

REVIEW

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Patient reported outcomes in oncology: changing perspectives—a systematic review

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Abstract

In public health context, oncology is associated with severe negative impact on patients and on their relatives' quality of life. Over the last decades, survival has remained at 50% worldwide for some tumor locations. Patient reported outcomes (PROs) assessment and, the corresponding use in clinical practice, help establishing patient individualized profiling involving caregivers. The purpose of this systematic review was to examine critical success factors for PROs assessment in daily clinical oncology practice. Additionally, we investigated how PROs collection can change oncology perspectives for patients and caregivers. According to PRISMA guidelines, 83 studies were included in this systematic review, whether related with implementation in daily clinical practice or associated with its use in oncology. PROs assessment gathers multi-professional teams, biomedical and clinical expertise, patients, families and caregivers. Institutional involvement, first line for caregiver's adherence, team continuous formation, encompassing training and support, design of clear workflows, continuous monitoring, and data analysis are crucial for implementation. PROs measures are decisive in oncology. Several items were improved, including caregiver–patient–physician communication, patient risk groups identification, unmet problems and needs detection, disease course and treatment tracking, prognostic markers, cost-effectiveness measurement and comfort/support provision for both patients and caregivers. Routine assessment and implementation of PROs in clinical practice are a major challenge and a paradigm transformation for future.

Keywords: Patient reported outcomes, Oncology, Critical success factors, Implementation, Caregivers

Introduction

Global burden of cancer in future

Globally, cancer is the second leading cause of death. In 2018, 18.1 million people worldwide had cancer, and 9.6 million died from this disease. It is expected that cancer cases per year will increase globally, and by 2040, it is anticipated that this figure will nearly double [1]. Moreover, severe negative impact on patients and their relatives' quality of life (QoL) is also expected. On the other hand, over the last decades, survival has reached 50% worldwide for some tumor locations [2], which naturally

increases the impact on patients and families' experiencing this illness.

Evidence-based interventions focus on early diagnosis and on treatment of curable cancers, as well as on provision of palliative care for all, in order to reduce premature mortality and to optimize QoL. Cancer burden is significant and increasing, involves several domains on individuals, namely physical, social, emotional and cognitive domains, and economical constraints, and it is associated with innumerable negative impacts on communities and on health systems. In addition, a stronger health system should promote stronger cancer care management [1]. However, cancer management is complex and, mainly in this field, the patient should be the keystone. Also, precision medicine ensures better care, enables earlier diagnosis and optimal treatments implemented by

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multidisciplinary teams, which is expected to guarantee high-quality value-based care. Early detection, quality treatments and patient centered interventions improve both survival rates and QoL, increasing patient confidence and compliance on oncology care [3, 4].

Patient reported outcomes for patients and caregivers

Patient reported outcomes (PROs) discussion and integration in research and clinical field is not new. PROs measures are multidimensional and subjective, grounded on patient's perceptions and are objectively quantified. Their use in clinical practice also helps establishing patient individualized profiling involving caregivers. On the other hand, stepped care model based on PROs data collection can be used to predict health outcomes in the future and to take clinical and economic decisions in order to better personalize medical services [2, 4–6].

Recognizing the inclusion of PROs measures in health systems, studies have been conducted to target their implementation in oncology. These measures, including health-related quality of life (HRQoL), capture de voice, thoughts, feelings, and experience during the oncology journey, clearly supporting patients and caregivers, demystifying concepts, clarifying procedures, favoring emotional support, increasing hope, improving communication, helping to create a safer practice environment for patients and providers, and improving patient safety.

They should also integrate advance care planning in life-threatening or life-limiting illness [7–12]. New techniques for remote advance care planning can also take advantage of mobile applications, namely to follow patient wishes by eliciting their individual values and preferences in order to better the quality of the care provided and to reduce their psychological distress [13, 14]. In addition, a recent systematic review showed that administering electronic PROMs may be a good way to perform a good advance care planning [15].

Looking at several reviews, we also evidence the utility of using PRO measures on family caregiver's support. They are crucial for the optimization of the well-being and HRQoL in oncology and to facilitate patients' experience. Signalizing specific affected domains that can guide strategies, PROs assessments allow to detect unmet problems and help locate investments with precision [16–19].

However, in research and clinical practice, we should always have evidence that the PROMs administered are reliable and properly validated [20]. We keep in mind that one of the purposes of PROs is to help the decision-making process and so, the measurement instruments used should be appropriate, safe, valid, sensitive and with good psychometric characteristics [21, 22].

The objective of this systematic review was to examine potential critical success factors involved in PROs

assessments in oncology clinical practice. Additionally, we investigated how collected PROs scores can modify oncology perspectives for patients and caregivers. All studies were included, whether they report implementations in routine clinical practice or were associated with their use in patient clinical decisions and caregivers' support. This review also addressed the factors that may affect PROs.

Materials and methods

The present systematic review examined PROs assessment in oncology clinical practice perspectives and critical success factors for implementation, in accordance with PRISMA guidelines [23, 24]. In this context, implementation is the carrying out, execution, or practice of a plan, a method, for doing something. When considering PROs in oncology, a conceptual definition of implementation means to integrate collection of PROs in routine practice in order to improve personalized oncologic care and support advance care planning.

