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Patient-Reported Outcomes

Core Domains for a Person-Focused Outcome Measurement System in Cancer (PROMS-Cancer Core) for Routine Care: A Scoping Review and Canadian Delphi Consensus

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ABSTRACT

Objectives: The objectives of this scoping review study were 1) to identify core domains and dimensions for inclusion in a person-focused and self-reported outcome measurement system for cancer and 2) to reach consensus among key stakeholders including cancer survivors on the relevance, acceptability, and feasibility of a core outcome set for collection in routine clinical care. **Methods:** Following a scoping review of the literature, a Rand Delphi consensus method was used to engage key interdisciplinary decision makers, clinicians, and cancer survivors in reaching consensus on a core patient-reported outcome domain taxonomy and outcome measures. **Results:** Of the 21,900 citations identified in the scoping review, 1,503 citations were included in the full article review (380 conceptual articles, 461 psychometric evaluation articles, and 662 intervention studies) and subjected to data abstraction and mapping. Final consensus was reached on 20 domains, related subdimensions, and 45 self-report measures considered relevant and feasible for routine collection in cancer by the Delphi panel (PROMS-Cancer Core). **Conclusions:** Standardization of patient-reported outcome data collection is key to assessing the impact of cancer and treatment on the person for population comparison and monitoring the quality of clinical care. The PROMS-Cancer Core taxonomy of domains and outcome measures can be used to guide the development of a patient-reported outcome information system for cancer.

Keywords: cancer, consensus, health, patient-reported outcomes, scoping review.

Introduction

The cancer problem continues to grow in Canada, with more than 186,400 new cases of cancer and 75,700 deaths for 2012 [1]. In spite of significant progress in survival rates for many cancers, the diagnosis and treatment of cancer continues to exert a multidimensional impact on the quality of a person's life and that of the significant others [2]. Throughout the cancer journey and often extending beyond treatment, cancer patients experience significant physical, emotional, and social health consequences [3–8]. Underrecognition and undertreatment of these consequences is a costly burden for patients, their families, and the health system [9–13] and leads to significant physical and psychological morbidity [14,15]. The literature indicates that cancer patients report low satisfaction with emotional support, physical comfort, and continuity of care and that they do not receive enough information about the effects of treatment, specifically about posttreatment problems of fatigue, nutrition, and work-related matters [16,17].

Routine collection of patient-reported outcomes (PROs) data can improve the quality of clinical care through early identification of clinical problems and evaluation of the impact of cancer on the person. PRO data can also contribute to decision making at multiple levels, including the macro level (i.e., population surveillance and monitoring burden of cancer), the meso level (i.e., descriptive and analytic studies, patterns of service, effects of interventions on outcomes), and the micro level (i.e., facilitate patient and provider decision making) [18]. Consequently, defining a core set of PRO measures to monitor and improve the quality of cancer care was identified as a policy imperative in Canada [19] and the United States [20]. PROs are defined as those outcomes that matter to patients (person-focused) and are distinct but complementary to disease-focused outcomes such as survival and mortality [21]. PROs are defined as "any report coming directly from the patient about a health condition and its treatment" [22]. PRO data may focus on specific aspects of disease or treatment such as symptom experience, physical or psychosocial-sexual functioning, or more

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complex multidimensional health-related quality-of-life (HRQOL) outcomes [23].

The selection of PROMs for cancer is complex because there is a need to capture not only the multidimensional consequences of cancer and treatment across populations as a metric for quality performance but also disease- and phase-specific outcomes (i.e., posttreatment survivorship, i.e, fear of recurrence or lifestyle behaviors) that may be more meaningful for use in clinical practice. Agreement among clinicians, policy leaders, and administrative decision makers regarding the most important PROs for routine collection in cancer is lacking, and their use may be based more on clinician preferences rather than on specific criteria [24]. There is an urgent need for a guiding taxonomy of core PRO domains and dimensions in cancer that could be applied for population comparison with the addition of disease-specific and phase-specific PROs in subsequent phases of development and application.

Recently, a number of groups have focused their attention on reaching agreement on PROs for adoption in clinical practice, but national consensus in health systems using participatory and consensus methods to engage administrators, clinicians, policy decision makers, and survivors is still needed. This is required for early endorsement as a first step toward the adoption of selected PROs for use in clinical practice and for health policy change. Our work built on earlier studies, but unlike earlier reviews we used formal methods to gain consensus on core PRO domains and related subdimensions to develop a pan-Canadian core PRO measurement framework endorsed by a wide range of stakeholders including survivors for the Canadian cancer system. Patients should be engaged to express their views in the decision-making process of selecting PROs to ensure their relevance for capturing the impact of cancer from the perspective of the person [25].

This article presents the results of a scoping literature review and Delphi consensus study that used an integrated knowledge translation approach to engage a diverse group of stakeholders in the selection of PROs for the Canadian cancer system. The specific study objectives were to 1) identify a core taxonomy of person-focused PRO domains and subdimensions for routine collection in cancer; 2) identify a hierarchy of conceptually and psychometrically sound outcome measures to capture these core PRO domains; and 3) reach consensus among key stakeholders (administrators, clinicians, policy leaders, cancer survivors) regarding the most meaningful, valid, actionable, and feasible PRO domains and outcome measures for use in the development of a person-focused core measurement set for the Canadian cancer system.

