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ORIGINAL ARTICLE

Toward the development of a comprehensive cancer experience measurement framework

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Abstract

A diagnosis of cancer and its treatment often have a profound impact on an individual's health-related quality of life—affecting physical, psychological, social, occupational, and financial domains. Person-centered care (PCC)—defined as a respectful, responsive, and tailored approach that meets patients' needs, values, and preferences—is becoming an integral part of comprehensive cancer care. The implementation of PCC into clinical practice provides benefits such as improvement in the quality of patient care, enhanced health-related outcomes, and significantly higher satisfaction with care. However, to guide and document more precisely the effects of PCC, various authors have argued that a more comprehensive measurement framework is needed. The primary goal of this paper is to present such an evolving framework based on extant evidence and developed in the context of a series of expert stakeholder meetings spearheaded by the Canadian Partnership Against Cancer (CPAC) that began in 2012. Developed collaboratively, the Cancer Experience Measurement Framework goes beyond existing patient experience frameworks by focusing on four key elements and related measures: the patient perspective, the family perspective, the combined patient-family perspective, and interactions with the healthcare system. In light of current healthcare trends promoting cancer self-management, patients as partners, and patient and family engagement in care, it is imperative that we conduct ongoing assessments using shared and psychometrically sound measures to ensure sound comparisons across settings, as well as better cancer-related processes and outcomes for indivduals affected by cancer.

Keywords Patient experience · Measurement framework · Person-centered care · Cancer care · Patient-reported outcomes · Satisfaction with healthcare services

Introduction

Being diagnosed with cancer disrupts many aspects of one's life and is associated with increased needs for cancer information, guidance and support. As the number of individuals being diagnosed and surviving cancer continues to grow; currently at an all-time high of about one million in Canada [1], the healthcare system is challenged to provide tailored care for this growing segment of the population. An individual's cancer experience is defined herein as physical, psychological, social, interactional, and economic issues across the cancer trajectory (i.e., at diagnosis, during treatment, short- and long-term survivorship, and at end-of-life). More specifically, the experience includes domains related to one's intrapersonal lived experience with cancer as well as interpersonal and interactional issues pertaining to family, social networks, healthcare delivery systems, access to services, and cancer survivorship care.

Although Canadian surveys of the patient experience with cancer care document relatively high satisfaction rates [2], individuals affected by cancer continue to report various

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unmet needs and dissatisfaction with the informational and instrumental support provided. For instance, patients often describe feeling overwhelmed with the nature of cancer information provided, not receiving adequate information to help navigate the cancer care system, or poor timing in cancer information delivery [3]. In addition, patient surveys document dissatisfaction with the paucity of emotional and social support [4], delays in accessing care and poor cancer care service coordination. To respond to these challenges, various stakeholders have endorsed person-centered care (PCC) as a means to offer more personalized, integrated, and supportive guidance to patients and other affected members of the patients' network throughout the illness trajectory [5–8].

Whereas, various patient experience frameworks have been put forward (Table 1), the literature still lacks a comprehensive framework that (1) is specific to cancer; (2) includes key constructs; (3) includes measures previously shown to capture significant differences in the patient experience; and (4) proposes measures reflecting core categories of the patient experience along with interactional components (e.g., patients interacting with the healthcare system and with family members). Emerging from the literature and addressing issues conjointly ensure that all facets of the patient experience are captured [8]. One influential framework is the Warwick Patient Experiences Framework which has identified, through a systematic review, themes that are key to a high quality patient experience [10]. These include the patient lived experience, active participation, relationships, communication, information/support, responsiveness of services through an individualized approach and continuity of care. As mentioned above, although the Warwick model is considered to be the first model to explicitly link prior evidence to themes, no specific measures are proposed. Our framework includes themes identified by Staniszewska et al. (2014) while adding relevant measures. As such, our framework makes a significant contribution to the field as it can also guide the development of new measures and indicators for standardized assessment of person-centered experiences and cancer care system performance.

Hence, the goal of this paper is to comprehensively present a consensus framework based on emerging evidence to guide patient experience measurement and further theoretical and instrument developments. Initially conceptualized within the context of several stakeholder meetings spearheaded by the authors herein, we anticipate that the framework and its evolution will guide researchers, clinicians and healthcare decision-makers to document important metrics and provide key performance indicators that align with constructs depicted in the framework. Clinically, the use of a common measurement framework would ensure a more systematic approach to assess and guide patients and families toward the most relevant supportive resources. As such, the standardized measurement of the multidimensional aspects of cancer and its treatment would also allow for the identification of issues that need attention, the monitoring of how these issues evolve over time, comparisons across individuals and settings, and the mobilization of strategies to improve the quality of ongoing supportive approaches.