Scope of review

This review implemented a systematic methodology to identify critical success factors for PROs measures implemented in routine practice. Its research context encompassed the collection of PROs measures in oncology, the review of PROs intervention and prognostic factors, as well as research articles seen as relevant to health and social care in oncology. Implementation methodology and its influence on the measurement success was also considered.

We did not apply any restrictions related to socio-demographic or clinical characteristics, such as gender, age, ethnicity, tumor location, or TNM classification. However, we excluded other contexts as autoimmune or endocrine diseases, surgery, mental disorders, or chronic pain.

The following question was raised: use PROs in oncology routine clinical practice, does it make any difference? Several domains searched the basis of this question: caregiver–patient–physician communication, patient risk groups identification, unmet problems and needs detection, disease course and treatment tracking, prognostic markers, cost-effectiveness measurement and comfort/support provision for both patients and caregivers.

Also, we searched how PROs assessment gathers multi-professional teams, biomedical and clinical expertise, patients, families, and caregivers. In addition, we searched how institutional involvement, first line caregiver's adherence, team continuous formation (training and support), design of clear workflows, continuous monitoring, and data analysis does influence routine practice assessment implementation.

Search strategy

The search was performed on the following electronic bibliographic databases: Pubmed/Medline, PsycINFO, The Cochrane Library, Science Direct and Web of Science (Science and Social Science Citation Index). Grey literature and conference proceedings was also assessed [25, 26], as well as internet resources WHOQOL [27], Multinational Association of Supportive Care in Cancer (MASCC) [28], and International Society for Quality of Life (ISOQOL) [29, 30].

The search strategy allowed us to find published and unpublished studies. We only considered terms relating to or describing the intervention (PROs implemented and used in clinical practice). It included terms as oncology patients, caregivers, clinical decision-making, stepped care model, predictive prognosis, patient centered care, critical successful factors related to implementation of PRO measures, daily clinical practice, routine assessment, and electronic tools. These terms were combined with the Cochrane Medline filter for controlled trials of interventions.

There were no language restrictions and we focused on studies published between January 2011 and 2021 (10 years).

Initially, any type of article was considered eligible, including systematic reviews, research articles, or prospective and retrospective studies. This means that it was included any paper (1) reflecting the critical success factors considered for the intervention, (2) using electronic tools to optimize the implementation of systematic assessment of PROs in oncology clinical practice; (3) analyzing change perspectives in oncology clinical practice related to the use of PROs; or (4) addressing health and social care in oncology.

However, some studies were excluded, namely if (1) reporting implementation in other health chronic conditions rather than oncology; (2) were duplicated; (3) with full text not available, or (4) were not the original article.

Study quality assessment, data extraction, and analysis plan

All articles searched were filtered using broad selection criteria framed as questions:

- “Does the article address any aspect of PROs implementation and use in oncology?”
- “Is the article relevant to PROs collection and cancer?”

The study selection and data extraction were blinded and, after the search, all references were sent to a reference management system (Mendeley). Duplicate articles

were removed, and the titles and abstracts of the remaining articles were evaluated.

To identify eligible studies, three other questions were raised and answered: (1) was the topic related with the defined scope? (2) did it fit the inclusion and exclusion criteria? and (3) was the methodology appropriate?

A standardized pre-piloted form was used to extract data from the included studies in order to obtain an extraction process as comprehensive, transparent, and objective as possible. Two reviewers extracted data independently, and discrepancies were identified and resolved through discussion with a third author. This third reviewer scrutinized 10% of the data to verify the consistency of the extraction process and to solved discrepancies. Other CEISUC researchers were also contacted to provide missing or additional data [25, 26].

Each article was graded as having low, moderate or high relevance. Articles were considered of high interest whenever they effectively demonstrated impact on the considered items, and moderate those that prospected such items. Low relevance was attributed to all manuscripts that did not present any conclusions or perspectives in these domains.

Data from scoping literature were extracted into an electronic Excel data sheet and constructed by using a support checklist. The datasheet was divided into sections, with each section dedicated to a theory, area, concept, theme, or element from the framework of PROs intervention. After synthesizing the data and assessing the quality of the evidence, the writing of the systematic review article begun.

Results

Process selection

Figure 1 presents the PRISMA flowchart detailing record identification, selection, eligibility, and inclusion.

A total of 31,527 records were retrieved from the five data bases and grey literature. After removing the duplicated and the records not fulfilling the inclusion criteria, we came up with 83 records.

Study characteristics

Summary characteristics of these 83 selected articles are synthesized in Table 1 and, in Additional file 1: Table S1, we present the main characteristics of the articles.

