Operationalizing patient-centered cancer care: A systematic review and synthesis of the qualitative literature on cancer patients' needs, values, and preferences

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Abstract

Objective: Efficiently addressing patient priorities and concerns remains a challenge in oncology. Systematic operationalization of patient-centered care (PCC) can support improved assessment and practice of PCC in this unique care setting. This review aimed to synthesize the qualitative empirical literature exploring the National Academy of Medicine (NAM)'s PCC constructs of values, needs, and preferences among patients' during their cancer treatment experiences.

Methods: A systematic review of qualitative studies published between 2002 and 2018 addressing adult patient values, needs, and preferences during cancer treatment was conducted.

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Medline, EMBASE, PsycINFO, and SCOPUS databases were searched on September 10, 2018. Methodological rigor was assessed using a modified version of the Evaluation Tool for Qualitative Studies. Included study findings were analyzed using line-by-line coding; and the emergent themes were compared to the National Academy of Medicine (NAM)'s PCC dimensions.

Results: Twenty-nine primary studies were included in the synthesis. Descriptive themes for values (autonomy, being involved, family, hope, normality, and sincerity), needs (care coordination, information, privacy, support of physical well-being, emotional support (family/ friends, peer, provider), and self-support), and preferences (care coordination, decision-making, information delivery, source of social support, and treatment) were identified. "Cancer care context" emerged as an important domain in which these constructs are operationalized. This thematic framework outlines PCC attributes that oncology care stakeholders can evaluate to improve patient experiences.

Conclusions: These findings build on previous PCC research and may contribute to the systematic assessment of patient priorities and the improvement of oncology care quality from the patient perspective.

Keywords

cancer; patient-centered care; patient-centered outcomes research; qualitative research; quality of healthcare; systematic review; value-based purchasing

1 | BACKGROUND

The National Academy of Medicine (NAM), formerly known as the Institute of Medicine, defines care quality as "the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[1(p4)] A long list of "desired health outcomes" has been developed to assess and support improvements in care quality. However, considering who defines outcomes and how stakeholders' perspectives can affect healthcare quality improvement efforts is critical. The NAM recognizes patient-centered care (PCC) as a critical component of care quality, emphasizing the importance of incorporating patient perspectives in defining quality.[2] Several PCC models or frameworks have been developed,[2–14] of these, the NAM model is probably the most widely referenced in the literature. The NAM PCC model has six dimensions: (1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support and alleviation of fear and anxiety; and (6) involvement of family and friends.[2] While sub-components of PCC have been identified both broadly[2–5,7,9–15] and for oncology,[16,17] consistent and comprehensive PCC measurement and practice is still a concern. Improved assessment and implementation of PCC is increasingly important in cancer care due to the growing size and diversity of patient populations, high costs, and the growing number of care models and treatment options.[18]

Findings from the 2016 Cancer Care Patient Access and Engagement Report suggest that there is a system-level breakdown in addressing patient concerns in the inherently complex

oncology setting.[19] The report found that high proportions of cancer patients did not receive adequate information regarding: (1) care costs (>50%); (2) the rationale for, benefits, and potential side effects of treatment (approximately 33%); and (3) the availability of clinical trials (87%).[19] Further, more than 50% of respondents were not screened for distress,[14] as required by the Commission on Cancer and American College of Surgeons.[20] Another study among breast cancer patients (n = 395) found high patient-provider discordance regarding what occurred during consultations (eg, whether the patient was comforted), and the importance of certain consultation factors (eg, being told about the potential risks or side effects of additional treatment).[21] Despite the discrepancies observed in this study, high patient satisfaction scores were reported (mean = 91/100, range:13–100) using the Patient Services Received Scale and global satisfaction. These findings suggest that data from satisfaction measures can be misleading about the content and quality of patient-provider interactions, especially among seriously ill patients.[21] Advances are needed in the way patients' priorities are assessed and incorporated into cancer care.

To advance PCC in practice, it is important that PCC measures have high content validity that accurately reflect PCC and support its implementation in clinical practice. However, there have been issues in PCC measurement that stem from multiple definitions and models that are often applied partially or inconsistently in measures.[5,10,13,14,22,23] Some of the current issues in PCC measurement in oncology include: (1) a lack of standardized PCC measures applicable to a broad range of cancers;[24,25] (2) inconsistent assessment across all aspects of care experience (eg, access, advanced care planning, and management of comorbidities); and (3) a lack of readily available data to support timely and effective adjustments to care.[7,24,26] Improved PCC operationalization in oncology can address issues with standardization across cancer sites, the cancer care continuum, and among diverse patient groups. Furthermore, standardized assessments of PCC-related information could facilitate more efficient information-sharing leading to more timely and meaningful responses to patient concerns.

