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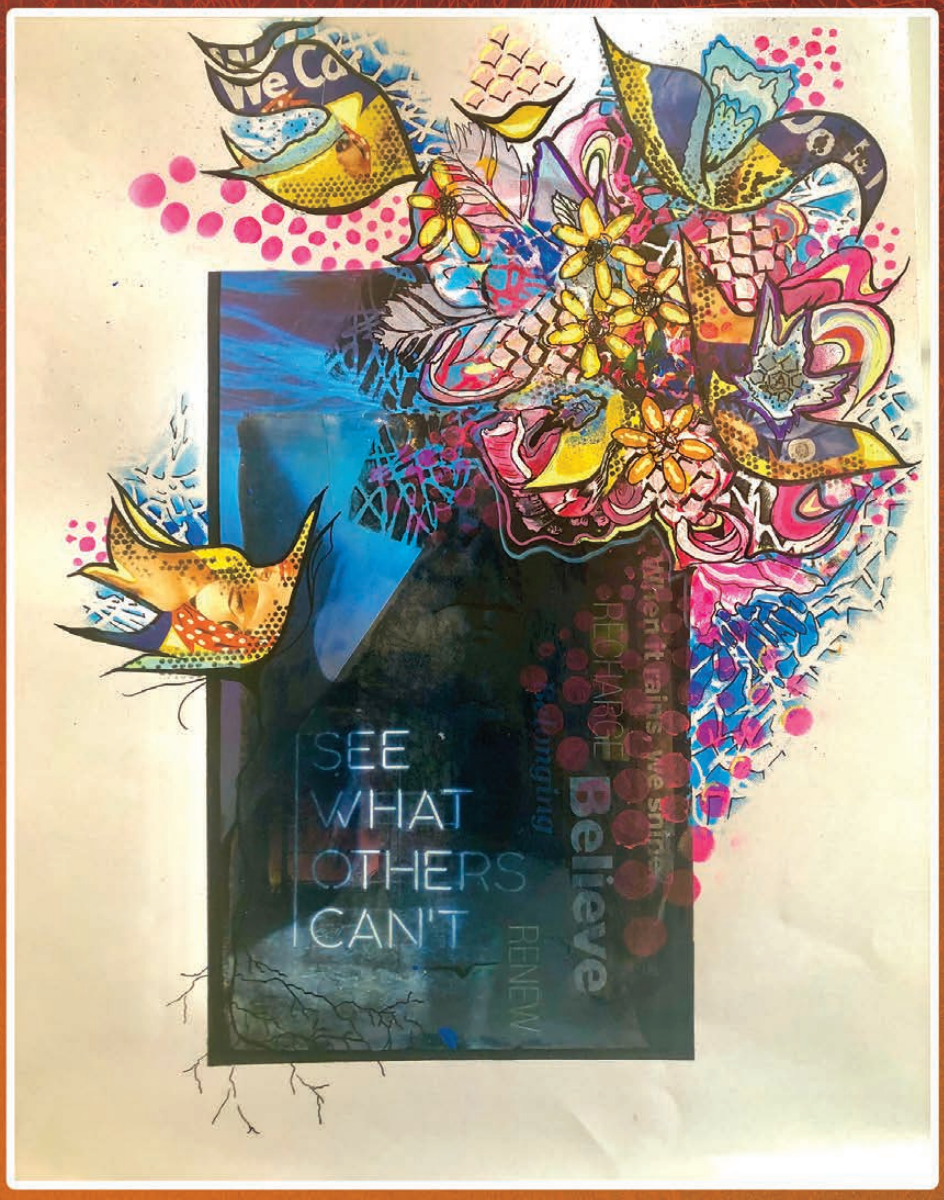