Based on study design, most studies were retrospective or prospective ($n=35$, 42.2%) and a minority of them were research articles ($n=21$, 25.3%). All studies reported PROs and most studies specifically explored HRQoL ($n=47$; 56.6%). Studies were also classified into two main domains: PROs applied to oncology perspectives ($n=81$; 97.6%) and PROs applied to oncology implementation ($n=62$; 74.7%). Overall, the vast majority of

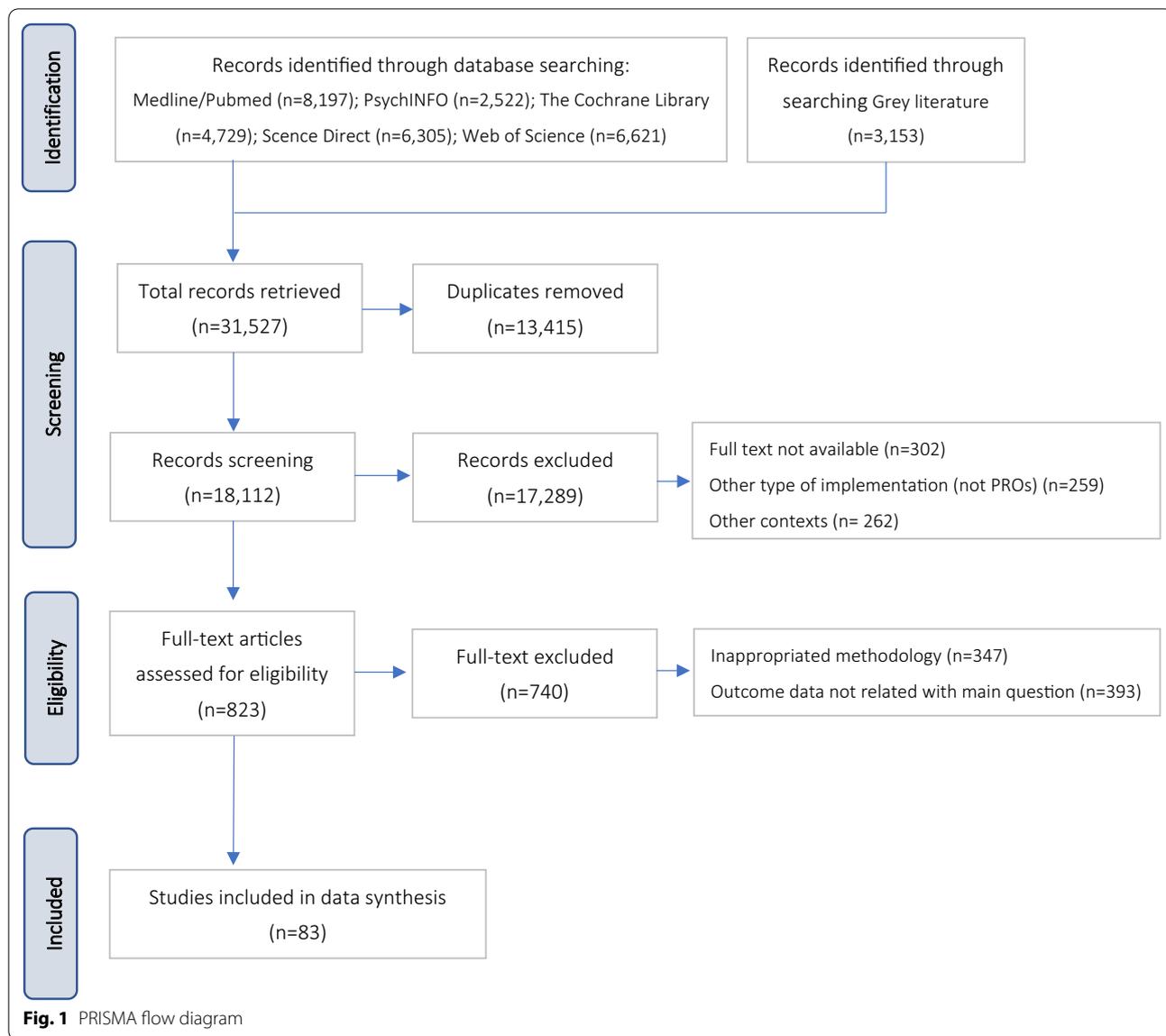


Table 1 Study characteristics of all studies (N = 83)

Characteristics	Classification	N (%)
Study design	Systematic review (SR)	27 (32.5%)
	Research article (RA)	21 (25.3%)
	Retrospective, prospective (RP)	35 (42.2%)
Based on HRQoL		47 (56.6%)
Oncology perspectives interest	High (H)	70 (86.4%)
	Moderate (M)	11 (13.6%)
	Low (L)	0 (0.0%)
Oncology implementation interest	High (H)	55 (88.7%)
	Moderate (M)	7 (11.3%)
	Low (L)	0 (0.0%)

studies were considered of high interest according to the methodological criteria—either for oncology perspectives or for oncology implementation (86.4% and 88.7%, respectively). Articles graded as with low relevance were excluded.

Table 2 summarizes the characteristics of the 83 articles selected.

HRQoL and retrospective and prospective articles were found to be associated to higher scores; high interest rated articles were more frequent along the years. We also observed an increase in articles related to HRQoL and a decrease in articles considered as research articles. However, despite the sample differences verified, a chi-square test did not confirm any significance of the differences observed.