1.1 | Closing the conceptual gaps in PCC in cancer care

Given the existing limitations of PCC measurement and operationalization, a review of the qualitative literature has the potential to refine existing conceptual frameworks. The NAM PCC model provides a well-referenced framework to structure a review and synthesis of the current PCC qualitative literature. The first dimension of the NAM PCC model (respect for patients' values, preferences, and expressed needs) differs from the other five dimensions because it calls for the consideration of patient-specific attributes, namely values, needs, and preferences. The other five dimensions represent specific ways that providers can respond to previously identified patient values, needs and preferences as recommended by the first dimension. For instance, the second NAM PCC dimension, coordination of care, reflects how providers can address patients' need for more streamlined or integrated services. The sixth NAM PCC dimension, involvement of family and friends, is indicative of a patient preference or need to include family and friends in healthcare experiences. We anticipated that new or more refined PCC domains relevant to cancer may be identified by exploring themes associated with cancer patient values, needs, and preferences in the literature.

Examining patient values, needs, and preferences may capture other factors important to cancer patients that may not correspond to the other five NAM dimensions, and support more streamlined PCC operationalization and organization of PCC dimensions. To date, no known review of the empirical qualitative literature on PCC-related dimensions for oncology has been conducted. This review aimed to: (1) systematically review and synthesize the qualitative empirical literature exploring expressed needs, values, and preferences among adult patients during their cancer treatment experiences, and (2) identify components of PCC particularly important in oncology to support its systematic evaluation and implementation in practice.

2 | METHODS

2.1 | Study design

This systematic review was conducted in accordance with the PRI-SMA statement[27] and thematic synthesis methodology outlined by Thomas and Harden was utilized to examine the identified PCC constructs among cancer patients.[28] A critical realist approach informed the thematic synthesis that required researchers to acknowledge that patients' descriptions of their cancer treatment in the primary studies may have been influenced by their beliefs, environment, and experiences.[29] The interpretation and reporting of these descriptions may have also been affected by the beliefs, environment, and experiences of the authors of the current and the original studies.[29,30]

This review was registered with PROSPERO (Registration no. CRD42017074718) and adheres to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines.[30] It was submitted for ethical review and declared exempt by the Committee for the Protection of Human Subjects at The University of Texas Health Science Center at Houston.

2.2 | Search strategy

Databases searched included Medline, EMBASE, PsycINFO, and SCOPUS. A health sciences librarian experienced in systematic reviews assisted with the search strategy development, search process, and documentation. The final search strategy included subject headings and keywords that reflected the following topic areas: cancer, PCC (including patient experience, preferences, views, satisfaction, expectations, and needs), and qualitative analysis (see Appendix A). EndNote 8[31] was used to manage citations.

2.3 | Eligibility criteria

Primary studies were included if they: (1) conducted original qualitative research; (2) reported descriptions of adult patients' (18 years old) needs, values, or preferences for cancer treatment; and (3) were published in English between 2002 and the search date (September 10, 2018). The 2002 start date was chosen to capture studies published after the 2001 NAM report. Studies were excluded if they: (1) focused solely on the symptom experience or on a single aspect of the treatment experience (eg, treatment-decision-making); (2) integrated findings for a mixed study population (eg, patients and caregivers) so

that we were unable to distinguish between the two populations; or (3) involved the evaluation of a pre-existing instrument, measure, or intervention.

2.4 | Study review and selection

Three research team members (KM, SR, ET) with behavioral science training independently screened the titles and abstracts of 200 randomly selected studies ($\kappa < 0.80$) to address any possible inconsistencies that might arise from a single researcher screening all the titles and abstracts. The team used Excel workbooks designed for systematic reviews and were blinded to author and journal names.[32] Discrepancies were resolved via discussion and consensus. One reviewer screened the remaining titles and abstracts using the established inclusion criteria, and two reviewers conducted full-text reviews of studies to determine final eligibility.

2.5 | Data extraction and quality appraisal

Study characteristics (eg, year, design, country, and so on), themes and results sections were extracted from each paper using a coding form (Appendix B). One researcher evaluated the studies for scientific and methodological rigor and quality using a modified form of the Evaluation Tool for Qualitative Studies (ETQS), (Appendix C).[33,34] The composite score and the percentage of ETQS criteria were calculated for each study.

