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From patient voices to optimal PROMs: a mixed methods framework for cancer survivorship care

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Abstract

Purpose Selecting patient-reported outcome measures (PROMs) that accurately reflect the unmet needs of cancer survivors (CSs) remains a challenge in oncology, as current processes lack a structured methodology. This study aimed to develop and test the feasibility of a replicable, patient-centred framework for PROM selection, ensuring alignment between survivors' lived experiences and standardised outcome measures across diverse healthcare settings.

Methods Our methodology integrated qualitative and quantitative approaches, mapping patient-expressed unmet needs onto the International Classification of Functioning, Disability, and Health (ICF). The process involved three steps: (1) identifying survivors' needs through focus groups, interviews and questionnaires, (2) linking these needs to ICF categories using validated methodologies and (3) systematically evaluating existing PROMs based on their coverage of these categories.

Application and results To demonstrate feasibility, we conducted a feasibility study involving 35 CSs and seven caregivers within the Italian healthcare context. Among the 14 PROMs analysed, the Cancer Rehabilitation Evaluation System (CARES) covered 94.3% of ICF-linked needs, emerging as the most suitable option. The framework's adaptability allows clinicians and researchers to identify context-specific PROMs for diverse populations and healthcare systems.

Conclusions This study provides a robust, evidence-based methodology for optimising PROM selection, bridging the gap between patient narratives and standardised measurement. This feasibility study demonstrates the framework's practical applicability in clinical practice, with potential for broader implementation across diverse healthcare contexts. Its global applicability ensures that survivorship care remains patient-centred, data-driven and contextually relevant.

Implications for Cancer Survivors By facilitating the selection of tailored PROMs, this framework enhances patient-centred survivorship care, ensuring that outcome assessments remain relevant to survivors' experiences and improving care quality across different settings.

Trial registration ClinicalTrials.gov Identifier: NCT06236373.

Keywords Cancer survivors · Unmet needs · Patient-reported outcome measures · CARES · ICF

Introduction

An individual is defined as a 'cancer survivor' (CS) from the moment of initial diagnosis throughout their remaining lifespan [1]. This definition encompasses not only those in the post-treatment phase but also individuals undergoing active therapy, those in remission, those for whom the disease has assumed chronic characteristics and those who have recovered [2]. According to the Global Cancer Observatory, as of 2022, there are over 53 million people who are living with a cancer diagnosis received over five years ago, more than 20 million of whom are in Europe [3]. With projections indicating a continued rise in cancer survivorship over the next decade, driven by advances in screening, early detection, treatment and demographic changes such as population ageing, it is essential to consider the implications of these trends for survivorship. Cancer survivorship, defined by the National Cancer Institute as a multidimensional state encompassing the wide-ranging challenges faced by individuals and caregivers following a cancer diagnosis, now represents an increasingly diverse and expanding global population [4]. Delivering effective survivorship care requires understanding and addressing CSs' unmet needs, i.e. those needs perceived as insufficiently addressed to achieve optimal

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Extended author information available on the last page of the article well-being [5, 6]. Unmet needs span multiple domains–physical, psychosocial, spiritual, informational and practical–and have been consistently reported across studies [7–11]. Yet, despite growing awareness, many of these needs continue to be overlooked in clinical practice [12].

Patient-reported outcome measures (PROMs) are crucial tools for identifying unmet needs rapidly and reliably [13]. However, most PROMs were developed and validated within specific sociocultural and healthcare contexts, such as the United States, Australia, Canada, the United Kingdom and South Korea, all of which are high-income countries with distinctive health system structures and priorities [14, 15]. This raises concerns about their transferability to different settings, particularly those with divergent healthcare models, resource constraints, or sociocultural dynamics. Accordingly, the applicability of these tools remains uncertain in diverse or underserved populations, and context-sensitive approaches to assessing unmet needs are warranted. In a previous overview of reviews, we systematically identified and analysed the PROMs with formally documented psychometric properties, as reported in existing systematic reviews. Using the COSMIN guidelines, we evaluated the methodological quality (risk of bias), validity and reliability of their approaches, finding significant heterogeneity in measurement rigour and limited evidence of cross-cultural validation[14]. This work highlighted a critical gap: few psychometrically robust PROMs are tailored to diverse populations. Our subsequent International Classification of Functioning, Disability, and Health-based analysis of PROMs content revealed further inconsistencies in how unmet needs are represented, reinforcing concerns about their generalizability [16].

The recent literature on cancer survivorship has increasingly emphasised the need for more context-specific approaches, as unmet needs vary depending on individual and contextual factors such as age, cancer type, treatment history, stage of survivorship and/or socioeconomic status. Contextual factors and social determinants, including family support systems, cultural norms and access to healthcare, also influence unmet needs [17–19]. In response to this identified gap, a systematic, replicable methodology is proposed. This approach links patient-expressed unmet needs to existing PROMs through the International Classification of Functioning, Disability, and Health (ICF) categories and systematically evaluates existing PROMs against these mapped domains. The ICF, developed by the World Health Organisation, provides a universal and internationally recognised framework for describing health and health-related states [20, 21]. It comprises 1,424 categories across four domains: Body Functions, Body Structures, Activities and Participation, and Environmental Factors. These categories are organised in multiple hierarchical levels, from broader classifications (e.g. second level) to more specific subcategories (e.g. third or fourth level), enabling the fine-grained mapping of complex needs. The ICF has been successfully applied to standardise the description of functioning and needs across populations and settings, including rehabilitation and chronic disease management [22]. By offering a shared language, the ICF facilitates communication among stakeholders and enables comparison of the content areas covered by different PROMs aimed at capturing the unmet needs of CSs [22]. Its structured, hierarchical organisation supports the identification of overlaps and gaps across PROMs, allowing for a comprehensive analysis of the specific areas addressed and facilitating the selection of the most appropriate tool based on the outcome domains of interest [23]. For example, categories such as *b144 Memory functions* or *e580 Health services, systems, and policies* can be used to map specific unmet needs reported by CSs. By adopting the ICF as a reference model, we aimed to ensure that the PROMs selected through our framework would be firmly grounded in patient experience and also applicable and adaptable across different healthcare systems.