PROs oncology perspectives

A total of 81 (97.6%) studies investigated whether PROs collection determined advantages for patients (n=67; 87.7%), caregivers (n=21; 25.3%) and health systems, communities and society (n=63, 75.9%), as shown in Table 3.

When studying PROs oncology patient perspectives, the most expressive association occurred between PROs collection and risk identification (n=50; 74.6%). In addition, the contribution to stepped care models design revealed the lowest association (n=28; 41.8%). When considering PROs caregivers’ perspectives, studies investigated four main positive effects: (1) caregiver burden measurement (n=16; 76.2%), (2) family support (n=14; 66.7%), (3) supportive guidance (n=7; 33.3%), and (4) communication improvements (n=7; 33.3%). Studies reporting PROs interest for healthcare systems, communities and society, highlighted their contribution to patient-centered care (n=51; 81.0%), how PROs can change future perspectives in oncology (n=40; 63.5%) and, in a lesser extent, their collaboration on drug approvals (n=4; 6.3%), economical decisions and cost-effective measures (n=4; 6.3%).

PROs oncology implementation

A total of 62 studies investigated PROs implementation in routine clinical practice (74.7%). A clear identification of critical success factors was present in 23 studies

Table 2 Selected articles type and rated interest considering the published year (%)

Type of article	2013	2014	2015	2016	2017	2018	2019	2020	2021
HQoL	14.3	14.3	37.6	20.0	29.4	22.5	17.9	20.5	30.8
Systematic reviews	14.3	21.4	0.0	30.0	14.7	10.0	12.8	5.1	15.4
Research	0.0	0.0	18.8	0.0	11.8	7.5	12.8	7.7	7.7
Retrospective and prospective	19.1	21.4	25.0	10.0	8.8	20.0	15.4	31.0	7.7
High interest	19.1	35.7	31.3	30.0	17.6	32.5	23.1	33.3	38.5
Moderate interest	9.5	7.1	8.3	10.0	17.6	5.0	17.9	5.1	0.0

Table 3 PROs: oncology perspectives

	N (%)	Perspectives	N (%)
Oncology patients	67 (87.7%)	Stepped care models	28 (41.8%)
		Prognosis value	34 (50.7%)
		Communication	37 (55.2%)
		Patient safety	40 (59.7%)
		Risk identification	50 (74.6%)
Caregivers	21 (25.3%)	Communication improvements	7 (33.3%)
		Supportive care guidance	7 (33.3%)
		Caregiver support and unmet needs identification	14 (66.7%)
		Caregiver burden	16 (76.2%)
Health systems, communities and society	63 (75.9%)	Futures perspectives in oncology	40 (63.5%)
		Economical decisions, cost-effective measures	4 (6.3%)
		Drug approval	4 (6.3%)
		Patient centered care	51 (81.0%)

The percentages’ sum can be higher than 100% since some articles addressed several domains

(27.7%) and the methodology description of implementation was described in 22 (26.5%), as identified in Table 4.

The most frequently identified critical factors for successful implementation were the clear workflows definition (n = 18; 78.3%) and staff involvement importance (n = 17; 73.9%), being the one with the lowest expression the institution approval (n = 11; 47.8%). On the other hand, implementation methodology was most often considered for clinical interventions (n = 20; 90.9%) and less considered for social purposes (n = 2; 9.1%). At last, routine clinical practice mostly described interventions for quality of care (n = 49; 79.0%) and clinical purposes (n = 46; 74.2%), while economical purposes (n = 8; 12.9%) was the least encountered. Table 5 reveals the amount (%) of articles found for each perspective considered in Tables 3 and 4.

To find out if the differences found in the sample were significant, a qui-square test for comparison of proportions was performed. It was possible to confirm that the differences observed in research articles regarding stepped care models, communication, caregiver support & unmet needs identification, and caregiver burden were significant, i.e., these articles were less related to cancer patients and their caregivers.

Regarding retrospective and prospective articles, the same test revealed that there was a lower incidence of this type of articles when considering institution approval, clear workflows, team continuous formation, data analysis, research intervention, clinical interventions, medical interventions, or physiological interventions and quality of care. Thus, articles that refer to oncology implementation, especially regarding “critical success factors” and

“implementation methodology”, appeared to a lesser extent in retrospective and prospective articles.

Moreover, manuscripts considered to have a higher level of interest revealed a higher proportion in articles related to cancer patients.

Discussion

PRO in oncology: changing perspectives

PROs may become a new center of influence in oncology, affecting both oncology quality of care and patient satisfaction. Their routine integration in oncology clinical practice and patients’ involvement in the disease course affected, in a decisive manner, the process of oncology care, understanding benefits and risks of a proposed treatment, and weighing the impact of a decision on symptoms, function, and life expectancy [31]. PROs collection and its incorporation in routine clinical practice must improve patient’s compliance, which can exceed 80% in daily routine care [31–35].