2.6 | Data analysis

The three main constructs of the NAM's first PCC dimension, values, needs, and preferences, were used as a priori structural codes and guided deductive analysis of the primary studies' findings.[2,28,35] Construct definitions were based on widely accepted definitions (Table 1). Three of the authors analyzed the data from the included studies' results sections using line-by-line coding.[28] Fourteen of the studies' results sections were independently coded by two researchers to establish a consensus on the emergent themes. After a consensus was reached, one researcher coded the remaining results sections. Only themes that were supported by patient quotations in multiple primary studies were included. The final coding scheme was reviewed by the remaining authors. The identified themes for values, needs, and preferences were compared to each other and the NAM PCC model[2] to see if the NAM PCC model could be further refined for operationalization. We outlined how the themes for values, needs, preferences might influence each other in clinical practice and attempted to reconcile their intersections and simplify the PCC conceptual structure.

3 | RESULTS

3.1 | Study selection, characteristics and quality assessment

A total of 6881 unique records were identified. Twenty-nine met inclusion criteria after screening and full-text review (Figure 1). Principal reasons for exclusion were not describing patient perspectives of the cancer treatment experience and not being a qualitative study. Descriptive statistics for primary study characteristics are provided in Table 2. A full summary of the primary studies' characteristics and their ETQS scores may be found in Appendix D. The quality assessment indicated that most studies were conducted with adequate scientific rigor for qualitative analysis (mean = 31.8 (83.7%), range: 23 (61%)–38

(100%). Of the 29 studies, 22 scored 30 or more points on the modified ETQS scale. Studies with lower scores tended not to report potential researcher biases or how they were addressed.

3.2 | Synthesis of results

In this thematic synthesis, the structural code, *cancer care context*, emerged in addition to the a priori structural codes: values, needs, and preferences. Table 3 depicts a high-level overview of all the structural codes, themes, and sub-themes identified in the synthesis. Selected quotations are included in the narrative below to illustrate selected subthemes, and a full listing of example quotations for all themes and subthemes are provided in Appendix E.

3.2.1 | Values—Themes related to patient values included the following: (1) autonomy, (2) being involved, (3) family, (4) hope, (5) normality, and (6) sincerity. *Autonomy* encompassed the patients' abilities to engage in their treatments on their terms and to participate in care discussions and support or approve care decisions. *Being involved* reflected patients' appreciation for participation and inclusion in their care. There were three sub-themes for this theme: (1) being listened to, (2) being involved in decision-making, and (3) taking action. *Family* encompassed the patient's concern for family members' welfare and well-being. *Hope* involved supportive words and actions that demonstrated a positive outlook on a patient's circumstances that served as motivation for some patients to continue treatments and overcome cancer. Multiple studies noted patients' desires for *normality* as a key aspect of coping with their condition. For some, it was a central goal and they made efforts to maintain and protect normality for themselves and their loved ones. Finally, *sincerity* emerged as an important factor for patients because it helped them to confirm the trustworthiness of their providers, another critical factor in their care experience. One patient from a study conducted among hospitalized cancer patients in Italy describes this in further detail:

> Sincerity is something one realizes subsequently; for, during the moment when it is verified that the things the doctor said really are what he said they would be, one understands a posteriori the sincerity of the doctor. A priori, a stronger act of trust is needed; for this it is important to have an empathetic rapport with patients.[42(p8)]

3.2.2 | Needs—Themes that emerged related to needs included: (1) care coordination, (2) information, (3) privacy, (4) support of physical well-being, (5) emotional support (family/ friends), (6) emotional support (peer), (7) emotional support (provider), and (8) self-support. Care coordination needs included gaining access to care, navigating the healthcare system, their treatment, and communicating with those involved with their care. There were five sub-themes for care coordination, and they involved timely care access and scheduling, providing holistic care, and advising and answering patient questions. Some of the factors that impeded their access to care were costs, care location, and the availability of medications and providers.[50,53] *Information* was repeatedly mentioned by patients across the studies as being a very important aspect of their care. There were 10 information needs subthemes. The types of information that were identified as being pertinent included details about their specific diagnosis, prognosis, what to expect before, during, and after treatment,

answers to questions, and information about supportive services and resources. One patient described some of the challenges experienced trying to obtain prognosis information:

> I want to ask, like, do I need to get my affairs in order. Am I going to die? You want the doc to bring it up almost so you don't have to. But when he don't, then, it's on us to ask and I don't know how to bring it up.[50(pe293)]

In addition to the well-expressed needs for information, the need for *privacy* emerged as a theme and was characterized by a desire to be free from unauthorized or unwelcomed sharing of personal space or information to achieve wellbeing.