Methods

The study design was composed of two phases and methods: 1) phase 1, a structured scoping review of a broad range of empirical literature by using methods specified by Arksey and O'Malley [26] to identify a) PRO domains and their subdimensions relevant to cancer including their conceptual definitions and b) self-report outcome measures conceptually and psychometrically sound to measure these in breast, lung, colon and prostate cancer; and 2) phase 2, a rigorous, formalized RAND Delphi consensus process with two iterative rounds to reach agreement among stakeholders on a core concept taxonomy of PRO domains, subdimensions, and self-reported outcome measures. We also used an integrated knowledge translation approach to engage cancer clinical experts and survivors through all phases of the study. Integrated knowledge translation is similar to participatory action with its dual emphasis on studying a system and concurrently collaborating with health care decision makers in changing it together in what is regarded as a desirable direction [27].

Conceptual Framework

We built our work on the National Institute of Health's taxonomy of physical, mental, and social health outcome domains and subdimensions identified for a core Patient Reported Outcomes Measurement Information System (PROMIS) in the United States [28]. This framework focused on the scoping literature review and provided an analytic framework for synthesizing and mapping the state of knowledge of PROs in cancer. The broad domain areas in the PROMIS framework are applicable across a range of chronic diseases and conditions and include 1) Physical Health: physical function/disability, cognitive function, and common symptoms (fatigue, pain, dyspnea); 2) Mental Health: emotional distress (depression, anxiety) and psychosocial adjustment; 3) Social Health: social role participation and social support; and 4) an overarching multidimensional HRQOL domain composed of physical, psychological, social, and spiritual well-being components. Our intent was not to replicate PROMIS but to identify literature in the years subsequent to reviews led by PROMIS teams and reach consensus among Canadian stakeholders on a core PRO domain taxonomy to guide the development of an information system for the Canadian cancer system. Prior to the initial phases of the study, we obtained feedback from our expert panel on the importance of the domains and subdimensions in the PROMIS conceptual framework. Subsequently, minor adaptations to the PROMIS framework were made including changing the term "mental" to "emotional," adding other prevalent symptoms in cancer such as nausea and vomiting, and adding other dimensions considered important to capture such as return to work and financial impact.

Phase 1: Scoping review methodology

We followed six stages for the completion of a structured scoping review as articulated by Arksey and O'Malley [26]: 1) identifying the research question; 2) identifying relevant studies; 3) study selection; 4) charting the data; 5) collating, summarizing, and reporting the results; and 6) consultation. Scoping studies focus on a range of evidence to convey the breadth and depth of literature in a given field and unlike a systematic review do not evaluate the quality of the evidence for the purpose of meta-analysis [29,30]. Our guiding literature review question was as follows: What PRO domains and dimensions are essential for characterizing the impact of cancer from a person-focused perspective, and are their psychometrically sound PRO measures available to capture these for use in routine clinical care?

Data Sources and Inclusion Criteria

We focused our search on PRO outcomes for breast, colorectal, lung, and prostate cancer across the differing phases of the cancer trajectory (active treatment, palliative care, posttreatment survivorship). These cancer types were included in the search as these are the most prevalent cancers in Canada [1]. We searched 11 electronic databases from 1997 to 2009: CINHAL, MEDLINE, Sociological Abstracts, PsycINFO, Health Star, Web of Science, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects, Cochrane Controlled Trial Registry, EMBASE, and Health and Psychosocial Instruments; checked the reference lists of selected articles to identify further relevant literature; hand-searched reference lists of six key cancer journals from 2002 to 2009; searched Google scholar to identify unpublished gray literature focused on PROs in cancer such as health system reports or proceedings from international consensus meetings; and searched cancer organization Web sites to ensure inclusion of a complete list of terms for PRO domain areas to guide the literature search. We also consulted with a library science specialist with cancer literature and database expertise to ensure appropriateness of search terms and to tailor these for each

database. Small tests of the terms were conducted in each database prior to running the full search to ensure a structured and rigorous review of the literature. This process combined specific Medical Subject Headings and text words (Medical Subject Heading/thesaurus terms) available in Medline that most closely matched each text word from a trial of text words and those from previous PRO reviews and the PROMIS framework [31–35]. The following search terms were used: self-reported, patient-reported, patient-focused, patient-centered, patient-based (also replacing the word "patient" for "person") outcomes as well as specific terms relevant to the domain areas such as cognitive function, social support, quality of life, satisfaction, quality of health care, emotional distress, depression, anxiety, psychosocial adjustment, economics, or costs articulated in our revised conceptual framework. These terms were combined with key terms for cancer, cancer patient, neoplasms, and specific terms related to phases of the cancer continuum for each cancer type (breast, prostate, colon). Terms were combined with Boolean operators and truncated where necessary. The initial search was done in Medline providing a template for the search terms used in other databases. Study inclusion criteria were as follows: published in a peer-reviewed journal as a full manuscript; presents data on a person-focused and self-reported health outcome in adults with a minimum of 100 subjects in total; full article available in English; randomized controlled trial or controlled clinical trial for intervention studies and use of validated measures; concept analysis studies defining a domain, subdimensions, or outcomes in the conceptual framework; development or psychometric testing of an outcome measure for a PRO domain or dimension. Case reports, letters, editorials or opinion articles, and qualitative studies (with the exception of concept analysis studies) were excluded.