Table 1 Most popular patient experience frameworks (2001–2017)

Health Quality Ontario's Patient Engagement Framework (2017) [9] http://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf
Warwick Patient Experiences Framework (WaPEF; Staniszewska et al. 2014) [10] https://academic.oup.com/intqhc/article/26/2/151/1802817
NHS Patient Experience Framework (NHS National Quality Board, 2011) [11] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215159/dh_132788.pdf
International Alliance of Patients' Organizations (IAPO, 2007) [12] http://iapo.org.uk/sites/default/files/files/IAPO%20Patient-Centred%20Healthcare%20Review%202nd%20edition.pdf
The Senses Framework (Nolan et al., 2006) [13] http://shura.shu.ac.uk/280/1/PDF_Senses_Framework_Report.pdf
U.S. National Health Council Report (Cronin, 2004; NCGC, 2012) [14, 15] Pg 37, Table 5: https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0050751/pdf/PubMedHealth_PMH0050751.pdf
World Health Organization: Responsiveness of Health Care Systems (2003) [16] http://www.who.int/healthinfo/paper53.pdf
Institute of Medicine Framework (Gerteis et al., 1993; IOM, 2001) [17, 18] http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf
Picker: Principles of Patient Centred Care (Picker Institute, 1987) [19] https://www.picker.org/about-us/picker-principles-of-person-centred-care/

Patient experience and engagement

Embedding the patient perspective is considered a hallmark of quality comprehensive clinical care and research; crucial to understanding processes associated with health-related behaviors and outcomes [20]. According to the Beryl Institute, the patient experience in healthcare is defined as "the sum of all interactions, shaped by an organization's culture that influence patient perceptions across the continuum of care" [21]. In addition to people's experience with healthcare, research also addresses individuals' experience with health and illness [22]. Key elements to this approach include *personal experience*—individuals' perceptions related to their health and care across health and illness trajectories, *interactions*—"the orchestrated touch-points of people, processes, policies, communications, actions, and environment" [23], *culture*—the vision, values, individuals within and outside organizations, and community, and *perceptions*—"what is recognized, understood and remembered by patients and support people" [23]. What constitutes the *continuum of care* spans before, during, and after the delivery of healthcare services [21]. Patient and family members' engagement refers to their involvement and participation in processes through which they integrate information and professional advice within their own needs, preferences and capabilities to optimize health. Recently, the concept of patient and family engaged care reflects the notion that individuals' (and caregivers') perspectives and expertise pertaining to their bodies, lifestyle, and goals are incorporated into care planning and are considered when identifying areas for quality improvement [24].

Given that healthcare is a knowledge-based endeavor, scientific evidence about the patient experience and engagement should be considered alongside biomedical, clinical, and epidemiological types of knowledge generation to optimize health and healthcare delivery—particularly in an era of personalized/precision medicine where patients' medical care is increasingly individualized and made "unique". Within the last decade, there has been significant progress in moving beyond global patient satisfaction surveys to more precise approaches and tools that capture multidimensional aspects of the patient experience for the purpose of comprehensive descriptions, timely interventions and healthcare system reengineering [25]. There are several challenges and opportunities in this emerging field of inquiry: First, how do we best capture patients' actual health/illness experiences? How do they vary by health problems, contextual factors such as age, gender and socioeconomic status, stage of disease, and particular phases of the illness trajectory? In addition, patient and family personal accounts of health, illness and healthcare interactions may differ from those of healthcare professionals, patient groups, policy makers or healthcare managers. Finding ways to document converging and diverging aspects of the patient/family experience is quickly becoming a priority. It is through definitional precision, the identification of promising and psychometrically sound measures and ongoing assessments that improvements in the experience and the quality of care will better meet the multidimensional needs of cancer patients and their families [24].

Core concepts of person-centered care

A person-centered care (PCC) approach revolves around the attitudes, needs, preferences and experiences of patients and families. Key concepts in PCC include dignity, respect, communication, information sharing, collaboration, and participation with those affected by an illness. PCC is delivered through education, shared knowledge, friends and family involvement, collaboration and team management, sensitivity to non-medical and spiritual dimensions of care, respect for the patient's needs and preferences, and the free flow and accessibility of information [24, 26, 27]. A telling recent example from Loiselle's study of personal preferences for cancer information in a large sample of newly diagnosed individuals ($N = 2{,}438$) shows five distinct patterns of cancer information preferences with nearly 40% of the sample reporting their preferences for avoiding cancer information altogether (Loiselle CG, 2018, Cancer information-seeking preferences are associated with distinct patient experiences and satisfaction with cancer care, unpublished.)

As such, PCC is comprised of multiple features that include patients' preferences, emotional support, physical comfort, information and education, continuity and transition, co-ordination of care, and access to care. These features ultimately can come together to inform and improve the patient experience; the sum of an individual's perceptions, expectations and interactions related to his or her health and care throughout the cancer journey.