There was one theme related to physical wellness, support of physical well-being, and four themes related to emotional support: (a) emotional support (family/friends), (b) emotional support (peer), (c) emotional support (provider), and (d) self-support. *Support of physical well-being* represented the need for assistance in protecting and maintaining the health and function of the patient's body during treatment. The importance of care and assistance from family and friends emerged as a theme called *emotional support (family/friends). Emotional support (peer)* was also a theme as some patients emphasized the unique ability of other cancer patients to empathize with their condition and provide useful advice. *Emotional support (provider)* referred to supportive actions that assisted patients in coping with their cancer and treatments and promoted healing. There were seven sub-themes for emotional support (provider) that included but were not limited to: (1) checking on patient, (2) friendliness, and (3) relationship/repeated interactions. Finally, some patients discussed the need for self-support or the ability to self-assess and adjust to their condition and the situations they encountered as a cancer patient. Self-support had five subthemes that included but were not limited to: (a) being strong, (b) faith/spirituality, and (c) ability to trust provider. Trust emerged as a theme in several studies but in the following quotation, a breast cancer patient from a study conducted in India describes how she believes that a lack of trust and specifically, faith in providers can exacerbate suffering among some patients:

> Today most of the rural based patients tend to have immense faith in the doctors… faith is beyond belief… faith is the ultimate. They say, 'If the doctor says, I have to do this, I have to do this'…they don't even question…He's God…that faith cures people more than other stuff but yet if you see among the general populace especially the urban, without counseling, they're suffering a huge lot.[68(p395)]

3.2.3 | Preferences—Five themes related to patient preferences included: (1) care coordination, (2) decision-making, (3) information delivery, (4) source of social support, and (5) treatment. *Care coordination* centered on preferences related to the planning and organization of their care. Home visits and telephone and email communication or consultations were appreciated because they saved time and helped minimize the stress, inconvenience, and dangers of traveling while ill. Alternatively, others welcomed the opportunity to interact with others during clinic visits. *Decision-making* preferences varied among patients, with some viewing involvement in treatment decision-making as non-negotiable and others not wanting to participate at all. There were those who trusted the clinical judgment of their providers to make the best care decisions. *Information delivery* focused on preferences for how information was communicated. Many patients wanted

information from their providers; however, there were variations in preferences for the quantity, timing, and source of information. *Source of social support* referred to preferences surrounding receiving comfort, assistance, and advocacy from a specific person, place, or thing. Some patients felt that their best source of support was other cancer patients, particularly those who shared similar characteristics whether it be diagnosis, age, or family structure. For example:

> Only patients with similar experience can understand me. I have encountered difficulties… I really want to know how others deal with the difficulties.[63(p129)]

Patients had differing preferences regarding their cancer *treatment*. For example, some preferred surgery over chemotherapy, and in the case of breast cancer, some wanted a double mastectomy vs a mastectomy. Some patients wanted to try everything to fight their cancer while others preferred for as little treatment as possible, even when it came to their side-effects. Finally, some wanted breaks their treatment regimen or to cease treatment altogether, as one patient with brain metastases from non-small cell lung cancer shared during an interview study:

> If I thought I had to go through that pain again no I wouldn't wish to carry on I'd wish to call it a day. It sounds silly but I'd say that's not, that's not human, I think that's undignified way of suffering in pain. You know er….Na I would refuse treatment"[69(p597)]

3.2.4 | Cancer care context—The cancer care context domain themes reflected different transitions or characteristics of the cancer experience that patients must traverse. They included processes that most patients experience, some patients managed these processes better than others. The cancer care context had five themes: (1) psychological response to diagnosis, (2) treatment planning and selection, (3) "transition from well to ill," and (4) waiting. *Psychological response to diagnosis* captured the different mental and emotional experiences patients had during their cancer care. This theme had nine sub-themes including but not limited to: (a) being overwhelmed, (b) feeling isolated, and (c) reflection. *Treatment planning and selection* captured the process of determining what, if any, treatment to receive; it had one subtheme, acknowledging and accepting the need for treatment. This sub-theme described the process of accepting a cancer diagnosis and deciding whether to agree to begin a therapeutic regimen to treat cancer. "*Transition from well to ill*"[54] encompasses the period of adapting to having cancer and receiving treatment when the symptoms of their illness or side-effects of their treatment may become more noticeable. This theme had five sub-themes including but not limited to: (a) adjusting to illness, treatment, and reduced quality of life (QOL), (b) difficulty discerning normal from abnormal, and (c) managing multiple burdens. The last theme for the cancer care context, *waiting*, referred to time patients spent anticipating an information, an appointment, or a procedure, which often caused distress. A prostate cancer patient describes his experience waiting:

