported outcome measures across radiotherapy providers in England. *Clin Oncol* 2023;35:199–208. <https://doi.org/10.1016/j.clon.2022.11.004>.
- [36] Cheung YT, Chan A, Charalambous A, Darling HS, Eng L, Grech L, 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;30:1427–39. <https://doi.org/10.1007/S00520-021-06545-7/TABLES/3>.
- [37] Generalova O, Roy M, Hall E, Shah SA, Cunanan K, Fardeen T, et al. Implementation of a cloud-based electronic patient-reported outcome (ePRO) platform in patients with advanced cancer. *J Patient-Reported Outcomes* 2021;5:1–11. <https://doi.org/10.1186/S41687-021-00358-2/FIGURES/2>.
- [38] Graupner C, Breukink SO, Mul S, Claessens D, Slok AHM, Kimman ML. Patient-reported outcome measures in oncology: a qualitative study of the healthcare professional's perspective. *Support Care Cancer* 2021;29:5253–61. <https://doi.org/10.1007/S00520-021-06052-9>.
- [39] Nordan L, Blanchfield L, Niazi S, Sattar J, Coakes CE, Uitti R, et al. Implementing electronic patient-reported outcomes measurements: challenges and success factors. *BMJ Qual Saf* 2018;27:852–6. <https://doi.org/10.1136/BMJQS-2018-008426>.
- [40] Di Maio M, Basch E, Denis F, Fallowfield LJ, Ganz PA, Howell D, et al. The role of patient-reported outcome measures in the continuum of cancer clinical care: ESMO Clinical Practice Guideline. *Ann Oncol* 2022;33:878–92. <https://doi.org/10.1016/j.annonc.2022.04.007>.
- [41] Basch E. *Implementation of Patient-Reported Outcomes in Routine Medical Care*. 2018 ASCO Educ. B. 2018.
- [42] Billings NE, N M F Tromp V, Aaronson NK, RJA Hoek, Bogaard HJ, Onwuteaka-Philipsen BD, et al. Quality of life after patient-initiated versus physician-initiated response to symptom monitoring: the SYMPRO-Lung trial. *JNCI J Natl Cancer Inst* 2023;00:1–11. <https://doi.org/10.1093/jnci/djad159>.
- [43] Basch E, Stover AM, Schrag D, Chung A, Jansen J, Henson S, et al. Clinical utility and user perceptions of a digital system for electronic patient-reported symptom monitoring during routine cancer care: findings from the PRO-TECT trial. *JCO Clin Cancer Informatics* 2020;4:947–57. <https://doi.org/10.1200/cci.20.00081>.