Fundamentally, the goal of a healthcare system is to improve processes and outcomes related to health status, not just to offer services. However, there is a lack of documentation on how these goals are achieved [28]. Standard mortality and survival data are essential for monitoring quality and treatment effectiveness, but they fall short on providing evidence on the impact of cancer and its treatment on the quality of care and the patient experience [29]. Consequently, patient-reported outcomes (PROs)—namely health issues told by patients that matter to them are seen as complementary to disease-focused outcomes [30]. PROs assist in monitoring processes related to the patient experience and, when their measurement is implemented effectively in routine care, can enhance patient-provider communication, reduce symptom distress, and improve quality of life [31, 32]. PROs allow for the measurement of changes in health status related to illness and care interventions as perceived by patients; an important validation of whether effective and quality healthcare is delivered [33, 34]. Thus, patient experience measurement enables a better estimation of the care processes that contribute (or must be changed) to achieve better health outcomes measured through PROs. A robust and comprehensive measurement system, such as the one proposed herein, embedded within healthcare organizations would include both PROs and patient-reported experience measures (PREMs) [32].

Context for the development of the framework

By 2012 in Canada, cancer agencies across the country were working toward implementation of PROs to improve the patient experience. Many institutions were using tools such as the NRC Picker Ambulatory Oncology Patient Satisfaction Survey (AOPSS) to measure the patient experience and the Edmonton Symptom Assessment System (ESAS) in conjunction with the Canadian Problem Checklist (CPC) to assess PROs to detect psychosocial distress, physical symptom severity, and symptom management [33]. However, these tools were not being used consistently regionally and nationally.

The lack of a common patient experience measurement framework is not unique to cancer. It constitutes an obstacle to systematically evaluating the patient experience to guide the development of more effective and personalized interventions and inform quality improvement efforts.

In response to these gaps and the need to better understand and document key components that may contribute to an enhanced patient experience, the Canadian Partnership Against Cancer (CPAC) created a Patient-Reported Outcomes (PROs) initiative. A national survey with four regional consultations and deliberations of a national patient experience steering committee appointed by the provincial cancer agencies, all identified that addressing patient experience outcomes was a priority in their regions. CPAC sponsored the PROs initiative to advance standardized measurement and to provide benchmarking locally, nationally, and internationally to influence practice changes.

Methods for development of the framework

Specifically, the PROs initiative objectives were to leverage existing priorities and create new opportunities to (1) develop and reach consensus on a Pan-Canadian framework and core set of indicators to measure improvements in the patient experience and (2) uptake a common set of evidence-informed assessment tools and resources to support person-centered program design, testing, and implementation. With these objectives in mind, as an initial step in 2012, a small working group met in person and through teleconferencing to draft the framework to ensure consistent concepts, definitions, metrics and indicators that would drive the work toward common measurement and reporting. This project was spearheaded