> …[a]nd ahead of the tests, I can tell you that they…[t] hey do affect me. It feels like there's some kind of…[t] here's a wall you have to get past, and it's been like that all the way from the very beginning … It grows and gets higher and higher, …the

closer I get to the test, the heavier it feels and…[t]here's a certain concern or something, but at the same time you want to get it over with and get the results. 62(p4)

3.2.5 | Relationships between identified themes for values, needs, and preferences, and current NAM PCC model

—We decided to use needs as a comparator to evaluate the relationships between the themes for values, needs, and preferences. Needs had more themes and sub-themes than the other structural codes and could be used to define the use of values and preferences in practice. Needs are conditions that can be met in the clinical context and are considered critical to patients' well-being and an individual's values influence what conditions (needs) are most important. Thus, understanding a patient's values can help providers better understand and address their needs with the needs being the major focus. Patient preferences reflect patients' perceived importance of variations in care intended to promote well-being but are not critical to well-being. Therefore, respecting a patient preference such as getting care at a specific location can partially contribute to addressing a patient need such as improved care access. By focusing on the themes for needs in our comparison of the synthesis findings and the NAM model we were able to operationalize five distinct PCC dimensions (1) coordinating and integrating care, (2) communication, (3) providing emotional support, (4) respecting the patient as a person, and (5) promoting physical health/well-being that corresponded to the needs themes from the synthesis and are very similar to the NAM PCC model with a few key differences. Please see Appendix F for operational definitions, specific actions that address patient needs, and potential measurement questions for each updated PCC dimension.

4 | DISCUSSION

We conducted a systematic review and thematic synthesis of the qualitative PCC literature and identified a set of predominant themes for values, needs, and preferences that paralleled the NAM's PCC model among a broad range of cancer diagnoses and care settings. The similarity between our findings and the NAM PCC model suggest that there may not be significant differences in PCC dimensions across disease sites, however, there may be important differences at the sub-dimension level to consider. The emergent thematic domain, cancer care context, highlighted unique aspects of the cancer care experience that may influence the relative importance of some PCC dimensions. An updated PCC model for oncology with operational definitions and corresponding actions was generated by concentrating on the identified patient needs that emerged from the synthesis. Focusing on needs and emphasizing the importance of categorizing and addressing sub-dimensional factors may help to simplify the organization of PCC models and their diverse components to support the delivery of more comprehensive and effectual PCC. Establishing a set of common patient needs and proposing that the assessment of values and preferences be used to help meet patient needs in a manner that is appreciated at the individual level may help address persistent issues in PCC measurement and evaluation.

4.1 | Relevance to existing measures of PCC

Current PCC measures often reflect the symptom experience and related impacts on QOL. There is strong evidence that supports the importance of evaluating and addressing the symptom experience in promoting cancer patient survival.[70] PCC is conceptually distinct from these aspects of the care experience and may have unique effects on care outcomes. However, evidence of PCC's association with such outcomes is lacking due to the challenges of measuring these more subjective aspects of care. Patient experience surveys such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) capture many of the themes that were identified in this synthesis.[71] However, some aspects of cancer care treatment experience that were identified as being important to patients in the present study are not assessed by the CAHPS Cancer Care Survey.[71]

The CAHPS surveys are currently used by the Centers for Medicare & Medicaid Services to evaluate care. They are well-positioned to evaluate and promote PCC in practice as healthcare payment shifts from fee-for-service to value-based models. Making small changes to existing measures such as the CAHPS has the potential to address existing gaps in PCC measurement. One simple approach to assess each of the PCC dimensions is to ask if all the patient's needs for each PCC dimension were met. For example, the assessment of *promoting physical well-being* could be enhanced by an item inquiring about providers' discussion of any physical well-being issues and whether all their support needs were met in this area. Similar questions could be asked for *communication*, *coordinating and integrating care*, and *providing emotional support*. With regards to specific PCC dimensions, survey items that assess whether cancer care team members respected patients' personal values and preferences could be added to evaluate *respecting the patient as a person*. Assessing whether patient values and preferences were incorporated into care could be used to determine whether the PCC dimension, *coordinating and integrating care* was implemented in a manner that would be appreciated at the individual level. Existing items could be modified to determine if all cancer care team members including providers and office staff were helpful, courteous, and respectful to patients to evaluate *providing emotional support*. Oftentimes patient experience surveys such as the CAHPS approximate whether patients' values, needs, and preferences have been accounted for in clinical practice. In some cases, these factors may not be captured, leaving gaps that may be filled by systematically using the needs, values, and preferences concepts.