The survivorship experience is intrinsically relational, as cancer affects not only the individual patient but the entire family system [24]. Informal caregivers, most often family members, develop a close understanding of survivors' daily challenges through their supportive role and are themselves significantly impacted by the cancer experience, facing psychological distress, practical difficulties and changes in their own quality of life [25]. While they may also face their own psychological or practical difficulties, caregivers often identify and give voice to unmet needs that CSs themselves may underreport or normalise. Including caregiver perspectives on CSs' unmet needs thus offers an additional lens to exploring the complexity of survivorship and helps capture needs that may otherwise remain overlooked, acknowledging cancer as a condition that affects the broader family system rather than solely the individual patient [26].

We demonstrated the application of this methodology within an Italian cancer centre, identifying the PROMs most suited to that specific context. Nevertheless, the framework was developed for utilisation on a global scale, with the objective of facilitating personalised, evidence-based survivorship care worldwide. The objective of this study was to provide clinicians and researchers with a methodologically transparent and context-sensitive approach to PROM selection that truly reflects the perspectives of CSs and guides the integration of patient perspectives into care planning.

Methods

Study design and procedures

A convergent parallel mixed-methods design was employed whereby qualitative and quantitative data were collected concurrently and analysed independently before being integrated to provide a comprehensive understanding of CSs' unmet needs. We developed a three-step framework to guide the selection of context-specific PROMs for CSs. First, survivors' unmet needs were identified through a combination of qualitative and quantitative approaches, including focus group meetings, individual semi-structured interviews and preparatory questionnaires that explored survivorship-related challenges. Second, all expressed needs were systematically linked to the ICF categories using validated linking rules [20, 27–29]. Third, existing PROMs ($n = 14$, identified through a previously published overview of reviews) were evaluated based on their coverage of the identified ICF categories, considering also their psychometric properties [14].

To demonstrate the feasibility of this framework, we applied it in a cross-sectional study conducted at a comprehensive cancer centre located in a large urban area in northern Italy (Azienda USL-IRCCS of Reggio Emilia). This setting, serving approximately 9000 cancer patients annually, provided a cohort of 35 CSs and seven caregivers.

The study protocol was registered on ClinicalTrials.gov (ID NCT06236373).

Participant selection

Adult CSs undergoing follow-up care between April 2023 and January 2024 were recruited from the cancer centre.

Inclusion criteria focused on survivors of any cancer types with both an incidence of $\geq 5\%$ and a five-year survival rate of $\geq 65\%$ in Italy, according to national epidemiological data, who had completed active treatment [30]. Based on these thresholds, the included tumour types were breast, prostate, colorectal, thyroid cancers, myeloma and lymphoma. Caregivers of CSs were also invited to participate to capture relational and contextual factors influencing CSs' unmet needs and to explore the distinct challenges experienced by those providing informal support during the survivorship phase.

Participants were excluded if they had severe pre-existing cognitive impairments (e.g. dementia, severe intellectual disability, or other neurodegenerative conditions) that precluded providing informed consent or engaging meaningfully in study activities such as focus group meetings and interviews. These exclusions were distinct from cancer-related cognitive difficulties (such as chemotherapy-induced cognitive impairment or 'chemo brain'), which were not exclusion criteria given their relevance to the survivorship experience. Cases of severe pre-existing cognitive impairment were identified through clinical evaluation by healthcare staff, with support from medical records when needed. Furthermore, participants undergoing concurrent cancer treatments were also excluded. Maintenance therapies were not considered active treatment in this context, provided that participants had completed curative or intensive oncology protocols.

Preparatory questionnaire

Before the qualitative sessions, participants completed a structured questionnaire designed to stimulate reflection on unmet needs related to survivorship. The questionnaire, derived from existing PROMs [14], investigated the frequency and perceived importance of 25 key needs using Likert scales. Participants rated both how often each need was experienced and its impact on their daily life in the previous three and 12 months. The preparatory questionnaire methodology and psychometric evaluation of source PROMs have been previously published [14].

The preparatory questionnaire is attached as Appendix 1.

Focus groups and individual interviews

One week after completing the preparatory questionnaire, participants joined focus groups or individual interviews, depending on availability. Discussions reflected on questionnaire topics but also allowed the emergence of additional unmet needs. Focus groups were organised by cancer type to foster open dialogue among CSs, while caregiver discussions were held separately. The recruitment process was guided by the principle of data saturation, ceasing when no new significant theme or insight emerged from the discussions [31, 32]. The qualitative methodology and full thematic analysis are reported in a separate qualitative study currently under review [33].