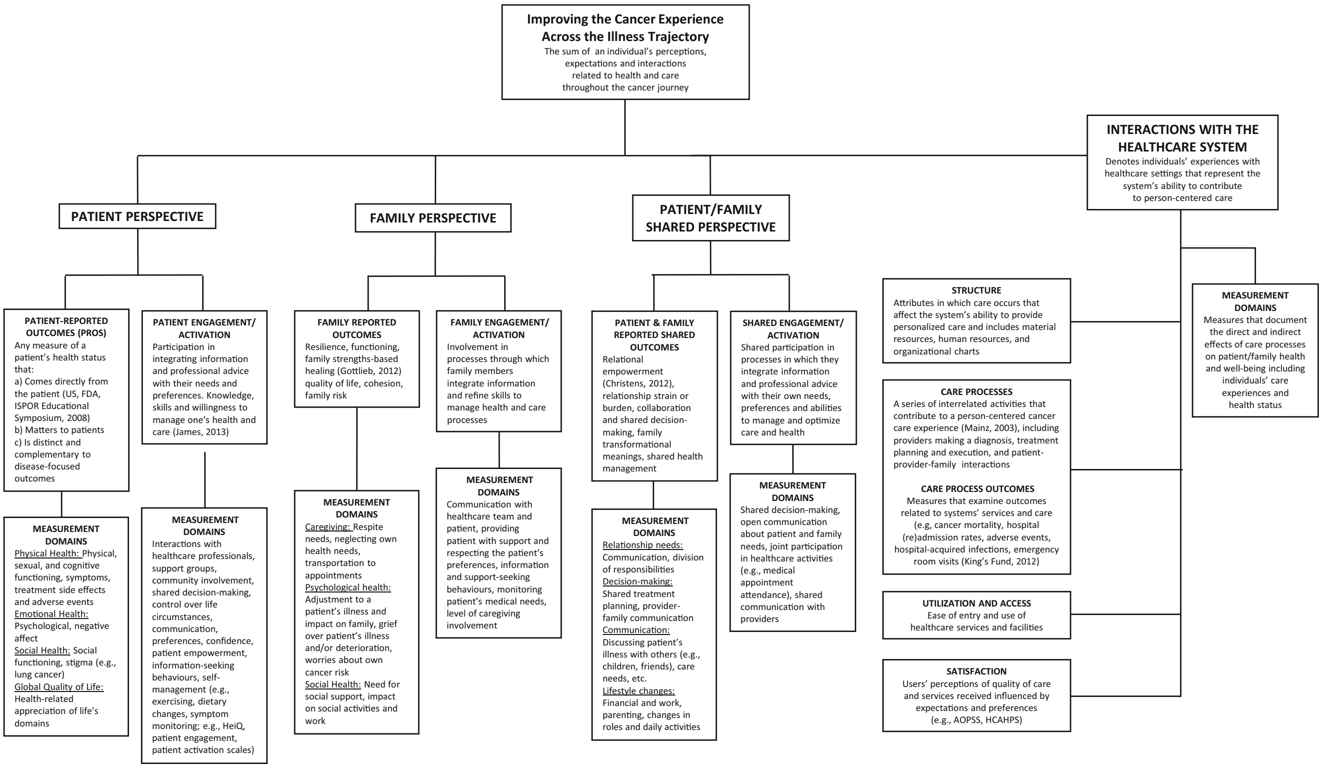

Fig. 1 The Cancer Experience Measurement Framework (CEMF)

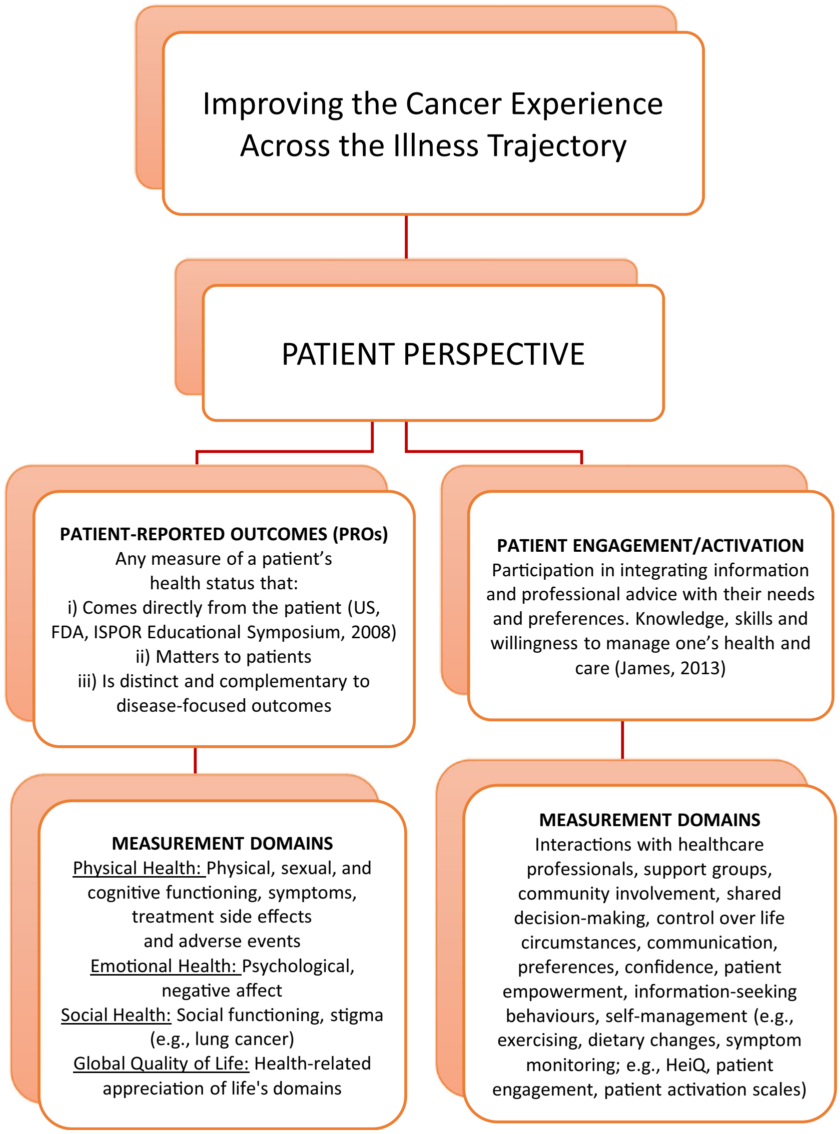

Fig. 2 The patient perspective

Improving the Cancer Experience Across the Illness Trajectory

PATIENT PERSPECTIVE

PATIENT-REPORTED OUTCOMES (PROs)
Any measure of a patient's health status that:
i) Comes directly from the patient (US, FDA, ISPOR Educational Symposium, 2008)
ii) Matters to patients
iii) Is distinct and complementary to disease-focused outcomes