Data Abstraction and Management

An online reference manager was used to maintain a database of citations and sources. Two investigators independently reviewed abstracts for inclusion, and any issues that emerged were discussed with a third reviewer to determine final inclusion of full articles. Prior to abstraction of full article data, three investigators independently pilot tested the inclusion and exclusion criteria on randomly selected studies. The data abstraction tool was also tested on 10 randomly selected studies with abstraction of data from full articles independently checked by two reviewers. In addition, we appraised each self-report instrument for conceptual clarity on the basis of definitions in concept analysis studies and commonly accepted psychometric criteria of acceptable reliability (internal consistency, stability or test-retest, equivalence or interrater), validity (content, criterion, construct), responsiveness (sensitivity to change), clinical utility, floor/ceiling effects, and precision (specificity and sensitivity) [36]. Members of the research team (M.F., D.D.) had psychometric expertise, and one of the members (D.D.) had extensive experience in the use of nurse-sensitive PROs for use in hospitals and home nursing agencies.

Phase 2: Consensus Processes

Expert panel participant selection

A purposefully selected sample of 16 Canadian experts involved in different roles in cancer care including representation from five cancer survivor associations was invited by mail to participate as a representative of their national cancer organization. To support the external validity of the consensus process, expert panel participants had to be active members of their respective associations and nominated by their association; also, their curriculum vitae had to reflect the expertise required for the panel with agreement among the research team members prior to final inclusion on the panel. Organizations and disciplines represented by the expert panel are summarized in Table 1. Most panel members held dual roles as clinicians, researchers, administrators, and members of their respective associations or were a cancer survivor.

Table 1 – Expert panel representation (n = 16).

Stakeholder group represented	Discipline or expertise
Canadian Cancer Society	Administrator and breast cancer survivor
Canadian Cancer Advocacy Network	Administrator and prostate cancer survivor
Ovarian Cancer Canada	Survivors (n = 2)
Canadian Association of Radiation Oncologists	Radiation oncologist
Canadian Association of Social Workers	Social worker
Canadian Association of Medical Oncologists	Medical oncologist
Canadian Association of Nurses in Oncology	Nurse
Canadian Hospice Palliative Care Association	Palliative care physician specialist
Canadian College of Family Physicians	Family physician
Canadian Association of Psychosocial Oncology	Psychologist
Canadian Breast Cancer Foundation	Survivor
McGill Rehabilitation Program	Nurse
Colorectal Cancer Association of Canada	Survivor
Dieticians of Canada-Oncology Network	Dietician
National Lung Cancer Association	Survivor

RAND Consensus process methodology

We used a two-round modified Delphi process based on the RAND/UCLA Appropriateness Method [37,38]. This method is described as the only systematic method that combines expert opinion and evidence with content, construct, and predictive validity and reproducibility consistent with well-accepted diagnostic tests [39,40]. The consensus process methods and specific steps taken were as follows: Round 1: Expert panel members received a package containing a synthesis of the literature and glossary of terms; a hard copy of the Delphi rating questionnaire; and instructions on completing the questionnaire, either using an online survey or a mailed hard-copy version. The rating process was completed in two rounds. In the first round, panel members were asked to rate the outcome domains, subdimensions, and measures on a Likert scale of agreement from 1 to 9 for each separate criteria adapted from Herman and Palmer [41] (Table 2). The Web-based survey was pilot-tested a priori by three members of the research team (not included in the Delphi analysis). Round 2: A second round was completed at a face-to-face meeting facilitated by an expert in the RAND consensus method who was not a member of the research team. Each member of the panel, prior to this meeting, was provided with the first-round ratings as well as the group rating for each domain or measure indicator. This two-round process allowed participants a chance to reflect on their opinions and those of other members from the previous stage. At the face-to-face meeting, participants discussed each domain, their related subdimensions, and outcome measures prior to a final anonymous vote.

Table 2 – Criteria for selecting core PRO outcome domains and measures for cancer.

Attributes of domains and measures	Definition
Meaningful	Identifies a common problem area across cancer populations; valued by clinicians and administrators; person-focused; important domain for monitoring quality of clinical care
Feasible	Attributes for measurement are precisely specified, data can be collected across populations; affordable to collect data
Actionable	Amenable for modification by team; comprehensive; norms/ benchmarks or standards are available for comparison; interpretable
Validity of measures	Measure is psychometrically sound; validity and reliability are reported; measures the attributes and concepts for this domain (content or face validity based on conceptual/operation definitions)

PRO, patient-reported outcome.

Analysis of consensus round rankings

The round rankings were analyzed by using methods established in past applications of the RAND/UCLA Appropriateness Method [37]. A median panel rating and measure of dispersion was used to obtain statistical group responses for each of the domains, dimensions, and related outcome measures based on a set of widely endorsed indicator criterion [37]. As shown in Table 2, additional criteria were used to evaluate the psychometric properties of PRO measures that were also subjected to two rounds of voting by the panel. The panel was provided with a summary of the conceptual properties and related measurement constructs synthesized from the literature with a checklist for each instrument that summarized whether the constructs were captured by the measure and its psychometric properties.

Consensus results for the PRO domains and outcome measures from round 1 were discussed at a face-to-face meeting. The main focus of the discussion, however, was on items that were equivocal or there was disagreement. Panel members were considered to be in disagreement when at least three members judged an indicator as being in the highest tertile (ratings 7, 8, or 9) and others rated it as being in the lowest tertile (ratings 1, 2, or 3) (dispersion). Domains and outcome measures with a median rating of 7 or higher on all criteria were endorsed and briefly discussed at the meeting, with all panel members revoting on all items. This method allows each panelist to hold equal weight in determining the final results in the selection of domains and measures to be included.