Data analyses

Sociodemographic data (age, sex, living situation, education level and employment status) and disease-related factors (cancer type, time since end of treatment and use of maintenance therapy) were analysed using descriptive statistics by a multidisciplinary research team.

Qualitative and quantitative data were analysed independently before being integrated to provide a comprehensive understanding of CSs' unmet needs. Qualitative data from focus group meetings and interviews were analysed thematically to identify the breadth and depth of unmet needs experienced by participants. Quantitative data from the preparatory materials, where participants rated the frequency and perceived importance of listed unmet needs, were analysed descriptively.

Data integration and triangulation

Data triangulation occurred at the interpretation phase, where qualitative themes were compared with quantitative rankings to identify areas of convergence and divergence [34]. This integration allowed for the identification of unmet needs that were both highly impactful on participants' lives (as evidenced through rich qualitative narratives) and perceived as frequent and important (as demonstrated through quantitative ratings). The convergence of findings from both data sources strengthened the validity of the results and informed the subsequent ICF mapping process, ensuring that the framework captured the most salient and impactful unmet needs of the local CS population.

For each unmet need, a Relative Importance Index (RII) was calculated to integrate both frequency and perceived importance, according to the following formula [35]:

$$\mathrm{RII} = \frac{\sum w}{AN} = \frac{5n_5 + 4n_4 + 3n_3 + 2n_2 + 1n_1}{5N}$$

where w is the weighting assigned by each respondent (from 1 to 5), n is the number of respondents selecting each option, A is the highest weight (5 in this study) and N is the total number of respondents. Principal component analysis with optimal scaling (PRINQUAL procedure of the SAS/STAT module version 15.1, included in SAS System statistical analysis software version 9.4) [36, 37] was used to synthesise rankings based on RII scores for frequency and importance.

Linking process

The data for the analysis were derived from the unmet needs reported by CSs in our local setting. These were collected through their responses to the preparatory questionnaire and from the 'new' needs that emerged during the focus group meetings and individual interviews.

Regarding the data collected through the preparatory questionnaire, the unmet needs encompassed in its 25 items were linked to the ICF by our research group. The linking methodology and results are described in a recent publication [16].

The decision to adopt the ICF as a conceptual framework was based on its unique capacity to provide a comprehensive and standardised lens to understand the multidimensional nature of cancer survivors' unmet needs. Going beyond disease classification, the ICF includes physical, psychological, social, contextual and environmental components of health and functioning, aligning with the complex and often interrelated challenges faced by cancer survivors [38, 39]. This enables the systematic linking of patient-reported experiences with functioning domains, ensuring comparability, transparency and completeness in identifying and categorising unmet needs while facilitating interdisciplinary communication and supporting a biopsychosocial, person-centred approach with enhanced transferability across diverse clinical and cultural contexts [40].

Data collected through focus group meetings and interviews revealed new unmet needs, which yielded meaningful concepts. Two independent reviewers (AC and SC) extracted and linked these concepts to the ICF using the updated linking rules procedure by Cieza et al. [27–29]. Disagreements were resolved through discussion and consultation with a third reviewer (LG).

The new unmet needs were merged with those identified through the questionnaire analysis and linked to the most precise and appropriate ICF category (i.e. second or third level), which represented either body structures, body functions, activities, participation, or environmental factors.

Linking analysis and PROMs selection

Once the complete linkage between all the unmet needs identified by our participants and the ICF had been established, our objective was to determine the most comprehensive PROM(s) that covered the majority of these 'core' ICF categories, i.e. the ones best representing the most relevant unmet needs reported by the study participants. This was to determine whether one (or more) suitable PROM was readily available to capture the unmet needs of the local population appropriately. To achieve this objective, we constructed a two-way table comparing the 14 PROMs coverage of the 35 core ICF categories identified through our analysis. Coverage percentages were calculated, and tools were ranked to determine optimal alignment with CSs' unmet needs.

Application of the framework and results

To test the feasibility and applicability of the proposed framework, a structured methodology was applied to inform the selection of the PROM(s) that optimally align with the unmet needs of local CSs using a cohort of 35 CSs and seven caregivers at a comprehensive cancer centre in Italy. Participants' characteristics are reported in Table 1.

The process is summarised in Fig. 1, which illustrates the application of the three-step framework and its output in terms of mapped needs and PROM selection.

Preparatory questionnaire analysis

All participants who completed the preparatory questionnaire (100% retention) subsequently took part in focus group meetings or individual interviews, ensuring continuity in data collection.

Table 2 presents unmet needs ranked by perceived frequency over the preceding three months. The three most frequent unmet needs were managing sexual concerns,