Cancer information-seeking profiles: A self-report measure of patients' distinct preferences for information about their cancer

by Carmen G. Loiselle

ABSTRACT

Objective: *Contemporary cancer care approaches, such as value- and strengths-based health care, involve integrating patients' needs and preferences, as the cancer experience unfolds. Distinct cancer information-seeking behaviours among patients are increasingly found to influence patient-provider communication, treatment-related decision-making, health processes and outcomes, as well as patient satisfaction with cancer care services. My program of research has already documented diverse cancer information-seeking profiles (CISP) among patients. These profiles can easily be captured by a theory-driven and empirically sound self-report single-item measure presented herein.*

Methods: *Guided by Self-Evaluation Theory (SET) – which posits that individuals vary in their motivation to seek information about the self – quantitative work established that SET motives could be reproduced in health-related contexts (N = 600). Qualitative inquiry subsequently explored information-seeking among individuals with various cancer diagnoses. Based on this series of studies, a CIPS measure (containing a general question which prompts individuals to choose the most representative statement based on five descriptions of distinct informational profiles) was tested in a large sample of individuals with diverse cancers.*

Results: *In this latter sample (N = 2,142), patients were administered the CISP and the Ambulatory Oncology Patient Satisfaction Survey (AOPSS). The most frequently reported CISP was complementary (50.2%, i.e., search for cancer information that added to what patients already knew), followed by minimal (25.2%, i.e., no search for cancer information), then guarded (14.4%, i.e., avoiding negative and only seeking hopeful cancer information), peer-focused (6.4%, i.e., search for cancer information from similar others), and last, intense (3.8%, i.e., seeking as much cancer information as possible). These profiles were also differentially related to care satisfaction with intense profiles being the least satisfied across all cancer care domains.*

Conclusions and Practice Implications: *The CISP measure can readily assess patients' profiles in the search for (or avoidance of) information about their cancer so that more personalized interventions can be provided. Future research exploring how CISP evolves, as the cancer experience unfolds, is also worthy of further study.*

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INTRODUCTION

Patient engagement is now recognized as a crucial component of person-centred care affecting health-related processes and outcomes. Defined as individuals' desire and capacity to actively take part in their own health and care while collaborating with healthcare professionals, patient engagement serves to optimize outcomes and enhance healthcare experiences (Higgins et al., 2017). However, we have yet to document specific personal characteristics that contribute to, or reduce patient engagement.

In cancer care, two constructs continue to garner evidence as key in health and illness management: People's preferences for involvement in treatment-related decisions (see Noteboom et al., 2021, for a review) and health information-seeking preferences (Loiselle, 1995, 2019; Lambert & Loiselle, 2007). My program of research focuses on documenting key motives that can predict distinct health-related information-seeking behaviours (Loiselle, 1995, 2019), how preferences for such information vary across individuals, health threats, and social contexts (Loiselle, 1995, Loiselle et al., 2006; Lambert et al., 2009a, 2009b; Loiselle et al., 2010; Loiselle et al., 2019) and the prevalence of distinct cancer information-seeking profiles and how these are linked to patient experiences and satisfaction (Loiselle, 2019). The purpose of this short paper is to highlight the groundwork that was completed on the topic and propose a brief theoretically-grounded tool that captures these profiles called the Cancer Information-Seeking Profiles (CISP) measure.

BACKGROUND

Theory development and research into underlying motives guiding people's search (or avoidance) of information about the self began in the early 1990s (Sedikides & Strube, 1997). Under Sedikides's doctoral supervision, I began exploring specific motives proposed by Self-Evaluation Theory (SET) and whether these motives are also operative when people gather information about their health (Loiselle, 1995). Health information-seeking is defined as a self-regulatory strategy that individuals rely on to organize transations between the self and health-related contexts with the goal of balancing instrumental benefits and subjective costs stemming from informational outcomes (Loiselle, 1995; Trope & Neter, 1994).