5 | CONCLUSION

This study presents a detailed summary of cancer patients' values, needs, and preferences that helps to further operationalize PCC in the oncology setting. Several of the NAM's PCC dimensions were extended by the themes and sub-themes from the thematic synthesis to support further refinement of existing PCC measures, specifically in oncology. The themes from this synthesis could be periodically assessed to examine whether cancer patients' needs (care coordination, information, privacy, support of physical well-being, emotional support —family/friends, emotional support—peer, emotional support—provider, and self-support) are being met, and whether their preferences (care coordination, decision-making,

information delivery, source of social support, and treatment), and values (autonomy, being involved, family, hope, normality, and sincerity) are being considered during their care.

Future research should examine the conceptual structures of existing PCC measures in cancer care and compare them to the findings of qualitative research describing important aspects of patients' treatment experiences to address the identified gaps in PCC measurement and implementation. Furthermore, future studies of PCC in cancer should situate the PCC concepts that are being evaluated by these measures within an existing outcome model such as the Economic, Clinical, and Humanistic (ECHO) model,[72] to help clarify relationships between related PCC concepts and other cancer care outcomes.

5.1 | Study limitations

This study may have omitted some important aspects of PCC in cancer because it was a secondary analysis of published qualitative research and we were not able to analyze the data with the same level of nuances as a primary analysis. However, the use of broad concepts such as values, needs, and preferences, does allow for the investigation and inclusion of a broad range of factors that may contribute to PCC among diverse patient populations. The robustness and transferability of the present findings may be affected by the primary studies' use of different qualitative methodologies conducted in diverse settings. However, this diversity provided a wide range of patient views reflecting multiple countries, cancer diagnoses and treatments, ages, genders, religious beliefs, ethnicities, occupations, and educational levels, and may have contributed to our study having richer findings and greater generalizability.

5.2 | Clinical implications

The National Quality Forum asserts that quality measures should not only have strong psychometric properties but generate important and actionable data.[73] The identified patient needs often reflected gaps in system-level processes that when left unaddressed could diminish patient experiences. Values and preferences reflected possible variations in care that were more meaningful to patients and if identified and considered, could enhance their experiences. For example, values and preferences for sources of social support can be elicited during clinical encounters by providers using communication tools to inform them of how to individually address needs for emotional support (via periodic intake assessments or electronic health records). Utilizing the definitions of value, need, and preference may serve to streamline PCC assessment, and direct how collected data should be used to modify care. These findings can also advance cancer quality at the national level by informing the refinement of existing measures. Such measures could be included in the quality measures used in value-based payment models such as the American Society of Clinical Oncology's Patient Centered Oncology Payment Model to support advances in cancer care quality.[74]