Table 1 Participants' characteristics

Status	Type of cancer	*N*	Mean age (SD)	Sex	Living	Education level	Profession	Mean months elapsed since the end of treatment
Pt	Prostate	7	73.1 (±6.4)	M $n=7$	Alone $n=1$; with a partner $n=5$; with family $n=1$	Mandatory schooling $n=3$; high school diploma $n=1$; university degree $n=3$	Office worker $n=1$; retired $n=6$	16.0 (±7.8)
Pt	Breast	9	59.6 (±4.1)	F $n=9$	With child/children $n=2$; with family $n=4$; with a partner $n=3$	High school diploma $n=4$; university degree $n=5$	Teacher $n=2$; physiotherapist $n=1$; office worker $n=2$; nurse $n=1$; retired $n=2$; self-employed $n=1$	13.8 (±13.0)
Pt	Lymphoma	4	59.0 (±4.7)	M $n=1$; F $n=3$	With family $n=2$; with a partner $n=2$	Mandatory schooling $n=3$; high school diploma $n=1$	Bricklayer $n=1$; metalworker $n=1$; unemployed $n=1$; nurse $n=1$	12.3 (±10.9)
Pt	Myeloma	5	61.8 (±6.8)	M $n=2$; F $n=3$	With a partner $n=4$; with family $n=1$	Mandatory schooling $n=3$; high school diploma $n=2$	Supermarket cashier $n=1$; butcher $n=1$; housewife $n=1$; retired $n=2$	Maintenance therapies ongoing
Pt	Colorectal	5	59.4 (±7.7)	M $n=3$; F $n=2$	With a partner $n=4$; with child/children $n=1$	Mandatory schooling $n=1$; high school diploma $n=2$; university degree $n=2$	Baker $n=1$; teacher $n=1$; retired $n=1$; surveyor $n=1$; artisan $n=1$	44.6 (±14.1)
Pt	Thyroid	5	40.8 (±9.2)	M $n=1$; F $n=4$	Alone $n=2$; with family $n=2$; with a partner $n=1$	High school diploma $n=2$; university degree $n=3$	Chemist $n=1$; teacher $n=1$; student $n=1$; office worker $n=1$; metalworker $n=1$	42.6 (±48.6)
Status	**Type of cancer**	***N***	**Mean age (SD)**	**Sex**	**Relationship with CS**			
Cg	Prostate	2	61.5 (±3.5)	F $n=2$	Wife $n=2$			
Cg	Thyroid	2	66.5 (±5.5)	F $n=2$	Mother $n=2$			
Cg	Breast	1	73	M $n=1$	Husband $n=1$			
Cg	Colorectal	2	68.5 (±3.5)	F $n=2$	Wife $n=2$			

Pt patient, *Cg* caregiver, *M* male, *F* female, *SD* standard deviation, *n* number

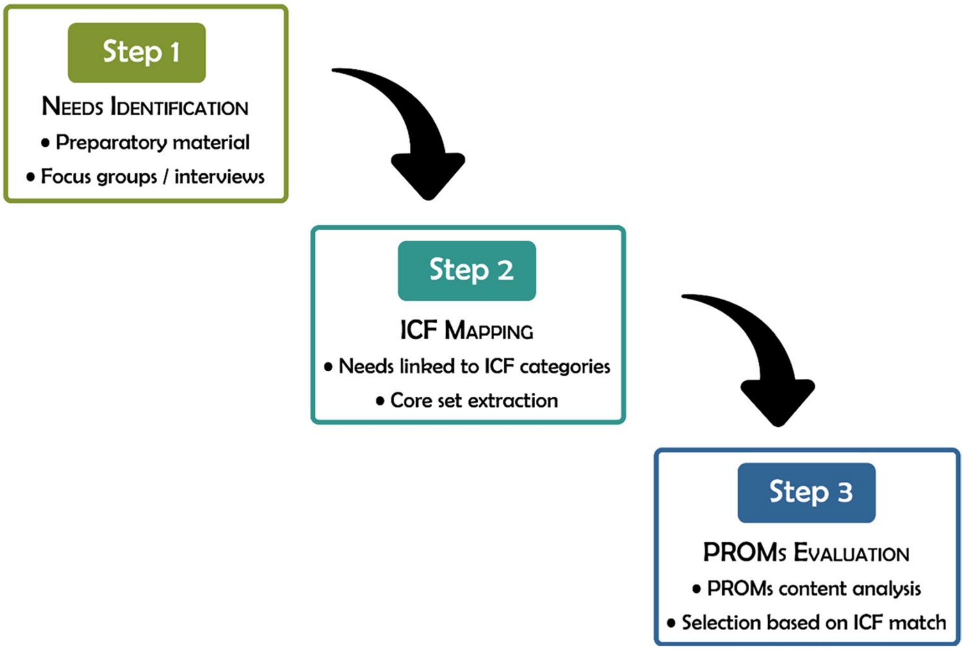

Fig. 1 Three-step framework for PROM selection based on unmet needs in cancer survivors

Table 2 Unmet needs in order of perceived frequency

Unmet needs in order of perceived frequency[1]	12–3 months trend
Need to manage sexuality	↔
Need to manage drug and treatment side effects	↓
Need to realise one's spiritual needs	↔
Need to manage aspects of movement and exercise	↔
Need to manage lack of energy, strength or desire to do things	↑
Need to manage lack of memory and/or concentration	↓
Need to manage pain	↑
Need to manage diet and nutrition	↑
Need for emotional support	↓
Need for more comprehensible information	↔
Need to have health services available when needed	↑
Need to manage feelings of loneliness	↔
Need not to feel restricted in one's routine for fear of experiencing pain	↑
Need to manage one's finances	↓
Need not to feel like a burden on others	↓
Need to manage bladder	↔
Need to feel that complaints are taken into account by health professionals	↑
Need for independence in the use of transport	↓
Need to manage bowel	↓
Need to feel support from others	↔
Need to easily obtain drugs, aids, therapies	↔
Need to support and manage relationships with partners and family	↓
Need to manage the work/school environment	↓
Need to have clear information about required time off from work	↓
Need to manage substance abuse	↔