Results

Studies Identified

As shown in the consort chart depicted in Fig. 1, following the exclusion of duplicate articles and those that did not meet the inclusion criteria, a total of 1503 articles were included for further review and data abstraction (380 conceptual articles, 461 psychometric evaluation articles, 662 intervention studies). An additional 37 studies were identified through reference lists and contributed to the final 1503 articles included. The conceptual articles were used to further define the constructs or elements to inform a PRO domain or subdimension and the conceptual validity of outcome measures. For example, concept articles suggested that the constructs of duration, frequency, intensity, distress, and impact or interference should be captured in outcome measures of symptom experience. Distinct conceptual properties were also identified for other PRO subdimensions based on concept analysis articles and reviews and many of the measures that were psychometrically valid were not necessarily conceptually sound. Consequently, many measures were given a low score on validity and were not retained in the second round of voting.

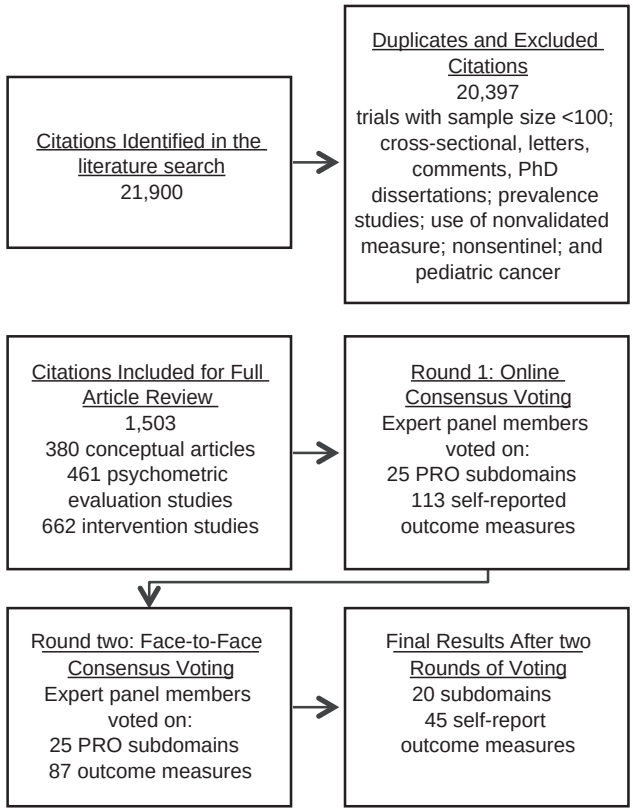

Fig. 1 – Consort chart: scoping review and Delphi consensus. PRO, patient-reported outcome.

Final set of PRO domains and measures

The rankings for each round for domains and measures are shown in Table 3. In round 1, the panel rated on 25 subdomains of physical, emotional, and social health and HRQOL and 113 related self-report instruments by using the criteria listed in Table 2. Of the 16 expert panel stakeholders, all were engaged in voting on PRO domains and discussions to voice their view of the meaningfulness of the domains and subdimensions. Three survivor members of the panel, however, did not specifically vote on the outcome measures because they felt unqualified for rating these on the basis of psychometric criteria. In the round 2 face-to-face meeting, any outcome domains and outcome measures with a median score of more than 5 on both extremes of the scale (1–3 or 7–9) were presented with facilitated discussion. In this round, the panel discussed the results from round 1 and

Table 3 – Two rounds of consensus rankings: median scores for patient-reported outcome measures (n = 13).