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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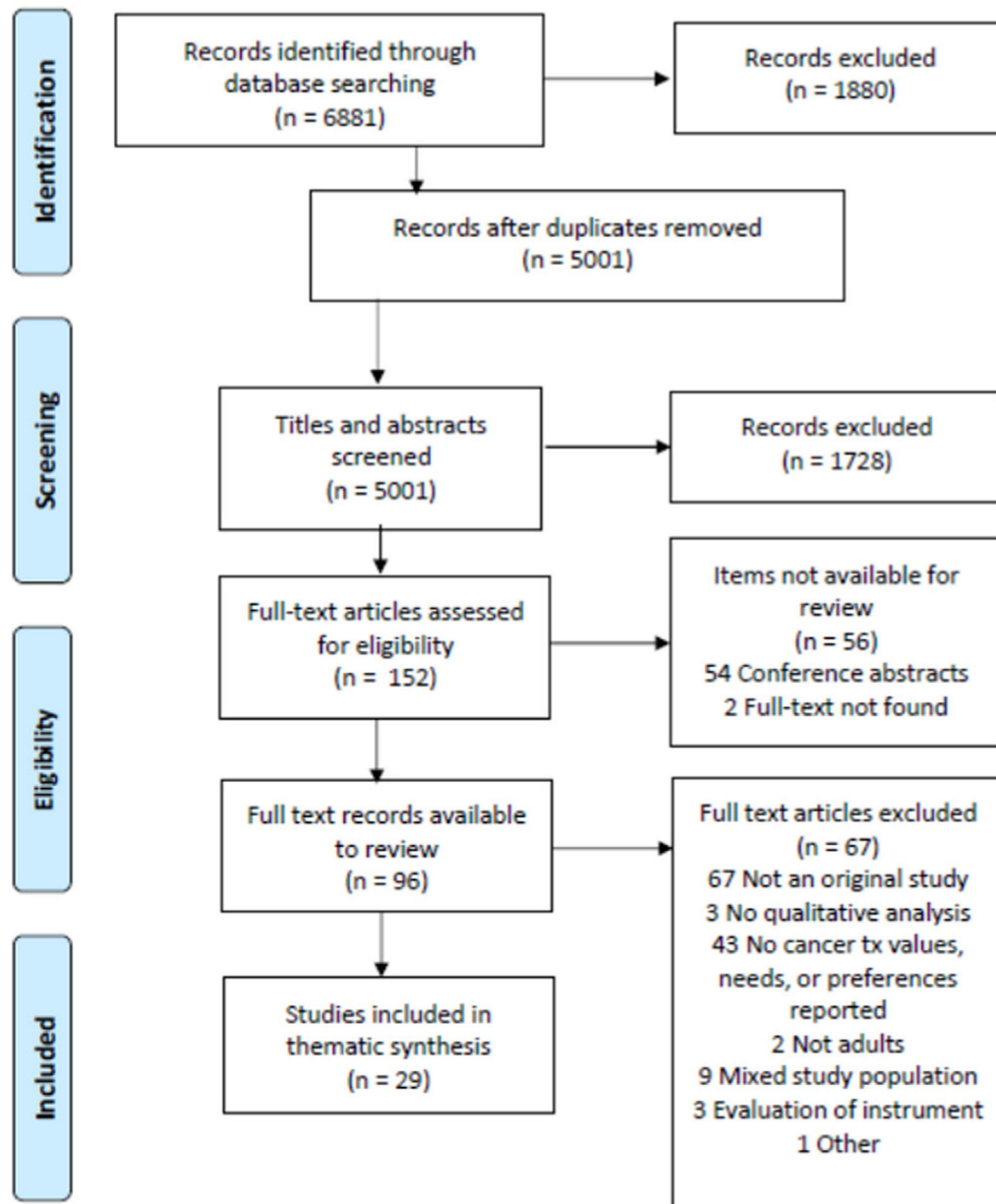
FIGURE 1.
Flowchart of study inclusion and exclusion for thematic synthesis of cancer PCC literature, 2002–2018

TABLE 1

Conceptual definitions for the three core constructs of PCC

Construct	Definition
Patient needs	Conditions considered necessary for human well-being which may be influenced by individual values and perceptions.[36] Needs may be categorized as follows: (1) normative need–determined by expert or professional (2) felt need–determined by perception of individual; may be equated to a want (3) expressed need - felt need that is communicated (4) comparative need–obtained by observation or study of individual or group to determine gaps in the provision of a service or between current and desired states.[36,37]
Patient values	Beliefs that represent an individual's interests (individualistic, collectivist, or both) and are motivated by human needs (eg, enjoyment, security, self-direction, and so on) this may be evaluated on a scale of importance (eg, from very important to unimportant) as a guiding principle in someone's life.[38]
Patient preferences	Assessments that reflect the relative importance of dimensions of health care (eg, treatment options, clinical behavior of providers, and care outcomes) and are determined by cognitive processes, values, experiences, and reflection; they may be expressed as actions or statements.[39]

TABLE 2

Descriptive statistics of the cancer sites of participants and geographic location and time period of the primary studies (n = 29), cancer PCC thematic synthesis, 2002–2018