[1] From the most pressing to the least pressing; ↑ increasing trend; ↓ downward trend; ↔ stable trend

Table 3 Unmet needs in order of perceived importance

Importance[#]	Unmet needs in order of perceived importance[1]	Frequency[#]
1	Need to manage lack of memory and/or concentration	6
2	Need to manage aspects of movement and exercise	4
3	Need to manage drug and treatment side effects	2
4	Need to manage pain	7
5	Need to have health services available when needed	11
6	Need for emotional support	9
7	Need to manage lack of energy, strength or desire to do things	5
8	Need to manage feelings of loneliness	12
9	Need for more comprehensible information	10
10	Need to manage one's finances	14
11	Need for independence in the use of transport	18
12	Need to feel that complaints are taken into account by health professionals	17
13	Need not to feel like a burden on others	15
14	Need to manage sexuality	1
15	Need to realise one's spiritual needs	3
16	Need to manage bowel	19
17	Need to easily obtain drugs, aids, therapies	21
18	Need to manage diet and nutrition	8
19	Need to manage bladder	16
20	Need to manage the work/school environment	23
21	Need not to feel restricted in one's routine for fear of experiencing pain	13
22	Need to support and manage relationships with partners and family	22
23	Need to feel support from others	20
24	Need to have clear information about required time off from work	24
25	Need to manage substance abuse	25

[1] From the most important to the least important; [#] Ranking; Lower than in the frequency-based ranking in red; Higher than in the frequency-based ranking in blue; Same ranking in black

treatment side effects and spiritual well-being. Over the preceding year, 40% of needs had decreased in frequency, 36% remained stable and 24% showed an increasing trend.

When assessed by perceived importance, the ranking changed: managing memory and concentration difficulties, exercise-related issues and treatment side effects emerged as top concerns (Table 3). Needs related to sexuality and spirituality, initially highly ranked by frequency, dropped significantly in importance. Table 4 shows the unified ranking obtained by combining frequency and importance assessments through principal component analysis with optimal scaling [36, 37].

A full description of the preparatory questionnaire analysis is provided in Appendix 2.

Qualitative data analysis

Thematic analysis of focus groups and interviews identified 44 individual codes, grouped into 16 topic areas and four primary themes: dignity and respect, desire for normality, control over one's life and existential frailty.

Eight additional unmet needs not captured by the questionnaire were identified:

- Needs related to physical exercise
- Need to manage sleep problems
- Need to rationalise the fear of recurrence
- Need for support from and relationships with healthcare professionals
- Need to feel 'normal'
- Need for healthcare professionals who communicate more effectively with each other.
- Need for services that include the entire family
- Need for inpatient and outpatient services that support one's overall well-being.

A detailed analysis is reported elsewhere [33].

ICF linking

The complete set of unmet needs was systematically linked to existing ICF categories, identifying 35 core

Table 4 Unmet needs in order of relevance

Importance	Frequency	Unmet need	New order
3	2	Need to manage drug and treatment side effects	1
2	4	Need to manage aspects of movement and exercise	2
1	6	Need to manage lack of memory and/or concentration	3
4	7	Need to manage pain	4
7	5	Need to manage lack of energy, strength or desire to do things	5
6	9	Need for emotional support	6
14	1	Need to manage sexuality	7
5	11	Need to have health services available when needed	8
15	3	Need to realise one's spiritual needs	9
9	10	Need for more comprehensible information	10
8	12	Need to manage feelings of loneliness	11
10	14	Need to manage one's finances	12
18	8	Need to manage diet and nutrition	13
13	15	Need not to feel like a burden on others	14
12	17	Need to feel that complaints are taken into account by health professionals	15
11	18	Need for independence in the use of transport	16
21	13	Need not to feel restricted in one's routine for fear of experiencing pain	17
16	19	Need to manage bowel	18
19	16	Need to manage bladder	19
17	21	Need to easily obtain drugs, aids, therapies	20
20	23	Need to manage the work/school environment	21
23	20	Need to feel support from others	22
22	22	Need to support and manage relationships with partners and family	23
24	24	Need to have clear information about required time off from work	24
25	25	Need to manage substance abuse	25

