

DOCUMENT SUMMARY This 2023 scoping and critical review by Thiessen et al. examines the development of 21 information needs assessment tools used in the cancer context. The study finds that most tools are for breast cancer or are tumor non-specific, with very few designed for informal caregivers. Critically, the review highlights that individuals with lived cancer experience were rarely involved in the initial item identification for these tools, and most instruments have not undergone rigorous psychometric testing, potentially limiting their ability to reflect patients' true information needs and priorities.

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METADATA Category: RESEARCH Type: review Relevance: Supporting Update Frequency: Static Tags: [#information-needs, #cancer-care, #patient-reported-outcomes, #assessment-tools, #psychometrics, #scoping-review, #patient-engagement, #supportive-care] Related Docs: Can be linked to documents on patient-centered care, clinical tool development, or communication in healthcare settings. It provides a practical application of the need to avoid the "expert" biases mentioned in Rosenhan and Tversky/Kahneman. Supersedes: N/A

FORMATTED CONTENT

Examining the development of information needs assessment tools for use in the cancer context: A scoping and critical review

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Abstract

Background. Information needs are one of the most common unmet supportive care needs of those living with cancer. Little is known about how existing tools for assessing information needs in the cancer context have been created or the role those with lived cancer experience played in their development.

Objectives. This review aimed to characterize the development and intended use of existing cancer specific information needs assessment tools.

Methods. A systematic scoping review was conducted using a peer-reviewed protocol informed by recommendations from the Joanna Briggs Institute and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-SCR) checklist.

Results. Twenty-one information needs assessment tools were included. Most tools were either breast cancer (n=8) or primary tumor nonspecific (n=8). Patients and informal carers participated in initial identification of questionnaire items in the minority of cases (n=6) and were more commonly involved in reviewing the final questionnaire before use or formal psychometric testing (n=9). Most questionnaires were not assessed for validity or reliability using rigorous quantitative **psychometric testing**.

Significance of results. Existing tools are generally not designed to provide a rigorous assessment of informational needs related to a specific cancer challenge and are limited in how they have been informed by those with **lived cancer experience**. Tools are needed that both rigorously address information needs for specific cancer challenges and that have been developed in partnership with those who have experienced cancer. Future directions should include understanding barriers and facilitators to developing such tools.

Introduction

Information sharing and the cancer journey

Information can be defined as the awareness an individual has of the patterns of reality, including the structures placed upon reality by humans. People seek information to reduce the uncertainty they have about the nature of their reality, including how to meet their goals both in the short and long term. Uncertainty is an important source of stress, as stress occurs when individuals perceive that the challenges they are facing may exceed the resources they have. The cancer journey is one where individuals face many new and unfamiliar challenges, often simultaneously. This makes information a key supportive care need because of its ability to decrease uncertainty and support the effective management of personal resources such as time, energy, and finances.

Health-care providers play an important role in the provision of information for both patients and their care partners. Health-care providers are consistently identified in survey research as one of, if not the most, important informational resources for patients with cancer and their informal caregivers. The information that comes from health-care providers is generally described as high-quality, in that it is usually found to be both credible and applicable by the health-care recipients receiving it. However, credibility and applicability alone do not necessarily guarantee the information that health-care providers share will be useful or that it will address all of an individual's information needs.

Information sharing in cancer care: A critical lens

Critical education theory explores how power and politics in educational settings impact the well-being of individuals and societies. In his work, **Paulo Freire**, who is considered a foundational figure in the early evolution of critical education theory, explored how the education system in Brazil reinforced classism and propagated poverty for Brazil's poorest citizens. Freire described that the traditional Brazilian education system viewed students as empty vessels, and it was the educators' job to deposit the knowledge into the pupils that would ultimately lead to their value in society and as human beings. This is the **banking concept of education** where educators, and the system they operate in, determine what is important for the learners to know, disregarding the challenges the learners are trying to overcome in their own lives and communities. As part of his work to teach literacy, Freire developed the problem-based education approach. This approach involved first engaging with communities to understand the issues that were important to them, and then developing a literacy curriculum that encouraged dialogue around these issues.

Freire's work raises important questions about what is known about the information needs of those living with cancer and whether what is considered to be important by health-care professionals (i.e., **normative informational needs**) reflects the actual information needs of those living with cancer (i.e., **expressed informational needs**). This is not a small issue given

the reported prevalence of unmet information needs, cited between 50% and 100% for patients and informal caregivers, in both the curative and non-curative contexts.

