

DOCUMENT SUMMARY

This 2023 scoping and critical review by Thiessen et al. examines 21 information needs assessment tools used in the cancer context. The authors find that existing tools are generally not designed for specific cancer challenges and, critically, have had limited input from patients and caregivers during their development. Drawing on critical education theory, the paper argues that this lack of patient partnership risks creating tools that reflect professional biases rather than the actual, expressed needs of those living with cancer, calling for new, rigorously co-developed instruments.

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METADATA

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- clinical_report_dimensional_assessment_neurodiversity_affirming
 - research_report_neurotypical_baseline_critique **Supersedes:** N/A
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FORMATTED CONTENT

Examining the Development of Information Needs Assessment Tools for Use in the Cancer Context: A Scoping and Critical Review

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. **Results:** Twenty-one information needs assessment

tools were included. Most tools were either breast cancer specific (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). 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.

Introduction

Information is a key supportive care need for people with cancer because of its ability to decrease uncertainty and support the effective management of personal resources. Health-care providers are consistently identified as one of the most important informational resources, but the information they identify as important to share may be affected by their scope of practice, personal biases, or limited perceptions of the patient's needs.

Information Sharing in Cancer Care: A Critical Lens

Critical education theory, particularly the work of Paulo Freire, provides a valuable perspective. Freire described the "**banking concept of education**," where educators deposit knowledge into students viewed as empty vessels, disregarding the actual challenges the learners are trying to overcome. This raises important questions about whether the **normative informational needs** (what professionals think is important) reflect the **expressed informational needs** (what those living with cancer actually need).

This is not a small issue given the reported prevalence of unmet information needs, cited between 50% and 100% for patients and informal caregivers... These high rates of unmet need highlight an urgency for tools that accurately assess informational needs.

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. This review was undertaken to identify existing tools and summarize how they were developed, including the influence of patients and informal caregivers.

Methods

A systematic scoping review was conducted following a peer-reviewed protocol. Databases searched included MEDLINE, EMBASE, CINAHL, Scopus, Web of Science, the Cochrane Database of Systematic Reviews, and PsycInfo for articles published up to January 1, 2022. Articles 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.

Results

Forty-eight articles describing the development and use of 21 questionnaires were identified.

What Questionnaires Have Been Created?

- The most common tools were either **not specific to a type of cancer (n=8)** or were focused on the **breast cancer experience (n=8)**.
- Two questionnaires were identified for prostate cancer, and one each for gynecological, hematological, and head and neck cancer.
- Most questionnaires were designed for use as **research tools (n=14)** or for quality improvement (n=2). Only 4 were intended for direct incorporation into clinical practice.
- Only 2 questionnaires were designed specifically to assess the information needs of informal carers.

How Have Questionnaires Been Developed and Validated?

The development process typically involved two steps before psychometric testing:

1. **Initial Item Selection:** This was most commonly done by adapting previously developed questionnaires (n=9) or through a literature review (n=7).
2. **Item Finalization:** A draft was then typically forwarded to healthcare professionals and/or patients for feedback.

Critically, the initial selection of questionnaire items was based on either direct input from patients/informal caregivers or qualitative research involving them in only **6 of the 21 identified questionnaires**. In 8 instances, patients or carers were not identified as having been involved in any aspect of questionnaire development.

Regarding validation:

- 12 of the 21 questionnaires had undergone quantitative testing of psychometric properties (e.g., internal consistency, reliability).
 - For 2 questionnaires, no evidence of validity testing was identified.
 - Only one questionnaire, the **EORTC-INFO25**, was identified to have had its psychometric property testing guided by established guidelines.
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Discussion

This review identified 21 information needs assessment questionnaires. The findings suggest that existing questionnaires may be limited in their ability to accurately assess what is most important to those living with cancer for several reasons.

First, very few questionnaires are suitable for assessing information needs regarding specific cancer challenges. Most are global assessments.

Second, and most importantly, the expressed information needs of those living with cancer may not be reflected in existing questionnaires. Initial item selection commonly relied on pre-existing literature and the expertise of research teams. **Patients and carers were only involved in this**

initial, critical process in 6 cases. More commonly, they were involved at the later stage of reviewing a pre-created draft.

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.

Moving forward, teams developing such questionnaires are encouraged to actively and meaningfully engage those living with illness in the development process.

Conclusions

Tools available for quantitatively assessing information needs in the cancer context are limited. While several tools exist for globally assessing information needs, few exist for specific parts of the cancer journey, and only a few exist for informal carers. More research is needed to develop tools that can be confidently used to assess these needs. In order to ensure that this work is in line with the priorities of those living with cancer, effective engagement with patients and informal caregivers should be a priority at all stages of measure development.