Table 5 Results of the ICF linking

Unmet need	Linked categories	Meaningful concept
Need to manage drug and treatment side effects	d5702 Maintaining one's health	Manage
	e1101 Drugs	Drugs/therapies
	Body Functions	Side effects
Need to manage aspects of movement and exercise	d5702 Maintaining one's health	Manage
	b789 Movement functions, other specified and unspecified	Movement
	b455 Exercise tolerance functions	Exercise
Need to manage lack of memory and/or concentration	d5702 Maintaining one's health	Manage
	b144 Memory functions	Memory
	b140 Attention functions	Concentration
Need to manage pain	d5702 Maintaining one's health	Manage
	b280 Sensation of pain	Pain
Need to manage lack of energy, strength or willingness to do anything	d5702 Maintaining one's health	Manage
	b130 Energy and drive functions	Energy/willingness to do
Need for emotional support	b152 Emotional functions	Emotional
	e575 General social support services, systems and policies	Support
Need to manage sexuality	d5702 Maintaining one's health	Manage
	d7702 Sexual relationships	Sexuality
Need to have health services available when needed	e580 Health services, systems and policies	Health services
Need to realise one's spiritual needs	d930 Religion and spirituality	Spiritual needs
Need for more comprehensible information	d138 Acquiring information	Information
	d310 Communicating with—receiving—spoken messages	Comprehensible
Need to manage feelings of loneliness	d5702 Maintaining one's health	Manage
	b160 Thought functions	Loneliness
Need to manage one's finances	d5702 Maintaining one's health	Manage
	d870 Economic self-sufficiency	Finances
Need to manage diet and nutrition	d5702 Maintaining one's health	Manage
	d5701 Managing diet and fitness	Diet/nutrition
Need not to feel like a burden on others	b152 Emotional functions	Feel like a burden
Need to feel that complaints are taken into account by health professionals	e5801 Health systems	Complaint taken into account
	e355 Health professionals	Health professionals
Need for independence in the use of transport	d230 Carrying out daily routine	Independence
	d470 Using transportation	Transport
Need not to feel restricted in one's routine for fear of experiencing pain	b152 Emotional functions	Feel restricted
	d230 Carrying out daily routine	Daily routine
	b152 Emotional functions	Fear
	b280 Sensation of pain	Pain
Need to manage bowel	d5702 Maintaining one's health	Manage
	b5150 Transport of food through stomach and intestines	Bowel
Need to manage bladder	d5702 Maintaining one's health	Manage
	b6202 Urinary continence	Bladder
Need to easily obtain drugs, aids, therapies	d5702 Maintaining one's health	Obtain drugs
	e1101 Drugs	Drugs/therapies
Need to manage the work/school environment	d5702 Maintaining one's health	Manage
	d845 Acquiring, keeping and terminating a job	Work
	d838 Education, other specified	School

Table 5 (continued)

Unmet need	Linked categories		Meaningful concept
Need to feel support from others	e399	Support and relationships, unspecified	Support
	d729	General interpersonal interactions, other specified and unspecified	Others
Need to support and manage relationships with partners and family	e399	Support and relationships, unspecified	Support/relationship
	e310	Immediate family	Partner/family
Need to have clear information about required time off from work	d138	Acquiring information	Information
	d845	Acquiring, keeping and terminating a job	Work
Need to manage substance abuse	d5702	Maintaining one's health	Manage
	e1101	Drugs	Substance
Need to manage sleep problems	d5702	Maintaining one's health	Manage
	b134	Sleep functions	Sleep
Need to rationalise the fear of recurrence	b117	Intellectual functions	Rationalise
	b152	Emotional functions	Fear
Need for support from and relationships with healthcare professionals	e399	Support and relationships, unspecified	Support/relationship
	e355	Health professionals	Healthcare professionals
Need to feel "normal"	b152	Emotional functions	Feel
	b160	Thought functions	Normal
Need for healthcare professionals who communicate more with each other	e355	Health professionals	Healthcare professionals
	d349	Communication—producing, other specified and unspecified	Communicate with each other
Need for services that include the entire family	e599	Services, systems and policies, unspecified	Services
	e310	Immediate family	Family
Need for inpatient and outpatient services that support one's overall well-being	e570	Social security services, systems and policies	Services
	d570	Looking after one's health	Well-being

ICF domains representing priority areas for survivorship assessment (Table 5).

PROM selection

Fourteen PROMs were evaluated against the 35 identified ICF categories (Table 6). The Cancer Rehabilitation Evaluation System (CARES) [41, 42] demonstrated the highest coverage (94.3%), followed by the Comprehensive Needs Assessment Tool (CNAT) (77.1%) [43, 44].

This application demonstrates that our framework can effectively align survivors' reported needs with existing measurement tools, ensuring context-specific, evidence-based PROM selection.

Discussion

Understanding and systematically measuring CSs' unmet needs is fundamental to advancing personalised survivorship care. Identifying and addressing these needs not only enhances well-being and satisfaction but may also improve adherence to follow-up instructions and reduce healthcare utilisation [17–19]. PROMs are essential tools in this context [45, 46], yet their selection remains challenging. Most available PROMs were designed within high-income sociocultural and healthcare contexts, often reflecting the structures and values of countries like the US, the UK, or Australia [14]. This limits their generalisability to systems such as Italy's publicly funded universal healthcare model or to populations with different cultural expectations and health beliefs.

Each healthcare context is characterised by specific contextual (e.g. healthcare system structure, availability of community services, family and social support) and personal (e.g. age, sex, cancer history, socioeconomic background) factors that shape how individuals interact with their surroundings and interpret their experiences, including illness. These contextual factors influence not only the manifestation of unmet needs but also their prioritisation and subjective importance. Although international studies have consistently highlighted the importance of psychological support, communication and information needs as well as comprehensive follow-up as key areas of concern for CSs [47, 48], direct comparisons of unmet needs across countries reveal both similarities and meaningful differences. For instance, a recent systematic review among Australian CSs identified psychosocial issues