A gap in the literature and research objectives

Little is known about the tools that exist for assessing information needs in the cancer context, or how those with lived cancer experience participated in their development. To characterize the tools that are available for assessing the information needs of those living with cancer, this literature review was undertaken. The **scoping review** methodology was used for this review.

This review was guided by the objectives of (a) identifying existing information needs assessment tools developed for the cancer context and (b) summarizing how they were developed, including how patients and informal caregivers influenced the information needs being assessed. The specific research questions that informed data collection and analysis were as follows:

1. What questionnaires have been created for evaluating the information needs of people living with cancer? a. What is the stated purpose of each questionnaire? b. What cancer contexts (i.e., cancer type, treatment intent, and population) have these tools been developed for?
2. How were the questionnaires developed? a. How were the questionnaire items initially identified and finalized? b. How were patients, informal caregivers, and health-care professionals involved in item identification, and finalizing the questionnaires? c. How were the questionnaires validated? d. What guided assessments of validity and reliability of the questionnaires?

Methods

Before conducting this review, a protocol, including search strategy, was developed based on guidance for scoping reviews from the Joanna Briggs Institute, published in a peer-reviewed journal, and the review was registered.

To be included in this review, papers needed to report on the development or initial testing of questionnaires for assessing the information needs of adult patients with cancer and/or their care partners at any point after initial diagnosis. Only peer-reviewed articles published in English that were available in full-text were included. Articles reporting on the development or use of questionnaires in the pediatric population and in the cancer screening context were excluded.

Results

Forty-eight articles describing the development and use of 21 questionnaires were identified in the literature. The article selection process identified 19,284 records, which was narrowed to 16,458 after removing duplicates. After screening, 113 reports were sought for retrieval, and 112 were assessed for eligibility. Exclusions for not reporting on development (n=39), not being an adult cancer population (n=11), and not being information-needs-only (n=14) resulted in 48 studies being included in the final review.

Most tools were designed to assess the information needs of patients, not informal caregivers, and were developed to be applicable either specifically in the breast cancer context or were cancer type nonspecific.

Table 1. Summary of identified information needs questionnaires

Unique questionnaires identified	n=21
Countries of First Author	
Canada	7
Australia	3
United Kingdom	3
Netherlands	2
Other	6
Questionnaire Designed for	
Patients	17
Informal caregivers	2
Both	2
Cancer Types	
Breast	8
All	8
Prostate	2
Other	3
Treatment Intent	
Curative	9
Both	6
Non-curative	1
Not specified	5
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What questionnaires have been created for evaluating the information needs of those living with cancer?

Information needs questionnaires that were either not specific to a type of cancer (n=8) or were focused on the breast cancer experience (n=8) were the most common. Notably, the only 2 questionnaires intended to assess the information needs of informal caregivers identified in this review were developed in the breast cancer context. Two questionnaires were identified in this review that had been developed to assess the information needs of those living with prostate cancer. Most questionnaires were designed for use outside of the front-line care setting as either research tools (n=14) or as part of quality of improvement work (n=2). Notably, 4 instruments were developed with the intention of being able to be incorporated into clinical practice.

How have information needs assessment questionnaires been developed and validated?

The development of the information needs assessment questionnaires, before psychometric testing, typically involved 2 steps.

1. **Initial item selection:** This occurred using some combination of 6 approaches including adapting previous questionnaires, literature review, direct input from health-care professionals, direct input from patients/caregivers, formal qualitative research with patients/caregivers, and formal qualitative research with health-care professionals. Adapting previously developed questionnaires was the most common method incorporated (n=9).
2. **Drafting and feedback:** The second step generally involved developing a draft of the questionnaire and forwarding it to health-care professionals and/or patients/caregivers for additional feedback.

Importantly, the initial item selection of questionnaire items was based on either direct input from patients/informal caregivers or qualitative research involving people with lived cancer experience in 6 of the 21 identified questionnaires.

Most instruments had undergone some aspects of psychometric testing. It was identified that quantitative testing of psychometric properties such as content validity, internal consistency, and reliability, in addition to an assessment of content validity, had been performed on 12 of the questionnaires. For 2 questionnaires, no evidence of validity testing was identified. Of the questionnaires identified, only the **EORTC-INFO25** was identified to have had psychometric property testing guided by established guidelines.