Study characteristic	n (%)
Cancer site	
Brain	1 (3.4)
Breast	7 (24.1)
Genitourinary	6 (20.7)
Gastrointestinal	3 (10.3)
Head and neck	2 (6.9)
Skin	1 (3.4)
Multiple cancer sites	9 (31.0)
Study location	
Africa	**1 (3.4)**
Nigeria	1 (3.4)
Asia	**2 (6.9)**
India	1 (3.4)
China	1 (3.4)
Australia	**1 (3.4)**
Europe	**16 (55.2)**
Belgium	1 (3.4)
France	1 (3.4)
Ireland	1 (3.4)
Italy	1 (3.4)
Netherlands	4 (13.8)
Sweden	1 (3.4)
United Kingdom	7 (24.1)
North America	**9 (31.0)**
Canada	4 (13.8)
USA	5 (17.2)
Time period	
2002–2005	3 (10.3)
2006–2009	5 (17.2)
2010–2013	7 (24.1)
2014–2018	14 (48.3)

TABLE 3

Descriptive themes and sub-themes for patient values, needs, preferences, and cancer care context, cancer PCC thematic synthesis, 2002–2018

Structural code	Theme	Subtheme(s)
General values	Autonomy[40–42]	
	Hope[42,43]	
	Being involved[40,44–47]	Being listened to[45,47]
		Being involved in decision-making[40,44,46]
		Taking action[42,43]
	Family[40,42,43]	
	Normality[42,48–51]	
	Sincerity[41,47]	
Needs	Care coordination[40,42,43,45,49,52–57]	Timely care access and scheduling[44,49,54,55,58]
		Advising/Answering patient questions[43,45,52,55,57]
		Advocacy[45,55]
		Follow-up after treatment[53,57]
		Holistic care[45,56]
	Information[40,42,44,45,47,49–52,54–56,59–64]	Available resources and support[45,51,52,62]
		Care stages and processes[40,42]
		Individual and diagnosis-specific[40,42,47,56,59,64]
		Knowledge of what to expect[42,47,61,62,64]
		Minimizing costs[40,52,62]
		Nutrition[45,52]
		Prognosis[47,55]
		Side effects/symptoms (physical and psychological)[45,51,52,61,62]
		Treatment options and rationale[42,47,59,60,63,64]
		Updates on condition and treatment[40,56]
	Privacy[47,60]	
	Support of physical well-being[43,51,65]	
	Social support (family/friends)[40,49,59,61]	
	Social support (peer)[45,51,55,56,59]	

Structural code	Theme	Subtheme(s)
	Social support (provider)[40,41,44,45,47,49–53,55–57,59–61,63]	Checking on patient[50,57,63]
		Friendliness[40,53,60]
		Relationship/repeated interactions[53,55]
		Respect and understanding[40,44,45,51,55,63]
		Talking with the patient[41,51,53]
		Spending time with the patient[47,53,55]
		Timely communication[49,53,61]
	Self-support[41–43,47,50,51,54,55,59]	Being positive[41,43,50,54,61]
		Being strong[43,54,59]
		Faith/spirituality[41,54]
		Ability to trust provider[41,47,52,57,59]
		Talking about cancer experience[41,51]
Preferences	Care coordination[43,44,51,53,55,59,60]	Consultation location[55,59]
		Provider[51,53]
	Decision-making[40,44,46,52,59]	Family involvement[43,60]
		Involvement[40,44,46]
		Timing[52,59]
	Information delivery[45,51,54,59,60,62]	Sources of information[54,60]
		Amount of information[54,59,62]
		Disclosure to others[45,51]
	Source of social support[40,45,49,51,55,56,59,61]	Peer[45,51,56,59]
		Provider[40,51]
		Family and friends[49,55,59,61]
	Treatment[42,45,51,54,55,59]	Amount of treatment[42,45,51]
		Break from or stopping treatment[54,55,59]
Cancer Care Context	Psychological responses[41–43,47–51,53–57,59,62,66]	Being overwhelmed[41,55]
		Fear[41–43,48–50,59]
		Feeling lost[43,55]
		Feeling isolated[50,53,59]
		Reflection[41,47,49]

Structural code	Theme	Subtheme(s)
		Sadness/depression[51,54,57]
		Shock/surprise[41,43,48,50,51,55,59]
		Uncertainty[47,48,54,56,62,66]
		Worry[41,51,57,59,66]
	Treatment planning and selection[46,50,57,59,65]	Acknowledging and accepting the need for treatment[46,50,59]
	"Transition from well to ill"[41,42,46–51,55–57,59]	Adjusting to illness, treatment, and reduced QOL[41,46–51,57,59]
		Acknowledging and accepting the reality of morbidity/mortality[41,42,46,48,49,51,54,59]
		Difficulty discerning normal from abnormal[56,59]
		Managing multiple burdens[41,50,55]
		Maintaining normality[42,48,51,59]
	Waiting[40,44,50,54,67]	