Table 6 ICF-based cross-analysis of local survivors' needs and 14 PROMs coverage

Meaningful concept(s)	Linked categories		PROMS													
			CaSUN	SUNS-SF	CARES-SF	CaNDI	SCNS-LF59	SCNS-SF34	SCNS-ST9	CARES	CNQ-SF	SUNS	CNAT	eHNA	NEQ	PNI
Manage	d5702	Maintaining one's health	X	X		X	X	X	X	X		X	X			
Drugs/therapies	e1101	Drugs			X	X				X			X			
Side effects		Body functions	X		X	X	X	X		X	X		X			
Movement	b789	Movement functions, other specified and unspecified								X	X	X				
Exercise	b455	Exercise tolerance functions				X				X		X	X	X		
Memory	b144	Memory functions		X		X				X		X	X	X		
Concentration	b140	Attention functions		X	X	X				X		X	X	X		
Pain	b280	Sensation of pain			X	X	X	X		X	X		X	X	X	
Energy/willingness to do	b130	Energy and drive functions		X	X		X	X	X	X	X	X	X	X		X
Emotional	b152	Emotional functions	X	X	X	X	X	X	X	X	X	X	X	X		X
Support	e575	General social support services, systems and policies	X	X	X	X	X	X		X	X	X	X	X	X	X
Sexuality	d7702	Sexual relationships			X		X	X	X	X			X	X		X
Health services	e580	Health services, systems and policies	X	X	X	X	X	X	X	X	X	X	X		X	X
Spiritual needs	d930	Religion and spirituality	X			X							X	X	X	X
Information	d138	Acquiring information	X	X	X	X	X	X	X	X	X	X	X		X	X
Comprehensible	d310	Communicating with—receiving—spoken messages			X		X	X	X	X		X				

Table 6 (continued)

Meaningful concept(s)	Linked categories		PROMS													
			CaSUN	SUNS-SF	CARES-SF	CaNDI	SCNS-LF59	SCNS-SF34	SCNS-ST9	CARES	CNQ-SF	SUNS	CNAT	eHNA	NEQ	PNI
Loneliness	b160	Thought functions		X		X	X	X		X	X	X	X	X	X	X
Finances	d870	Economic self-sufficiency	X	X	X		X			X		X		X		X
Diet/nutrition	d5701	Managing diet and fitness			X	X				X			X	X		X
Complaint taken into account	e5801	Health systems	X							X			X			
Health professionals	e355	Health professionals	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Transport	d470	Using transportation			X	X				X			X	X		X
Daily routine	d230	Carrying out daily routine			X	X	X	X	X	X	X	X	X			X
Bowel	b252	Defecation functions				X				X			X	X		
Bladder	b6202	Urinary continence			X					X						
Work	d845	Acquiring, keeping and terminating a job	X	X	X	X				X		X	X			
School	d838	Education, other specified				X										
Support	e399	Support and relationships, unspecified	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Others	d729	General interpersonal interactions, other specified and unspecified	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Partner/family	e310	Immediate family	X							X		X	X		X	X
Sleep	b134	Sleep functions			X	X	X			X	X		X	X	X	
Rationalise	b117	Intellectual functions	X	X	X	X				X		X				

Table 6 (continued)

Meaningful concept(s)	Linked categories		PROMS													
			CaSUN	SUNS-SF	CARES-SF	CaNDI	SCNS-LF59	SCNS-SF34	SCNS-ST9	CARES	CNQ-SF	SUNS	CNAT	eHNA	NEQ	PNI
Communicate with each other	d349	Communication—producing, other specified and unspecified			X					X				X		
Services	e570	Social security services, systems and policies	X	X	X					X		X			X	
Well-being	d570	Looking after one's health	X	X		X	X	X	X	X		X	X			X
	Coverage %		**48,6**	**48,6**	**68,6**	**71,4**	**51,4**	**45,7**	**34,3**	**94,3**	**40,0**	**62,9**	**77,1**	**54,3**	**34,3**	**48,6**

CaNDI Cancer Needs Distress Inventory, *CARES* Cancer Rehabilitation Evaluation System, *CARES-SF* CAncer Rehabilitation Evaluation System-Short Form, *CaSUN* Cancer Survivors' Unmet Needs measure, *CNAT* Comprehensive Needs Assessment Tool in cancer, *CNQ-SF* Cancer Needs Questionnaire-Short Form, *eHNA* electronic Health Needs Assessment, *NEQ* Needs Evaluation Questionnaire, *PNI* Psychosocial Needs Inventory, *SCNS-LN59* Supportive Care Needs Survey-Long Form 59 items, *SCNS-SF34* Supportive Care Needs Survey-Short Form 34 items, *SCNS-ST9* Supportive Care Needs Survey-Screening Tool-9 items, *SUNS* Survivors unmet needs survey, *SUNS-SF* Survivors unmet needs survey-short form

such as fear of recurrence, uncertainty about the future and stress as the most frequently reported unmet needs, followed by physical concerns like fatigue and difficulty performing daily activities [49]. In the UK, CSs most commonly reported unmet needs regarding the management of cancer recurrence-related anxiety [50]. Among female breast CSs in the Gaza Strip, psychological needs emerged as the predominant area, followed by health-system-related and physical needs [51]. Similarly, a mixed method systematic review among Japanese CSs confirmed psychological issues as dominant, followed by information and physical needs [52]. Conversely, a survey among Chinese women found that unmet needs related to symptom burden were most relevant [53]. Despite these commonalities, our application of the framework revealed context-specific nuances that may otherwise remain overlooked. In particular, aspects related to movement and exercise emerged as highly relevant in our cohort, an area less frequently reported among the most critical unmet needs internationally. This finding suggests a potential underrepresentation of movement and exercise-related domains in current survivorship assessments, warranting further investigation across different populations.