Domain	Dimensions	Outcome measure	Round 1		Round 2	
			Valid	Feasible	Valid	Feasible
Physical Health	A. Physical Function	1. Medical Outcomes Study (MOS) Physical Function*	8	8	8	8
		2. Eastern Cooperative Oncology Group (ECOG*)	7	8	7	8
		3. Sickness Impact Profile-Physical Function (SIP)	8	6	7	5
		4. Comprehensive Index Functioning-Cancer	6	8	6	7
	B. Symptom Experience	1. Memorial Symptom Assessment System (MSAS*)	8	8	8	8
		2. MD Anderson Symptom Inventory (MDASI*)	8	8	8	8
		3. Edmonton Symptom Assessment System (ESAS*)	7	7	7	7
		4. Oncology Toxicity Treatment Assessment	6	7	6	6
		5. Symptom Monitor	6	7	4	5
	C. Pain	1. Brief Pain Inventory (BPI*)	8	8	8	8
		2. McGill Pain Questionnaire (MPQ*)	8	8	8	8
		3. Pain-O-Meter (POM)*	7	8	7	8
		4. Numerical Rating Scales (NRS)*	8	8	7	8
		5. Visual Analogue Scales (VAS)*	7	8	7	8
		6. Memorial Pain Assessment Card (MPAC)	6	6	5	6
	D. Fatigue	1. Cancer Fatigue Scale*	8	8	8	8
		2. Piper Fatigue Scale Revised (PFS-R*)	8	8	8	8
		3. Multidimensional Fatigue Inventory (MFI*)	8	8	8	8
		4. FACT-Fatigue (FACT-F*)	7	8	8	8
		5. Brief Fatigue Inventory (BFI*)	7	8	7	8
	E. Sleep/Wake	1. Insomnia Severity Index (ISI*)	7	8	7	8
		2. Pittsburgh Sleep Quality Index (PSQI*)	8	8	8	8
		3. Athens Insomnia Index	7	8	6	7
	F. Nausea and Vomiting	1. Functional Living Index Emesis*	8	8	8	7
		2. Index of Nausea, Vomiting, Retching*	8	7	8	7
	G. Dyspnea	1. Cancer Dyspnea Scale*	8	7	8	8
		2. Medical Research Council Dyspnea Scale	5	6	5	6
		3. Shortness of Breath Questionnaire	6	7	5	5
		4. Chronic Respiratory Disease Questionnaire	6	7	6	5
		5. VAS Dyspnea	6	6	6	6
	F. Sexual Functioning	1. Deragotis Interview for Sexual Functioning (DISF*)	8	8	8	8
		2. International Index of Erectile Functioning –(IIEF*)	8	7	8	7
		3. Sexual Function Questionnaire (SFQ*)	8	8	8	8
		4. Golombok Rust Inventory of Sexual Satisfaction	5	6	5	6
		5. The Changes in Sexual Function Questionnaire	6	6	5	5
Emotional Health	A. Anxiety	1. Hospital Anxiety and Depression Scale (HADS)*	8	8	8	8
		2. State-Trait Anxiety (STAI*)	7	8	7	7
		3. Profile of Mood States and Short Form*	8	8	8	8
		4. Zung Self-Rating Anxiety Scale	6	7	6	6
	B. Depression	1. Center for Epidemiological Studies Depression (CES-D*) Scale	8	8	8	8
		2. Hospital Anxiety Depression Scale (HADS*)	8	8	8	8
		3. Profile of Mood States (POMS*)	8	8	8	8

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		4. Beck Depression Inventory	8	7	7	7
		5. Zung Self-Rating Depression Scale	6	8	6	7
	C. Anger	Not endorsed for core measurement				
	D. Substance Abuse	Not endorsed for core measurement				
	E. Psychological Adjustment	1. Mental Adjustment to Cancer (MAC*) scale	8	8	7	7
		2. MAC scale (Mini-MAC* scale)	7	7	7	7
		3. Psychological Adjustment to Cancer Scale	7	7	6	6
	F. Coping	1. Cancer Coping Questionnaire (CCQ*)	7	8	7	8
		2. Ways of Coping Questionnaire-Cancer (WCQ-C*)	8	7	8	7
		3. COPE-Short Form*	7	8	7	7
	G. Self-Concept/Body Image	1. Body Image Scale*	7	8	8	8
		2. Body Image Instrument	6	7	6	7
		3. Investment in Body Image	6	7	6	6.5
		4. Appearance Schemas Inventory	6	7	6	7
	H. Stress Response	Not retained for core measurement				
	I. Meaning and Spirituality	Domain endorsed but no consensus regarding PRO measures				
	J. Self-Efficacy	No cancer-specific measures of self-efficacy identified				
	K. Subjective Well-Being	1. Post-Traumatic Growth Inventory (PTGI*)	7	7	7	7
		2. Benefit Finding Scale (BFS*)	8	8	7	7
		3. Stress-Related Growth Scale	6	7	4	5
	L. Cognitive Function	1. Fact-Cognitive Scale (FACT-COG)*	7	7	7	7
		2. Sickness Impact Profile-Cognitive Scale	6	7	6	6
Social Health	A. Social Function	1. Psychosocial Adjustment to Illness (PAIS)*	7	7	7	7
		2. Social Adjustment Scale	6	6	6	6
		3. Social Adaptation Self-Evaluation Scale	6	7	5	6
		4. Katz Adjustment Scales	5	5	5	4
		5. National Comprehensive Cancer Problems Checklist	7	7	6	6
		6. Social Difficulties Inventory	7	7	6	6
	B. Social Support/Relationship	1. MOS Social Support Survey*	7	7	7	7
		2. Interpersonal Support Evaluation List	5	6	4	5
		3. Structural-Functional Support Scale	6	7	6	7
		4. Duke-UNC Functional Social Support Questionnaire	5	7	5	7
		5. Bottomley Cancer Social Support Scale	6	7	6	7
		6. Social Support Questionnaire	5	7	4	6
		7. Perceived Social Support from Friends and Family	4	6	4	6
	C. Social Isolation	Low scores for domain as not actionable terminology				
Quality of Life		1. European Organization for Research and Treatment of Cancer (Quality of Life Questionnaire Core 30 *)	7	8	7	8
		2. Functional Assessment of Cancer Therapy-Cancer*	8	8	8	8
		3. Functional Living Index Cancer (FLIC*)	7	8	8	7
		4. Quick Functional Living Index Cancer*	7	8	8	8
		5. McGill Quality of Life Questionnaire (MQOLQ*)	8	8	7	7
		6. Cancer Care Monitor*	7	8	7	8

* Patient-reported outcome measures retained.

Table 4 – PRO Domain framework and outcome measures.