PATIENT ENGAGEMENT/ACTIVATION
Participation in integrating information and professional advice with their needs and preferences. Knowledge, skills and willingness to manage one's health and care (James, 2013)

MEASUREMENT DOMAINS
Physical Health: Physical, sexual, and cognitive functioning, symptoms, treatment side effects and adverse events
Emotional Health: Psychological, negative affect
Social Health: Social functioning, stigma (e.g., lung cancer)
Global Quality of Life: Health-related appreciation of life's domains

MEASUREMENT DOMAINS
Interactions with healthcare professionals, support groups, community involvement, shared decision-making, control over life circumstances, communication, preferences, confidence, patient empowerment, information-seeking behaviours, self-management (e.g., exercising, dietary changes, symptom monitoring; e.g., HeiQ, patient engagement, patient activation scales)

by CPAC with expertise from academia, epidemiology, evaluation, psychosocial oncology, quality improvement, research, and patient and family representatives.

A nominal group technique (NGT) was used in meetings with the various stakeholders to generate essential domains and elements for the framework, to guide decision-making and reach agreement on the final version. NGT is a technique which seeks to guide group process inclusive of problem identification, solution generation, and decision-making. For example, it can identify strengths versus areas in need of development, rather than being used as a decision-making voting alternative [35]. A NGT approach supports participatory action and the voice of all participants including patients and is particularly suited for more timely decision-making for health policy change and system improvement.

The small group of stakeholders designed a preliminary framework following discussion and debate, drawing on their research and clinical experiences in the field and contributions to or familiarity with the existing literature on the topic [36–41]. The choice of the four main components (i.e., patient, family, shared family/patient and healthcare experience) is consistent with the literature on the topic and these key components were retained based on the expert group consensus. These were adopted unanimously as the best representation for the comprehensive and yet complex phenomenon. Constructs were then specified for each component to illustrate relevant content to be measured.

Subsequently, a national advisory group of representatives from cancer agencies and facilities from across Canada reviewed and provided input into the drafted framework and once approved, circulated it among healthcare leaders, senior executives, and other stakeholders within their provinces. When consensus was reached with the national advisory group, the draft framework was approved by the CPAC