Table 2. Summary of information needs measures including reason for development, intended use, cancer context, and country/context of development

Name	Rationale	Stated Use (Clinical, Research, Q.I.)	Cancer type	Curative vs. non-curative	Patients' vs. informal caregivers	Context of development
EORTC-INFO 25	Assess level of information received by patients with cancer.	Research	NS	Both	Patients	Austria, Croatia, Germany, The Netherlands,

							Norway, Spain, Sweden, and the United Kingdom
Bilodeau (NOS)	Assess patients' information priorities.	Research	NS	Both	Patients		Canada
Toronto Information Needs Questionnaire (TINQ-BC)	Measure informational needs during the first course of breast cancer treatment.	Research	Breast	Both	Patients		Canada (Ontario)
D'Alimonte (NOS)	Assess information needs regarding salvage radiotherapy.	Research	Prostate	Curative	Patients		Canada (Ontario)
Head and Neck Information Needs Questionnaire (HaNiQ)	Assess the information needs of Patients with head and neck cancer and carers.	Clinical practice	Head and neck	Both	Both		Australia
Dorri, NOS	Identify and investigate informational needs, delivery methods, and timing for receiving information about lymphedema.	Q.I.	Breast	Both	Patients		Iran

Feldman-Stewart (NOS)	Identify a core set of information needs regarding decision-making for early, potentially curable, prostate cancer.	Research	Prostate	Curative	Patients	Canada (Ontario)
Radiotherapy Information Needs Scale (RINS)	Assess radiotherapy-related information needs to guide patient education.	Research	Breast	Curative	Patients	Australia
Family Inventory of Needs Husbands (FIN-H)	Extend FIN to assess information needs of husband of patients undergoing breast cancer treatment.	Research	Breast	Both	Informal caregivers (husbands)	Canada (Manitoba)
Sri Lankans' Informational Needs Assessment Questionnaire of Breast Cancer (SINAQ-BC)	To guide the provision of relevant and accurate information in a socially culturally appropriate manner.	Research	Breast	NS	Patients	Sri Lanka
Maddock (NOS)	To assess online information needs.	Research	NS	NS	Both	Europe

Cancer Patients Information Needs Scale (CaPIN)	To explore and guide the provision of information for cancer patients.	Clinical practice	NS	NS	Patients	Germany
Papadakos (NOS) - Brain Mets	To guide the development of comprehensive informational pathways to meet the informational and supportive care needs of patients with brain metastases.	Clinical practice	Brain metastases (any primary)	Non-curative	Patients	Canada
Papadakos (NOS) - Gynecological I	As part of needs assessment for launching gynecological survivorship program.	Research	Gynecological	Both	Patients	Canada
Rees (NOS)	To assess the information needs of daughters of female breast patients with cancer.	Research	Breast	Curative	Informal caregivers (daughters)	United Kingdom (England)
Hematology Information Needs Questionnaire (HINQ-62)	To aid in the comparison of patients information needs across studies and in the assessment of	Research	Hematological malignancies	Both	Patients	The Netherlands

	particular patients information needs.					
Information Satisfaction Questionnaire (ISQ)	To inform the standardization of optimization and information within a region.	Q.I.	NS	Both	Patients	United Kingdom (England)
Quote-Chemo	To assess patients communication needs and experiences regarding chemotherapy.	Clinical practice, Research	NS	Both	Patients	The Netherlands
Breast Cancer Information Test-Revised (BCIT-R)	Test women's knowledge regarding surgical treatments options for early-stage breast cancer.	Research	Breast	Curative	Patients	United States
Zaid (NOS)	To understand the information needs of women who were diagnosed with breast cancer and the sources of information they use.	Q.I.	Breast	NS	Patients	Nigeria
Preference for Information	Assess patient information needs	Research	NS	NS	Patients	The Netherlands

Radiotherapy Scale (IPRP) regarding radiotherapy.