PROs: oncology patients

Five main advantages related with cancer patients are consistently and actually presented in literature regarding PRO incorporation in daily clinical practice. They are: (1) stepped care models design reflecting patient’s disease pathway [4, 5, 31, 32, 34, 36–57] (2) prognosis value [2–4, 22, 31, 34, 37–43, 47, 50, 53, 57–74] (3) communication improvements [4, 5, 10, 22, 31, 32, 34, 36, 38, 40–43, 46–50, 53, 55, 65–69, 71–82], (4) patient safety optimization [4, 5, 10, 30, 31, 34, 36, 39–43, 47, 48, 52, 53, 55, 56, 60–62, 64–66, 68, 70, 72–74, 77–87] and (5) healthcare risk identification, i.e., unmet problems identification, symptom detection and symptom control [2, 4, 5, 10, 12, 22,

Table 4 PROs implementation perspectives

	N (%)	Perspectives	N (%)
Critical success factors	23 (27.7%)	Staff involvement	17 (73.9%)
		Institution approval	11 (47.8%)
		Clear workflows	18 (78.3%)
		Team continuous formation	12 (52.2%)
		Data analysis	16 (69.6%)
Implementation methodology	22 (26.5%)	Research intervention	12 (54.5%)
		Clinical interventions	20 (90.9%)
		Medical interventions	13 (59.1%)
		Physiological interventions	8 (36.4%)
		Social interventions	2 (9.1%)
Routine clinical practice	62 (74.7%)	Use for clinical purposes	46 (74.2%)
		Use for research purposes	19 (30.6%)
		Use for economical purposes	8 (12.9%)
		Quality of care	49 (79.0%)

The percentages’ sum can be higher than 100% since some articles addressed several domains

Table 5 Proportion of articles found for each perspective considered and assigned interest (%)

	HRQoL		Systematic reviews		Research		Retrospective and protective		High interest		Moderate interest	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
<i>Oncology perspectives</i>												
Oncology patients												
Stepped care models	32.4	37.7	27.6	48.0	42.2	5.3	32.6	35.0	18.2	39.3	38.7	19.0
Prognosis value	26.5	51.0	41.4	40.0	45.3	26.3	34.9	47.5	27.3	49.5	45.5	28.6
Communication	44.1	44.9	46.6	40.0	51.6	21.1	34.9	55.0	22.7	52.5	51.6	28.8
Patient safety	52.9	44.9	53.4	36.0	51.6	36.8	39.5	57.5	27.3	55.7	54.8	28.6
Risk identification	50.0	67.3	63.8	52.0	65.6	42.1	51.2	70.0	50.0	63.9	62.9	52.4
Caregivers												
Communication improvements	8.8	8.2	10.3	4.0	6.3	15.8	7.0	10.0	9.1	8.2	8.1	9.5
Supportive care guidance	11.8	6.1	10.3	4.0	7.8	10.5	4.7	12.5	9.1	8.2	8.1	9.5
Caregiver support and unmet needs identification	17.6	16.3	24.1	0.0	7.8	47.7	16.3	17.5	27.3	13.1	14.5	23.8
Caregiver burden	17.6	20.4	24.1	8.0	14.1	36.8	18.6	20.0	27.3	16.4	16.1	28.6
Health systems												
Futures perspectives in oncology	50.0	46.9	51.7	40.0	43.8	63.2	46.5	50.0	27.3	55.7	56.5	23.8
Economical decisions, cost-effective measures	8.8	2.0	3.4	8.0	6.3	0.0	4.7	5.0	4.5	4.9	4.8	4.8
Drug approval	5.9	4.1	1.7	12.0	6.3	0.0	7.0	2.5	0.0	6.6	6.5	0.0
Patient centered care	64.7	59.2	63.8	56.0	65.6	47.4	51.2	72.5	50.0	65.6	64.5	52.4
<i>Implementation perspectives</i>												
Oncology patients												
Staff involvement	20.6	20.4	24.1	12.0	21.9	15.8	14.0	27.5	0.0	27.9	27.4	0.0
Institution approval	14.7	12.2	19.0	0.0	15.6	5.3	2.3	25.0	0.0	18.0	17.7	0.0
Clear workflows	20.6	22.4	31.0	0.0	23.4	15.8	9.3	35.0	0.0	29.5	29.0	0.0
Team continuous formation	14.7	14.3	20.7	0.0	15.6	10.5	4.7	25.0	0.0	19.7	19.4	0.0
Data analysis	17.6	20.4	25.9	4.0	21.9	10.5	7.0	32.5	0.0	26.2	25.8	0.0
Oncology patients												
Research intervention	8.8	18.4	20.7	0.0	15.6	10.5	4.7	25.0	0.0	19.7	19.4	0.0
Clinical interventions	29.4	20.4	29.3	12.0	26.6	16.8	14.0	35.0	9.1	29.5	29.0	9.5
Medical interventions	14.7	16.3	22.4	0.0	17.2	10.5	4.7	27.5	0.0	21.3	21.0	0.0
Physiological interventions	5.9	12.2	13.8	0.0	10.9	5.3	2.3	17.5	4.5	11.5	11.3	4.8
Social interventions	0.0	4.1	3.4	0.0	1.6	5.3	2.3	2.5	0.0	3.3	3.2	0.0
Oncology patients												
Use for clinical purposes	55.9	55.1	56.9	52.0	57.8	47.4	48.8	62.5	27.3	65.6	66.1	23.8
Use for research purposes	20.6	24.5	27.6	12.0	23.4	21.1	16.3	30.0	4.5	29.5	29.0	4.8
Use for economical purposes	8.8	10.2	6.9	16.0	10.9	5.3	11.6	7.5	0.0	13.1	12.9	0.0
Quality of care	58.8	57.1	70.7	28.0	54.7	68.4	41.9	75.0	59.1	57.4	58.1	57.1