Outcome	Domain	Subdomains	Dimensions	Final panel selected outcome measures
Patient Self-Reported Health	**Physical Health**	Physical Function	Objective Mobility (walking, balance, climbing stairs) Perceived Mobility (perceived difficulty in physical action) Activities: instrumental activities of living (role, work, caregiving, housework)	1. Medical Outcomes Study-Physical Function Scale 2. Eastern Cooperative Oncology Group (ECOG) Performance Status 3. Sickness Impact Profile
		Symptom Experience	Overall Symptom Experience Measures	1. Memorial Symptom Assessment Scale 2. MD Anderson Symptom Inventory 3. Edmonton Symptom Assessment Scale
			Pain	1. Brief Pain Inventory 2. McGill Pain Questionnaire 3. Numeric Rating Scales 4. Pain-O-Meter 5. Visual Analogue Scale
			Fatigue	1. Cancer Fatigue Scale 2. Revised Piper Fatigue Scale 3. Multidimensional Fatigue Symptom Inventory 4. Functional Assessment of Cancer (FACT)-Fatigue 5. Brief Fatigue Inventory
			Vomiting/Nausea	1. Functional Living Index Emesis 2. Index of Nausea, Vomiting, and Retching
			Dyspnea	1. Cancer Dyspnea Scale
			Sleep/Wake Function Disturbance	1. Pittsburgh Sleep Quality Index 2. Insomnia Severity Index
			Nutritional Status (new outcome identified)	• No instruments selected (further investigation warranted)
		Sexual Function		1. Derogatis Interview for Sexual Functioning 2. Sexual Function Questionnaire 3. International Index of Erection Dysfunction
	Emotional Health	Emotional Distress/ Negative Affect	Anxiety	1. Hospital Anxiety and Depression Scale 2. Profile of Moods States-Short Form

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Table 4 – *continued*

Outcome	Domain	Subdomains	Dimensions	Final panel selected outcome measures
				3. Spielberger State Trait Anxiety Scale
			Depression	1. Hospital Anxiety and Depression Scale 2. Centre for Epidemiological Study (CES)-Depression Scale 3. Profile of Mood States-SF
		Cognitive Function		1. FACT-Cog Further research needed regarding best measure
		Psychological Adjustment	Overall Psychological Adjustment	1. Mental Adjustment to Cancer (MAC) scale 2. Mini MAC scale
			Coping	1. Cancer Coping Questionnaire 2. Ways of Coping Questionnaire 3. COPE-SF
			Self-Concept/Body Image	1. Body Image Scale Further investigation warranted
			Meaning and Spirituality	• No Instruments were selected • Further investigation warranted
			Subjective Well-being	1. Benefit Finding Scale 2. Post-traumatic Growth Inventory
	Social Health	Social Health	Social Function	1. Psychosocial Adjustment to Illness Further investigation warranted
			Social Support/ Relationships	1. Medical Outcomes Study-Social Support Survey Further investigation warranted
	Quality of Life	Health-Related Quality of Life		1. European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) 2. FACT-General 3. McGill QOL Questionnaire 4. Functional Living Index Cancer 5. Quick-Functional Living Index Cancer 6. Cancer Care Monitor