*NS: not stated,
Q.I.: quality
improvement*

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Table 3. Item identification, selection, and psychometric evaluation of information needs questionnaires

Questionnaire	Initial Item Identification (Literature, Previous instruments, Input HPs, Input Pt/Cr, Qual. Pt/Cr, Qual. HPs)	Final Item Selection (Feedback HPs, Feedback Pt/Cr)	Psychometric evaluation
EORTC-INFO 25	Literature, Input HPs, Input Pt/Cr	Feedback HPs, Feedback Pt/Cr	+
Bilodeau (NOS)	Literature	Feedback HPs, Feedback Pt/Cr	+
TINQ-BC	Literature, Input HPs		+
D'Alimonte (NOS)	Literature		
HaNiQ	Previous instruments		+
Dorri (NOS)	Previous instruments	Feedback HPs	C
Feldman-Stewart (NOS)	Literature	Feedback HPs	C, +
RINS			
FIN-H	Previous instruments	Feedback Pt/Cr	+
SINAQ-BC	Literature	Feedback HPs, Feedback Pt/Cr	+
Maddock (NOS)		Feedback HPs	C
CaPIN	Previous instruments		+
Papadakos Brain Mets (NOS)	Previous instruments	Feedback HPs, Feedback Pt/Cr	C
Papadakos Gyne (NOS)	Previous instruments,	Feedback HPs,	C

	Qual. with Pt/Cr	Feedback Pt/Cr	
Rees (NOS)			
HINQ-62	Previous instruments	Feedback HPs, Feedback Pt/Cr	+
ISQ	Qual. with Pt/Cr	Feedback HPs, Feedback Pt/Cr	C
Quote-Chemo	Literature, Previous instruments, Qual. with Pt/Cr		+
BCIT-R		Feedback HPs	+
Zaid (NOS)			C
IPRP	Previous instruments		+

Qual.: qualitative research; Pt/Cr: patients and/or carers; HPs: health-care professionals; +: quantitative evaluation of psychometric properties; C: content validity assessment

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Discussion

This review identified and described the development of 21 information needs assessments questionnaires. The majority were designed for research or quality improvement, applicable to all cancers or specifically breast cancer. Very few were designed for specific points in the cancer journey, and only 2 were for informal carers. These findings suggest existing questionnaires may be limited in their ability to accurately assess what is most important to those living with cancer.

First, very few questionnaires were identified that are suitable for assessing information needs regarding specific cancer challenges. Of the 21 questionnaires, only 7 focused on specific challenges. The remainder were global assessments.

Second, this review suggests that the expressed information needs of those living with cancer may not necessarily be reflected in existing questionnaires. Initial item selection commonly relied on review of the pre-existing literature, previously developed instruments, and, presumably, the expertise of the research teams. Patients and carers were only identified to be involved in this process in 6 cases. In 8 instances, patients or carers were not identified as having been involved in any aspect of questionnaire development.

The expertise of health-care providers and the value of the peer-reviewed literature should not be discounted. However, the risks associated with not including patients and informal caregivers in developing questionnaires that are intended to assess their informational needs are important as discrepancies between what those receiving health care want to know and what those providing it feel is important to share are known to exist.

Using the lens of Freire's critical education philosophy, approaches for developing tools for identifying informational needs that do not rigorously engage with patients and informal caregivers to identify the issues to be addressed risk the promotion of health-care systems that are limited in terms of how they empower the individuals they claim to serve and the person-centeredness of the care provided.

Clinical implications

Given the prevalence of unmet information needs, it makes sense that incorporation of information needs assessment as part of routine care be a priority. From a health system and front-line clinician perspective, this review is helpful because it characterizes which tools may be helpful to incorporate into clinical practice. In particular, the **EORTC-INFO25** was found to be well validated and rigorously developed, including through the involvement of patient partners at early stages of development.

However, the relative lack of sophisticated tools tailored to identify information needs related to specific challenges occurring during the cancer journey remains problematic. Until more tools are available... clinicians are encouraged to consider that, despite best efforts, many informational needs will go unrecognized and unaddressed in the front-line clinical context.

Conclusions

The information needs of those living with cancer often go unmet. Tools available for quantitatively assessing whether information needs in the cancer context are being met are limited. While several tools exist for globally assessing information needs, few tools exist for assessing information needs at specific parts of the cancer journey where targeted informational educational interventions could be developed. Additionally, only a few tools exist for assessing the unique informational needs of informal carers. More research is needed develop tools that can be confidently used to assess the information needs of those living with cancer. In order to ensure that this work is in line with the priorities and needs of those living with cancer, effective engagement with patients and informal caregivers should be a priority at all stages of measure development.