31, 32, 34, 36, 37, 39–43, 45, 46, 49–51, 53, 55, 56, 58–62, 64–66, 68, 69, 71–82, 84, 88–90].

The present review identified parameters that appear to be most consistently associated with real changes in oncology. Risk identification (74.6%) and patient safety (59.7%) were the most evident topics, followed by communication improvements (55.2%) and prognosis value of PROs (50.7%) [32, 34]. Prior reviews highlighted that adverse events and medical errors are substantially related to communication breakdown and without

mentioning PROs, and that clinical manifestations are considerably underestimated, hampering high-risk patients' identification and patient safety [91]

Indeed, most studies reviewed the evidence that the communication processes in health systems are complex. PROs incorporation in oncology improves clinical practice [42, 47, 92], structures the communication, develops effective communication tools and communication skills training [93–95], and contributes to the delivery of effective oncology high-quality care [34, 39, 76], improved

patient-safety and patient satisfaction, and reduces patient anxiety [39, 42, 48, 49, 65–67, 77, 88].

The prognostic value of baseline and follow-up PROs, as independent predictor of the overall survival and likelihood of hospitalization, has been highlighted in randomized clinical trials and observational "real-world" cohort studies [37, 59, 61]. Mierzynska et al., in a systematic review updating a previous one, revealed that 93% of the trials consulted exposed at least one PRO domain as independently prognostic [59]. PROs have higher prognostic value than the one provided by clinical and sociodemographic variables. For cancer populations at various disease stages, PROs and traditional predictors increase the overall survival prediction ability by 6%, when compared to the traditional information used alone or together in multivariable analyses. A systematic review protocol published by Deliu et al. identified key areas of improvement and confirmed that well-conducted and reported prognostic model studies with a PRO predictor have great potential to improve healthcare delivery [38]. The physical functioning, global health and QoL domains were considered significant prognostic factors (prognosticators) and several domains have been evidenced [39, 40, 43] including patient-reported functional scores [37, 42, 60, 61, 63, 68], patient-reported symptom interference [38, 49, 59, 62, 65, 66], patient-reported depression [96], or patient-reported fatigue [67, 69].

Stepped care models design based on PROs data collection can reflect the patient's disease pathway, allowing the development of appropriate and sustainable long-term follow-up models for cancer survivors, foreseeing supported self-management and shared care (supportive care, epidemiological data, groups screening) [5, 32, 34, 36, 37, 40, 41, 43, 47, 49, 54, 56, 57, 65, 97]. Automated algorithms may support risk-stratified guideline-informed care [4, 31, 38, 42, 47, 50, 52, 53].

The present study reports that PROs can capture patient's essentials on disease pathway. They are crucial at baseline and follow-up stages and consistently consider them in research and clinical practice is a major concern for future in health systems [31–34, 37–42, 50, 51, 59–63, 65, 66, 69, 77, 88, 93, 94, 97–99].

PROs: oncology caregiver and families

A body of literature [70, 83, 84, 98, 100–107] consider four main topics about this subject: (1) communication improvements [16, 43, 89, 100, 108, 109], (2) supportive care guidance [16, 43, 84, 100, 102, 108], (3) caregivers support and families' unmet needs identification [12, 16, 17, 84, 89, 100, 102–106, 109], and (4) caregiver burden [12, 16, 17, 83, 85, 89, 98, 100, 102, 104, 107, 108]. The latter had the largest expression in our study (76.2%). This result is understandable if we admit that it actually

represents the convergence of the different identified contributions [36, 98, 103, 107, 110].

The roles and the responsibilities of informal caregivers (family members or friends), caring for dependent patients, are also a strong help and invaluable support to oncology patients. Caregivers are influencers of quality of cancer on multiple levels. The impact of this engagement on patients' lives and overall well-being needs to be measured, and literature reveals the need to develop instruments to better capture this issue. The authors also signalize that only few measures have been subject to psychometric evaluation in cancer caregivers. Shilling et al. in their systematic review identify instruments that measure the impact of caregiving and identify publications evaluating psychometric performance in the target population. They concluded that it was not possible to consider the performance of the measures across a group of studies as several domains were not well captured and measures needed to be adapted to current days because, some of them, have already 35 years [51, 98, 100].