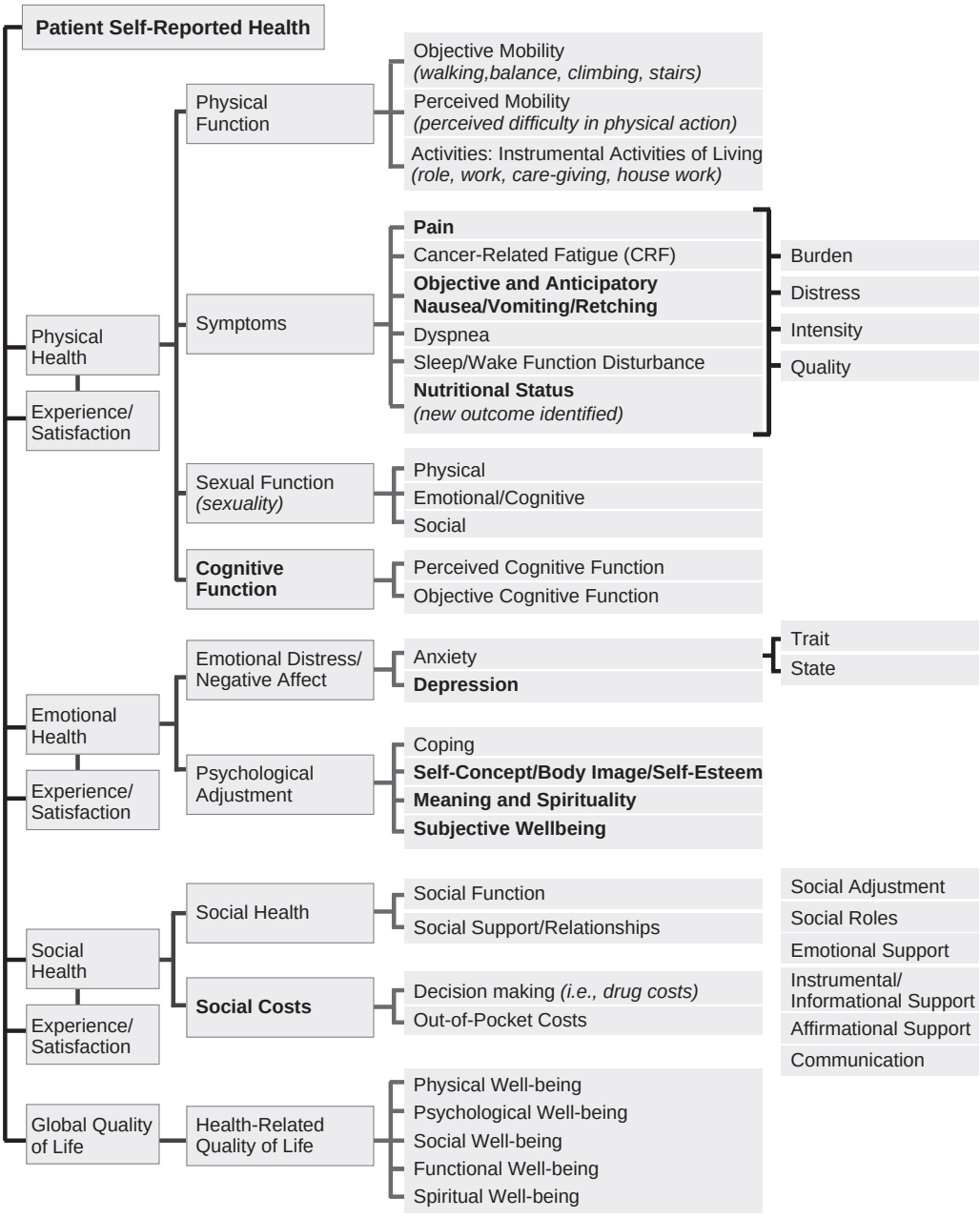

Fig. 2 – Person-focused core PRO domain and dimension taxonomy: PROMS-Cancer Core for Canada. PRO, patient-reported outcome.

anonymously voted on the 25 subdomains and related dimensions and the remaining 87 self-report instruments. There was agreement (range of 7–9) following round 1 on the core domains and dimensions to be included that did not change after round 2 voting. The second round vote proceeded to ensure that after face-to-face discussion this level of agreement remained. Most of the discussion focused on reaching consensus on outcome measures. Following round 1, 26 measures were excluded because of nonendorsement by the panel (lowest tertile = <3).

As shown in Table 4, after two rounds of voting, the expert panel achieved consensus on a final core set of 20 outcome subdimensions and 45 PRO measures. Figure 2 provides a pictorial representation of the final core domains and subdimensions taxonomy (PROMs-Cancer Core) derived from the round 2 Delphi vote and additional PROs recommended for further investigation and those that should be added to the framework (bolded).

Physical health

The final physical health domain PROs important for data collection in routine clinical care included Physical Function, Symptoms (pain, cancer-related fatigue, nausea and vomiting, dyspnea, and sleep/wake disturbance); Symptom Experience inclusive of dimensions of duration, frequency, distress, intensity, and impact; Sexual Function; and Cognitive Function. The panel recommended that a PRO domain Nutritional Status be added as a subdimension of the physical health domain. Despite numerous measures available to capture these domains, limitations were identified in the conceptual validity of the instruments. For instance, few captured the important dimensions of symptom experience that are key to understanding symptoms from the perspective of the person; that is, affective distress of the symptom was rarely captured. Content validity was most often conducted with health care professionals and rarely

included patients to determine clarity or relevance of measures from their perspective.

Emotional health

The important emotional health subdomains include Emotional Distress and Psychological Adjustment. *Emotional distress* represents negative effects of the disease and included two dimensions, *anxiety* and *depression*, both of which were identified as highly meaningful to evaluate as part of routine clinical care. *Psychological adjustment* represents both positive and negative responses to cancer and includes the dimensions of *coping* and *overall adjustment* and related subdimensions of *self-concept, body image*, *sexual health and self-esteem*; *meaning and spirituality*; and *subjective well-being*. Meaning and spirituality were considered interrelated by the panel and while these were endorsed as core domains there was unresolved debate about their definitions. Several outcomes such as *anger and substance abuse* were considered as important, but the panel did not reach consensus on these items as it was unclear how these would be measured. The relevance of anger as a PRO in multicultural populations and their overall relevance in a core PRO measurement system were debated and a decision made to exclude this dimension. Although, *self-efficacy* was identified as an important PRO outcome in the literature and by the panel, self-efficacy outcome measures specific to cancer were not identified and this subdimension was excluded.

Social health

The social health subdomain included the dimension Social Function, further defined as *social adjustment* and *social roles*, and the dimension *Social* Support/Social Relationships, which was further conceptually divided into *emotional support, instrumental support*, *affirmational support*, *and communication* on the basis of concept analysis articles reviewed. Of the self-report measures identified in the literature for this domain, the advisory panel felt that most PROs required further evaluation in cancer populations. Social Costs was identified as an important PRO outcome; however, the expert panel questioned whether social costs were actionable outcomes under the influence of the clinical team. In addition, the panel identified social isolation as an important predictor of psychological adjustment to cancer but the actionable nature of this indicator also requires further research and agreement was not reached on its inclusion in the core taxonomy.

Quality of life

HRQOL was also identified as a meaningful, feasible, and actionable outcome. *HRQOL* is multidimensional and includes *physical well-being, psychological well-being, social well-being, functional well-being,* and *spiritual well-being*. Existing quality-of-life measures included "generic" HRQOL measures, as well as those specific to disease/pathology (e.g., breast cancer), patient populations (e.g., pediatrics), or for utility (e.g., economic) purposes. Numerous measures exist to measure quality of life, but scales vary in their wording, and in their inclusion of dimensions such as spirituality and some measures were more heavily weighted in their global scores on functioning elements.