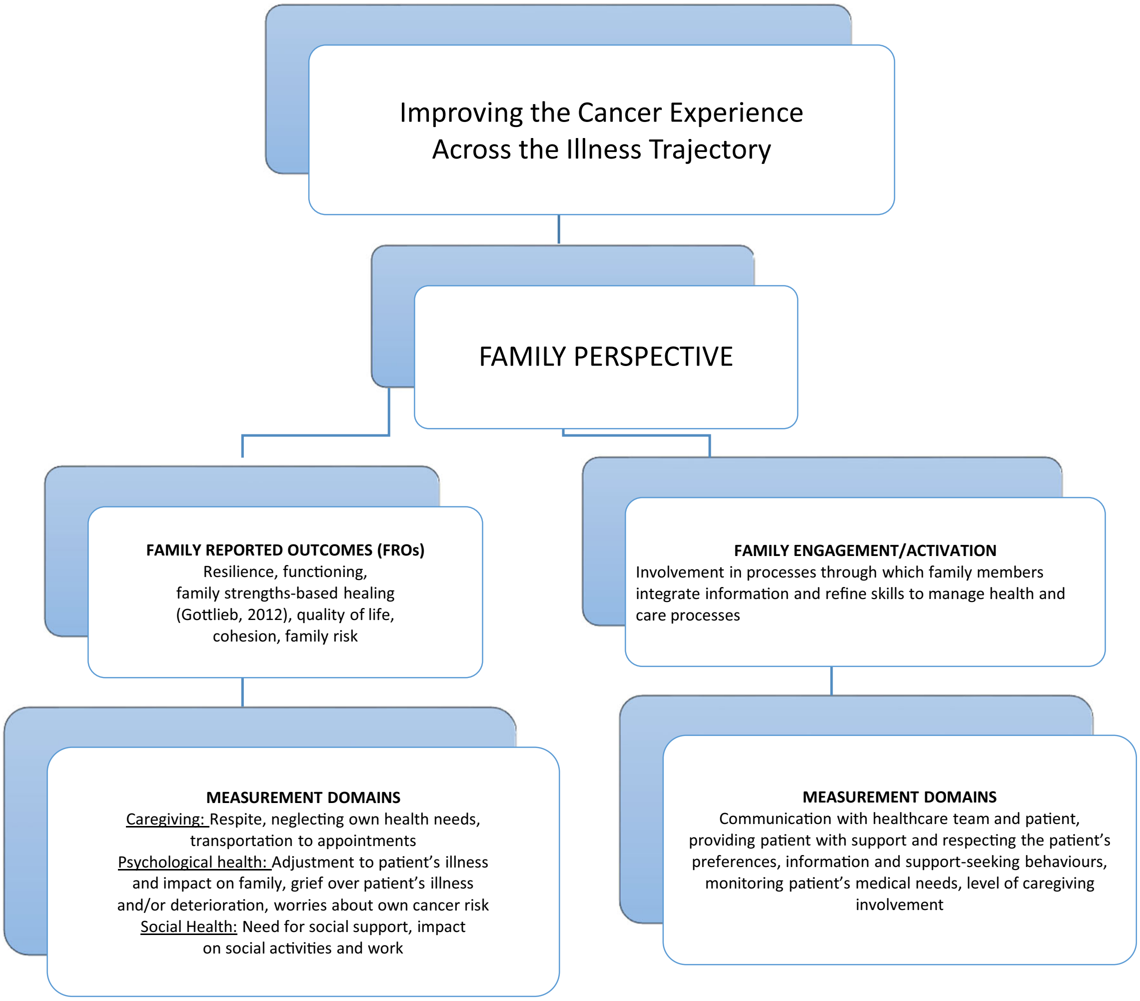

Fig. 3 Family perspectives

Board to become a key reference and guidance for patient-reported outcomes projects sponsored by the organization. Authors herein further developed the overall Pan-Canadian Cancer Experience Measurement Framework depicted in Fig. 1. This framework can be used for common term definitions and consistent approaches in the broad conceptualization and measurement of the patient experience in cancer or in subsets to address more focused aspects such as patients' perspectives/experiences (Fig. 2), family perspectives/experiences (Fig. 3), patient and family shared perspectives (Fig. 4) and interactions with the healthcare/cancer care system (Fig. 5). We now have the opportunity to use and further operationalize the framework in our respective cancer care institutions and document the extent to which measurement of these constructs further informs supportive interventions and quality improvement.

Although the proposed framework needs to be comprehensive, it was agreed by the advisory and working groups that the full scope may be overwhelming for many cancer centers that are beginning to document the effects of person-centered cancer care. As a result, the patient and health system components were the initial areas of focus for operationalization. The patient/family shared perspective and family perspective underscored the need to further identify essential elements to guide selection of measurement tools for these domains. In addition, the framework was construed as a guide to be implemented in a phased, step-wise approach whereby initially the focus may be on measuring the patient experience with illness and with the care they receive. Subsequently, contextual factors can be added to capture more comprehensive and interactional aspects.

Operationalizing the framework: PROs and PROMS

The most operationalized components of the framework can be exemplified by the work of Dr. Doris Howell, a nurse