Assuming that the experience of caring is multigenerational, literature revealed physical, psychosocial and emotional problems with multidimensional impacts on caregiver experience, and pointed out that some domains are poorly captured. These included changes on career aspiration and planning, paid employment and financial burden, sexual activity, as well as in roles and responsibilities, and family as a unit. Silveira et al. in 2018 concluded that being 18–30 or 46–60 years old, being a woman and having low education increase caregivers' risk factors to poor QoL related to care experience. All scores were worse in caregivers who cared for more than six hours a day [16].

The majority of all selected studies revealed that PROs assessment improves caregiver's comfort, support [16, 89] and global QoL (66.7%). Their perspectives and perceptions, systematically assessed and implemented at the earliest stages of the oncology process, allow to identify multidimensional problems about caregiver burden, reveal early caregiver unmet needs (60–70% of caregivers), and promote their QoL [43, 110]. This also may contribute to optimize strategies to monitor and implement caregivers' supportive care or to support interventions and health protection, including physical activity, nutritional intervention, behavioral and cognitive-behavioral therapy, psycho-education interventions, caregiver skill training, couples therapy, decision support, mindfulness-based stress reduction and goal management therapy [102, 103, 111].

On the other hand, communication constraints potentially exacerbate caregivers' distress, but communication in oncology context, remains a challenge. Effective communication for caregivers is essential to reduce caregiver

burden, promoting confidence and intimacy and improving caregiver and families' QoL [16, 98, 100, 102, 108].

Each caregiver develops his/her own type of conversation based on family patterns, self-efficacy, ethnic origin, duration of care and socio-demographic characteristics. Wittenberg et al. in 2017 presented four caregiver types based on patterns of family conversation, considering high/low levels of conformity and conversation: manager, provider of care, self and partner. They argue that PROs can provide detailed and personalized information about each type of caregiver communication, optimizing open and person-centered communication in oncology, content (illness, emotions, daily life, death, sexuality), style (language, atmosphere), timing and preferences [105].

Health systems, communities and society

Oncology care is a dynamic and multidimensional healthcare that evolves complex economical and clinical decision making and requires demanding care coordination [31, 47, 52, 85]. PRO may become a new center of influence in oncology for health systems, communities and society, supporting research directions and cancer comparative effectiveness research, political decisions, strategy and delivery of healthcare, funding and commissioning [31, 43, 52, 60, 65, 66, 112]. In fact, patient-centered care was the most reported domain in our study (81.0%), followed by futures perspectives in oncology (63.5%).

A significant financial burden for health care system is associated to cancer. Kerrigan et al. refer that 55% of the costs are comprised in patient hospitalization, increasing steeply in the last month before death. PROs incorporation in clinical practice has been shown to reduce healthcare costs, outpatient visits, hospital admissions and the number of emergency events [60].

PROs are now included by the US Food and Drug Administration (FDA) among the four types of clinical outcomes assessment measures that can be used to determine whether drugs provide a treatment benefit. HRQoL is included on the National Cancer Institute Common Terminology Criteria for Adverse Events scale to detect adverse events and define the doses. This reveals a growing interest and recognition by international health policy and regulatory authorities. PRO measures are relevant to acquirement, development and large-scale application of clinical outcome assessments in health care practice, regulatory and population or surveillance settings, program evaluations, case studies and economic analyses [38, 47, 86]. PROs incorporation in clinical practice are helping physicians in the decision-making process, allowing the assess to patient medication and guiding targeted cancer interventions both for patients and caregivers, reducing costs and increasing effectiveness, satisfaction

and outcomes [7, 32, 37, 43, 59, 60, 67, 113]. As MASCC advocates, supportive care makes excellent cancer care possible [28].

PROs in oncology: implementation

PROs reflect patients' perceptions, such as health status, symptoms, functioning, satisfaction, health behaviors, and QoL. They are multidimensional and subjective measures, standardized and objectively quantified. PROs are also complementary tools to "the black and white measures", usually tested and recorded by healthcare providers, such as survival, morbidity, recurrence rates, objective tumor response or disease remission [22, 114]. PROs were firstly addressed in retrospective studies but, for researchers and healthcare providers, the most important challenge was PROs incorporation in clinical practice, integrating the clinical protocols and using them on daily clinical decisions to personalize oncologic clinical care. Studies describe worldwide implementation experiences, carried out in the last 20 years. Linendoll et al.'s systematic review revealed in 2016 that half of the studies included where conducted after 2005, demonstrating a growing interest in oncology PROs [58]. Implementation use into routine clinical practice is feasible and practicable [22, 42, 43, 47, 49, 53, 58, 71, 78, 90, 115–118].

Critical success factors for implementation in routine clinical practice

Implementation strategies do impact implementation success. A number of critical success factors have been identified and should be considered when planning the strategy. Literature reflects that researchers, policymakers, healthcare professionals, patients and caregivers generally accept the dare of using PROs in real time, making available the big dream of including actual patients' perceptions on decision-making [22, 47, 48, 54, 71, 78, 90, 114–116]. The authors consider that it is essential to identify critical success factors for implementation in daily clinical practice and to deal with barriers. Ahmed et al. considered that PROs, as transformers of the health care system, to be more patient-centered, is still aspirational, revealing that future remains defiant [43].