Discussion

There is increasing recognition of the need to capture the patient's experience of treatment and care as a major indicator of health service quality and treatment effectiveness [42–45]. PRO data are ultimately a measure of patient experience of illness that can enrich the evaluation of treatment effectiveness and clinical services [45]. The use of PROs in routine clinical care has emerged as a health system imperative to improve population health [46] and as a metric for determining payment for quality [47]. This study identified a core PRO domain taxonomy and a hierarchy of outcome measures (PROMS-Cancer Core) specific for use as a guiding framework in the Canadian cancer system.

The value of capturing PRO data as part of routine care is substantial as it will enable early and ongoing identification of treatable emerging problems, monitoring of the effects of disease progression and response to therapy, promotion of informed decision making and treatment plans, and the selection of appropriate clinical interventions relevant to the individual [48,49]. Routine collection of PRO data as part of clinical care will also enhance understanding of the burden and the impact of cancer from the perspective of the person [50] and ultimately can improve the quality of clinical care and population health [51].

Some type of PRO data collection has been common practice in cancer clinical trials for many years [52,53]; however, PROs are rarely implemented as part of routine clinical practice [54]. Several issues with the use of PROs have been identified by researchers and clinicians including heterogeneity in outcome and domain definitions, instrument responsiveness, burden on patients and clinicians, use of instruments not conceptually sound or validated in cancer populations, and lack of consensus on what constitutes a clinically meaningful change, particularly with multidimensional measures such as HRQOL [55]. Moreover, most of the outcome measures available for research are not adequately tested for use in clinical practice as it applies to individual patients [56]. Clinicians report concern that self-report measurements lack objectivity and precision [57] and fear their use for monitoring the quality of clinical performance [58]. There is clearly a need for more precise measures for individual level tracking by using PRO measures as part of routine clinical practice [59] prior to wide-scale implementation.

Recent studies, however, do suggest that PROs are feasible for implementation in clinical care using computer-based platforms and are acceptable and valuable for improving communication between patients and clinicians [60–65]. A number of implementation challenges, however, must still be addressed to ensure the widespread uptake of PROs in routine clinical practice, particularly if our aim is to optimize health and quality of clinical care [66]. The timing of PRO data collection measurement in chronic illnesses such as cancer will be particularly challenging because the effects of cancer are both short term (acute) and time limited as well as persistent and chronic, with late effects emerging years after treatment completion. An enduring data infrastructure that allows for linking many sources of data and that is also accessible to clinicians as summated scores in real time will be essential [66]. The information management tasks to implement such a system is daunting, and such a system will unlikely be able to incorporate full outcome measures used for research purposes as identified in this study and further testing of PRO measures for clinical practice is still needed. Modern measurement approaches such as item response theory modeling can provide significant opportunities to improve rigor and efficiency of electronic patient-reported data collection and analysis that will facilitate removing the use of single items to tap PRO domains [67]. In addition, computer adaptive technology will help to lessen response burden and provide precise measurement of the PRO domains for individual patients, which may be critical for detecting clinically meaningful change [68].

Most important, the routine collection of PRO data must be viewed as valuable to the clinical encounter between the clinician and the patient, be affordable, and able to be integrated as part of clinical work flow processes [69,70]. Training of clinicians will be critical to the effective use of PRO data and the presentation of data in ways to facilitate meaningful interpretation by

clinicians to inform selection of appropriate and relevant interventions essential to improve outcomes [71–74]. Knowledge translation strategies should complement the implementation of PRO data to ensure best practices in the clinical management of the patient [46,75]. More important, the collection of PRO data must not be an additional burden to cancer patients who already experience considerable distress along the cancer journey. PRO measurement must be implemented in such a way that it is embedded as part of routine clinical care delivery and also enhances the principles and practice of person-centered care [76,77] and continuous quality improvement as an organization and clinical care priority. The recently developed User's Guide for Implementing PROs in Clinical Practice may help to guide the implementation process and the considerations for PRO use in clinical care [78].

Finally, this research has raised awareness of the use of PRO data in routine care to improve the patient experience of cancer; however, many additional steps are still required. Further consensus building is still necessary to reach agreement with a wider group of stakeholders in the Canadian cancer system that a core measurement approach based on the domains identified in this study is valuable. In addition, we will need to populate the proposed core domain taxonomy by using more precise measures for individual measurement possibly through the adoption of PROMIS short forms and computer adaptive technology programming combined with methods to ensure more meaningful outputs interpreted and scored for clinicians and patients that are tested in pilot studies.

Conclusions

The PRO concept taxonomy and instrument hierarchy developed in this study as part of an integrated knowledge translation approach will bring us closer to the implementation of a PRO measurement information system for the Canadian cancer care system. The inclusion of cancer survivors in the decision-making process has fostered the development of a PRO measurement framework that is person-focused to ultimately improve the "whole person" experience of cancer.

Limitations

Our study has a number of limitations that should be acknowledged. First, the literature search was restricted to English publications only. Although there could be reports published in other languages, previous studies have suggested that restricting literature searches to English does not bias systematic reviews of conventional medical interventions [79]. Second, scoping reviews provide information on the scope of a body of literature at only a single moment in time. Hence, they are, in essence, out of date shortly after their completion. Although our literature review was restricted to lung, breast, prostate, and colorectal cancer, the domains and subdimensions in the core taxonomy are likely relevant as core for other cancer populations.

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