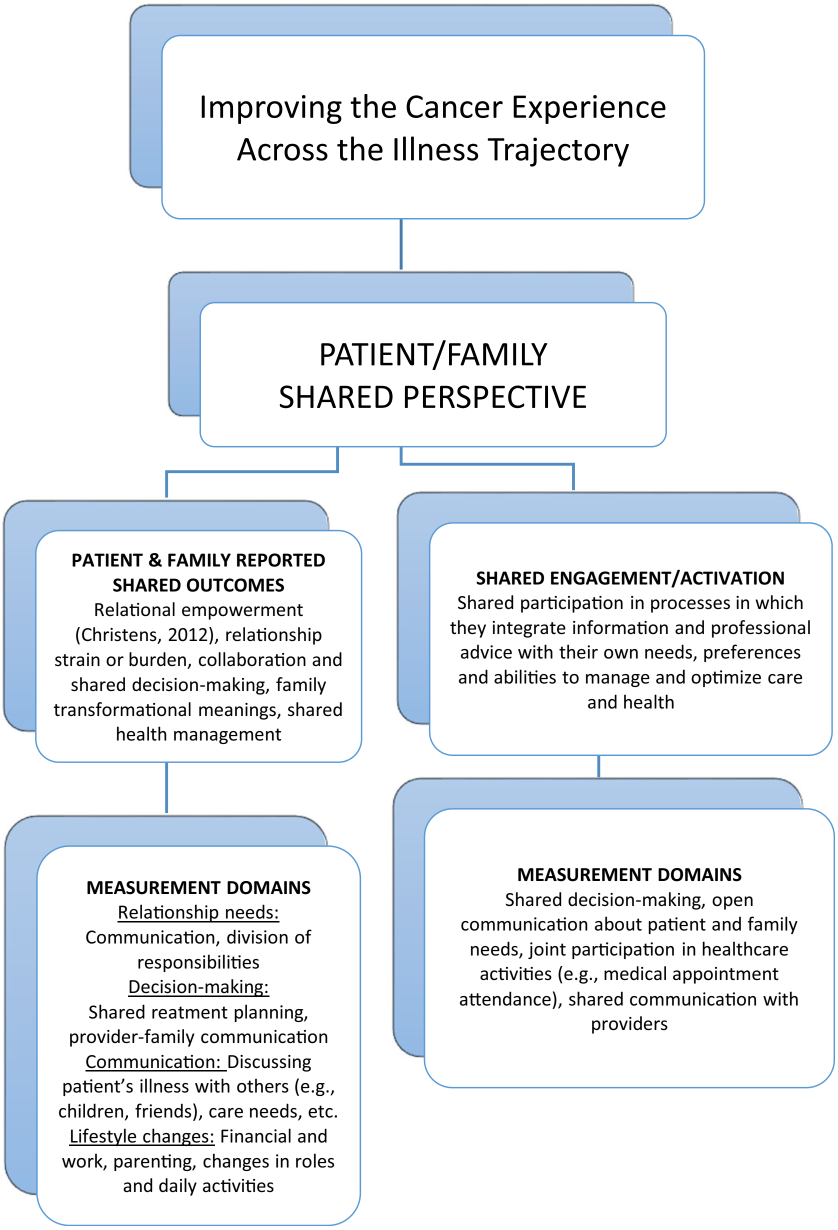

Fig. 4 Patient and family shared perspectives

researcher who has been a pioneer in the systematic documentation of patient-reported outcomes (PROs) through various means including digital health [41]. PROs, defined as what matters to the patient/family, include perceptions of the person's health condition, perceptions of/and interactions with the healthcare team and health system [42]. The Patient-Reported Outcomes Measurement System in Cancer—Core for Canada (PROMS-Cancer Core) consists of four core problem-specific domains of outcomes to capture the multidimensional impact of cancer and its treatment on patient self-reported health; physical, emotional, and social health, as well as global quality of life. The core cancer information system adapted from the National Institute of Health's Patient Reported Outcome Measurement Information System (PROMIS) was developed and endorsed through a Pan-Canadian consensus of healthcare policy and decision-makers, cancer clinicians, patients and their families and outcome methodologists [31]. Each domain is associated with sub-domains, dimensions and sub-dimensions. Recently, the feasibility and diagnostic accuracy of PROMIS was validated through computerized adaptive testing (CAT) for fatigue and sleep-disturbance [43].

The systematic assessment of PROs enables personalized, psychosocial and supportive care interventions that are tailored to the unique needs of individuals. Initially, indicators focused on common cancer-related problems