The limited number of PROMs capable of adequately covering the breadth of unmet needs, as represented by the 35 ICF core categories identified in our study, carries significant implications for clinical practice. In particular, the finding that only one PROM, the CARES, achieved over 90% coverage, while the second-best option covered only 77.1%, highlights a substantial gap in the availability of tools that are both comprehensive and suitable for routine use in diverse healthcare settings. This lack of high-coverage PROMs may lead to a fragmented understanding of patients' experiences, where relevant needs go undetected or underappreciated, ultimately compromising the quality and person-centredness of survivorship care. Clinicians relying on incomplete instruments risk overlooking domains critical to patients' well-being, such as spiritual concerns or environmental barriers. Furthermore, the lack of adequate tools impedes the systematic integration of patient voices in care planning and service evaluation. This underscores the urgent need for either adapting existing PROMs to reflect better the ICF framework or developing new instruments grounded in robust biopsychosocial models which can comprehensively account for the multifaceted experiences of cancer survivors in specific contexts.

Additionally, as machine learning and AI approaches gain traction in PROM development, our ICF-based framework could be adapted to guide the creation of adaptive instruments that dynamically adjust item selection based on patient responses while maintaining comprehensive coverage of the identified core categories. The framework proposed in this mixed methods study addresses these challenges by offering a structured, evidence-based approach to PROM selection. By linking CSs' expressed needs to the ICF categories and systematically evaluating PROMs based on their coverage, the methodology ensures that selected instruments genuinely reflect the lived experiences of specific populations. Applying this framework in an Italian cancer centre demonstrated its feasibility and clinical relevance. The Cancer Rehabilitation Evaluation System emerged as the PROM covering the highest proportion of relevant ICF categories (94.3%), with only minor gaps identified in spirituality and education domains. While the application focused on a specific healthcare setting, the framework's strength lies in its adaptability: it can be replicated across diverse systems and cultural contexts to ensure context-specific, patient-centred assessment. By systematically mapping survivors' narratives onto structured outcome measures, the proposed framework bridges the gap between patient experience and clinical evaluation. It provides healthcare providers with a practical, scalable tool to optimise aftercare services, inform the design of survivorship programmes and foster a more responsive, patient-centred approach to oncology care.

Future research should validate this methodology in larger and more diverse survivor populations as well as across various healthcare settings. Additionally, integrating the dynamic nature of survivors' needs over time and examining the clinical impact of tailored PROMs use could further enhance the robustness and applicability of this approach in routine practice.

Emerging technologies, including machine learning and natural language processing, are increasingly being explored to develop adaptive or AI-assisted PROMs. While these tools may enhance sensitivity to patient-specific concerns, their dynamic and data-driven nature may pose challenges for standardisation. In this context, the ICF can serve as a conceptual anchor, ensuring that AI-generated instruments remain comprehensive and comparable across systems. Future iterations of our framework could integrate such PROMs by mapping their content dynamically onto ICF categories as part of iterative validation processes.

Strengths and limitations

This study has several limitations. First, the sample size was relatively small; however, recruitment ceased once data saturation was achieved, consistent with qualitative research principles [54]. Second, our focus on prevalent cancers with high 5-year survival rates may limit the transferability of our findings to CSs of rarer cancers (e.g. sarcomas, pancreatic cancer) and/or cancers with significantly lower survival rates (e.g. lung cancer, glioblastoma). These populations often experience distinct challenges related to symptom Burden, treatment intensity, prognosis uncertainty and the availability of specialised supportive care, which our current sample may not fully capture. Future research should extend this methodology to a broader range of cancer types and survivorship experiences. Additionally, while 25 unmet needs identified through the preparatory questionnaire were prioritised using a structured approach, eight new needs emerging solely from qualitative data were not formally ranked. This decision was methodologically driven, as the in-depth, exploratory nature of qualitative data collection aims to uncover nuanced insights and new concepts rather than quantify their prevalence or rank order, which would be inappropriate for this type of data [55, 56]. Therefore, further studies should investigate the frequency and perceived importance of these additional needs using appropriate quantitative methodologies (e.g. large-scale surveys).

Nevertheless, this study has important strengths. To our knowledge, this is the first study to systematically link CSs with unmet needs as expressed through PROMs using the ICF classification system, thereby providing a robust and replicable method for PROM selection in clinical practice. Moreover, the PROMs evaluated in this study were selected based on their psychometric properties, assessed according to the COSMIN standards [14], ensuring the validity and reliability of the tools considered. The methodology proposed can be readily adopted by other researchers and clinicians seeking to align PROM selection with the unique needs of their patient populations.

Conclusion

Healthcare systems must foster a culture of continuous improvement to ensure that survivorship services evolve in tandem with patients' needs. Periodic evaluation of services, guided by patient-reported experiences, is critical to aligning aftercare with survivors' expectations and challenges.

This study introduces a structured, replicable methodology for selecting context-specific PROMs, grounded in CSs' lived experiences and linked systematically to ICF categories. The application of this framework in an Italian cancer centre confirmed its feasibility and highlighted its broader potential to enable healthcare providers worldwide to implement personalised, evidence-based survivorship assessments. The framework could also be integrated into survivorship care guidelines or embedded within electronic health records, supporting routine and structured assessment of unmet needs. By thoroughly understanding and addressing survivors' unmet needs, healthcare systems can improve the quality of aftercare, ensure it is comprehensive and tailored to individual needs and enhance patient satisfaction, ultimately promoting long-term well-being.

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Declarations

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