A majority of all selected studies reveals that robust technology support incorporated across the patient care spectrum will be essential in the future to overcome serious technical and logistic problems, allowing the use of PROs scores on the shortest time, ideally just a few minutes after questionnaires completion [50, 55, 71–73, 78–82, 97, 108, 116]. Our results highlight that this is a real need in future perspectives, linking PRO and oncology.

A properly developed computer platform is imperative for questionnaires completion. It allows data collection by self-administration, database construction,

development of evidence-based algorithms, including computerized alerts for symptoms and reminders, providing also documentation templates and PROs graphic reports with reference information and clinical utility [9, 50, 97].

PROs depend on rigorous quality of the collection and management of patient-reported data. Appropriate questionnaires must be properly selected. However, some PROs result from adaptations and some categories do not reflect patients concerns, being required more patients' active involvement and engagement in PRO measures development. The choice of the most adequate measures for the population of interest provides a plan to minimize potential bias, improving sensitive analysis and clinical utility. The development of digital platforms, which are repositories of translated and validated general and specific instruments is essential for its excellent exposure and selection [22, 25, 26, 77, 119].

Stakeholder engagement and institutional support have also been proposed as decisive steps to accelerate PROs implementation, proactively determining PROs as a priority, including their use in daily clinical practice, scaling costs, facilitating logistics and analyzing cost–benefit especially related to quality assessment sustainability and practice transformation [10, 22, 56, 77, 87, 120]. Because healthcare professional's involvement is crucial, clinical workflows should be considered on PROs assessment implementation, a topic highlighted in our study.

Providers' concerns must be discussed as well. From the literature, among the major worries are time spending, measure harmonization, user-friendly data displays, PROs use in clinical practice, PROs trust and utility, redundant work, reduced face-to-face interaction, impact on patient-clinician relationships and confidentiality. When professionals are involved into interactive training courses to assess PROs concepts, informatic platforms functioning or results interpretation, they express highest agreement for their relevance in oncology clinical practice, its viability and its usefulness as a health education tool and, above all, as a promoter of patient-centered healthcare [77, 90, 121, 122].

The PROs implementation in oncology can be complex and challenging. Three phases need to be considered: pre-implementation, implementation, and post-implementation. The continuous monitoring of the process, after initial and successful implementation, is really needed. All barriers must be solidly and continually identified, quantified and discussed to be solved. Oncology patients must consider PROs collection as part of the clinical approach and be sure that someone will use these outcomes to design clinical and research approaches, to improve their health and to optimize their QoL. Patient's voice is crucial to oncology care delivery, especially when

low health literacy is considered. Only PROs systematic collection makes that voice audible and a decisive influence in health context [42, 43, 49, 53, 57, 74, 77, 90, 123, 124].

Limitations and future perspectives

There are some limitations to the presented study. First, the study presents advantages on using PROs in oncology clinical practice and implementation concerns separately, but frequently studies bring together these two aspects. Second, implementation experiences are world widely related to general chronic diseases, not only in oncology context. However, some differences may also appear, mainly related with cancer health providers and oncology clinical workflows. Third, we did not evaluate if studies used any implementation science theories [125]. At last, mathematical models and informatics concerns were moderately considered.

Future approaches should demystify concepts, strengthen multi-professional approaches from researchers, clinicians, informatics, and mathematicians, and build robust, reliable, and adequate measures. They should also include consultations with patients or members of the public, whose importance is highlighted in the literature [126]. On the other hand, implementations models should be more common in health organizations around the world and presented systematically to scientific community.

Conclusions

PROs are decisive for patients and caregivers support in oncology. Several items were improved, including caregiver-patient-physician communication, patient risk groups identification, unmet problems and needs detection, disease course and treatment tracking, prognostic markers, cost-effectiveness measurement, and comfort or support provision for both patients and caregivers.

Critical success factors were identified, being recognized that PROs assessment gathers multi-professional teams, biomedical and clinical expertise, patients, families and caregivers. On the other hand, institutional involvement, first line caregiver's adherence, team continuous formation encompassing training and support, design of clear workflows, continuous monitoring, and data analysis are crucial for daily practice assessment implementation.

In addition, stepped care models based on patients' stratification and perceptions are the keystone to better personalize medical services. Patient centered care doesn't exist without patients' perceptions and participation in clinical decisions. PROs measures are also decisive for predictive prognosis and effective economical decisions.

Routine assessment and implementation of PROs in oncology clinical practice are a major challenge and a paradigm transformation for future.

Abbreviations

EQ-5D-5L: Euroqol 5dimensions 5 levels; GlmQ: Headache Impact Questionnaire; HADS: Hospital Anxiety and Depression Scale; ICC: Intraclass correlation coefficient; KMO: Kaiser–Meyer–Olkin; MIDAS: Migraine Disability Assessment Scale; mMIDAS: Modified Migraine Disability Assessment Scale; mMIDAS-P: Portuguese mMIDAS; QoL: Quality of life; VAS: Visual Analogue Scale.

Supplementary Information

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Additional file 1. Summary of studies' characteristics.

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Availability of data and materials

The dataset used and/or analysed during the current study is available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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