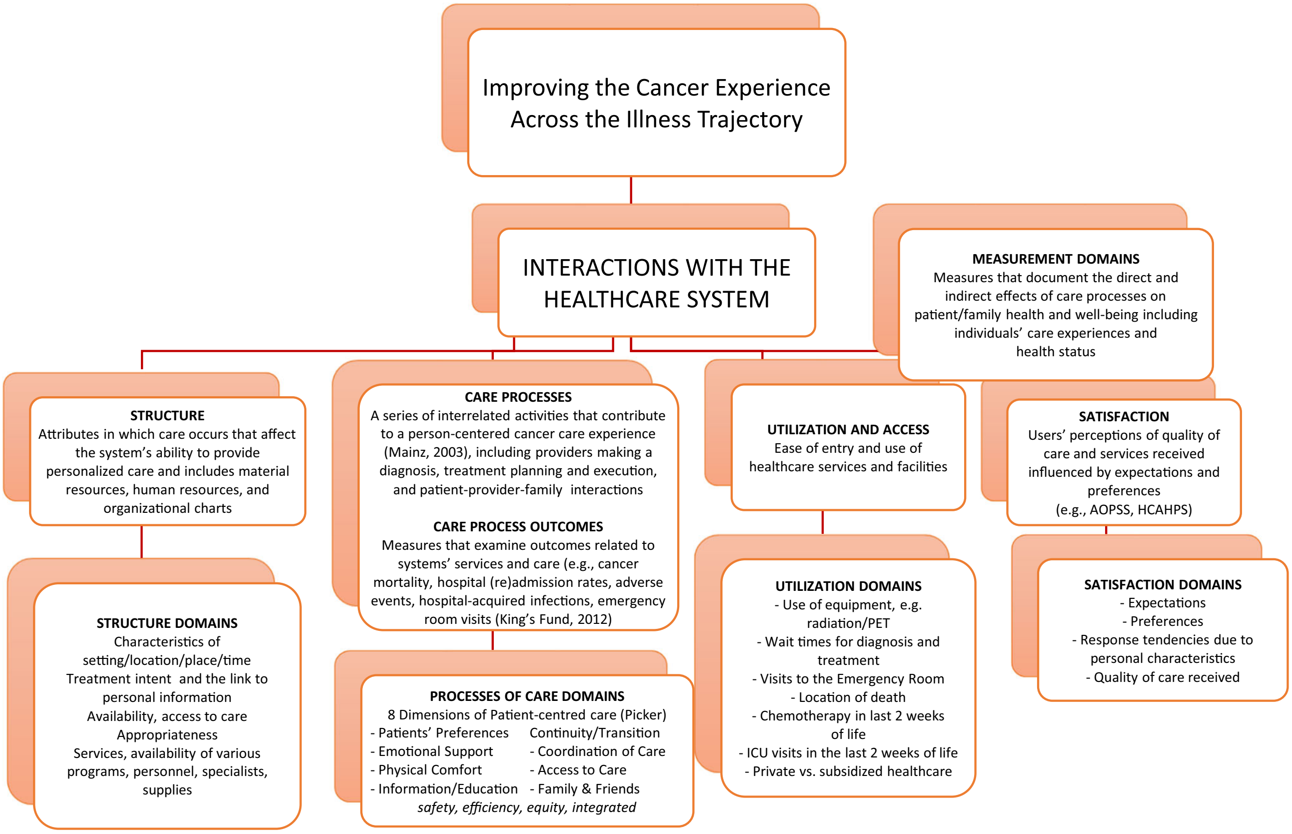

Fig. 5 Healthcare system perspectives

including pain, fatigue, anxiety, and depression, as these are highly prevalent and often impact the clinical course of disease and negatively influence psychosocial adaptation to cancer and its treatment.

Broad-based "real world" indicators also have included:

- The number of provinces with full/partial implementation of PROs
- The percentage of patients being screened for symptoms using standardized tools
- The percentage of patients who completed screening questionnaires that scored in the moderate or high distress range for pain/fatigue/anxiety/depression

The patient experience of care-related indicators thus provide insight into care processes that require change through targeted quality improvement efforts to achieve better health outcomes as measured by PROs and PREMs [44].

Challenges and next steps

The proposed framework developed by multi-stakeholders comprises clinical, research, organizational, and experiential components that are involved in shaping the patient cancer experience and health-related processes and outcomes. Such representation meant that we had to work toward gaining consensus on prioritizing common indicators and tools to be included in a comprehensive and yet manageable framework. The framework is construed as an evolving framework that can assist in capturing, assessing, organizing and translating data stemming from rapidly growing fields of patient and family engagement in care, patient as partners, and personalized medicine. Strategies to assess key concepts should involve multi-methods (e.g., quantitative/qualitative/mixed) to inform the establishment of criteria to guide decisions for short- and long-term indicators selection, while keeping in mind feasibility, accessibility, evidence to date and relevance to patients' cancer trajectories.

Obviously, cancer agencies and/or health agencies and senior executives remain accountable to funders for performance metrics through benchmarking and progress reports or "dashboards" that help monitor healthcare processes, refine standards of care, and guide the development of situation responsive programs. The evaluation of existing programs and/or the creation of new ones reinforce what is working well and catalyzes improvement where needed. *Point of care* measurement provides direct feedback from the patient's perspective as the cancer experience unfolds and the effects of that care on patient-related outcomes - laying the foundation from which change can be implemented to contribute to value-based care.

Whereas all these domains of assessment are definitely required, how to prioritize and garner uninterrupted funding to support ongoing data collection is challenging, particularly in current research and healthcare economic contexts.

In terms of next steps, it is foreseeable that the framework could readily be adapted to reflect other health/illness related experiences (e.g., various chronic illnesses) as key aspects of the experience are transferable (i.e., intra/interpersonal issues). Ultimately, the data collected using multidimensional constructs would serve to document and further tailor care, communication, and optimize physical and mental health outcomes for people facing various health threats. Generating new knowledge and implementing change would be for the benefit of patients, their support networks, healthcare providers, and the broader healthcare system. According to the CEMF's operational definitions, this framework could be also used in settings that do not explicitly adopt PCC.

Conclusion

A personalized, person-centered approach to cancer care means that key personal, interactional, and contextual factors must be explicitly addressed to systematically capture patient/family cancer experiences that matter most to them. The proposed and evolving measurement framework holds promise in reducing gaps in the evidence accumulated so far while providing much needed insights into elements that contribute to optimizing the cancer experience. In addition, the framework points to factors of a systemic nature that require careful attention to reduce cancer burden among an increasing number of affected individuals.

Further research is needed to elucidate potential links among the cancer experience, particular patient vulnerabilities and complexity, and the nature of interactions with cancer care. Future work would also capture, using mixed methods, the dynamic nature of the cancer experience as the illness trajectory unfolds according to patients' own personal journeys, exchanges with providers and family/friends, as well as their interactions with the broader healthcare system.

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Compliance with ethical standards

Conflict of interest Margaret Fitch received renumeration as a consultant from the Canadian Partnership Against Cancer in relation to this work.

Irene Nicoll received renumeration as a staff member from the Canadian Partnership Against Cancer in relation to this work.

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