For my dissertation work, I conducted three experiments among healthy young adults (N = 600). Participants were presented with hypothetical scenarios portraying early phases of symptom detection and initial contact with the healthcare

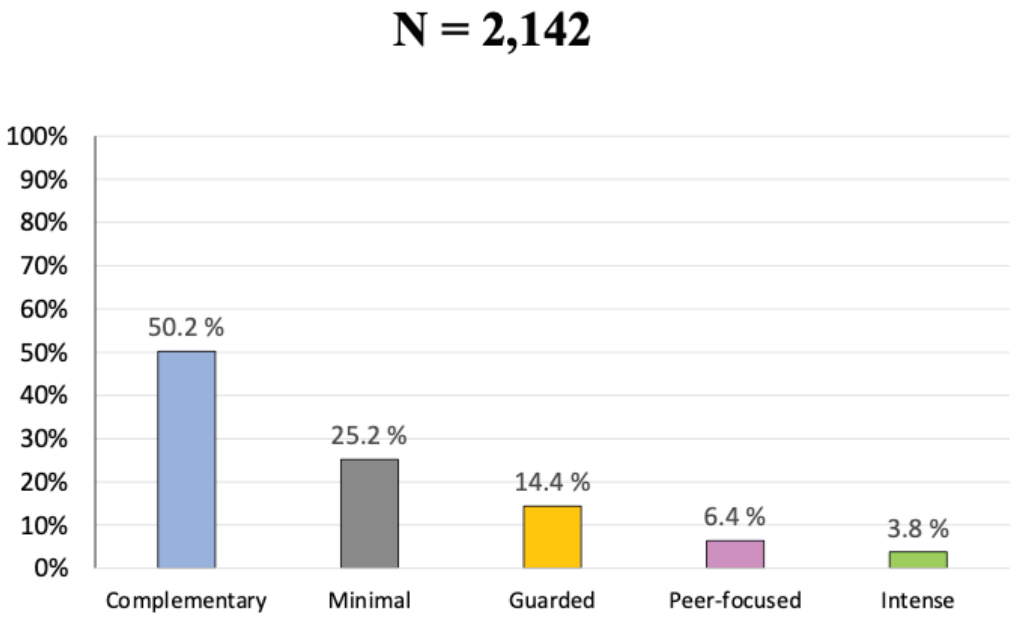
system (Loiselle, 1995). The scenarios varied in terms of diagnostic quality of screening tests, severity of health threats, and importance/satisfaction with facets of the self-concept that were threatened by illness. The overarching goal was to delineate the most powerful personal and contextual factors that would predict distinct health information-seeking behaviours, as proposed by SET. Overall, accurate self-assessment (i.e., seeking the most diagnostic health information available) emerged as the most dominant motive with partial support for self-protection (i.e., seeing health information that enhances positive and decreases negative outcomes). More specifically, self-protection motives were detected when potential health threats were more severe and when they affected a facet of the self-concept rated as highly satisfactory by participants (Loiselle, 1995).

Subsequent to this work, my research team sought to further explore SET motives among individuals affected by cancer and this, through qualitative and quantitative means among diverse samples (see Loiselle et al., 2006; Lambert et al., 2009a, 2009b, for more details). Again, distinct motives emerged that were in line with SET underpinnings. The next logical step was to study the prevalence of CISP in large samples of individuals diagnosed with various types of cancers. For instance, in a recent study (Loiselle, 2019), participants treated for cancer within the past six months and seen at one of three University-affiliated cancer centres in Montreal, QC, completed the CISP (Appendix 1) and a well-known measure of patient satisfaction, the Ambulatory Oncology Patient Satisfaction Survey (AOPSS; National Research Corporation, 2003). The sample comprised 60.5% women, 45 years old or older (94.1%; ranging from 18 to 75+) with 74.6% reporting a first cancer diagnosis. The most common diagnoses were breast (31.2%) followed by colorectal/bowel (13.4%), lung (8.9%), and lymphoma (8.6%). Findings showed that half of all respondents (50.2%) self-identified as *complementary seekers*, 3.8% as *intense*, and 6.4% as *peer-focused*. Those reporting not seeking or selectively seeking cancer information, fell into 2 categories: *minimal* (25.2%) or *guarded* (14.4%; Figure 1).

When linking profiles with sociodemographic and AOPSS data, CISP were found to be significantly associated with sex, χ^2 (4, N = 2,108) = 12.00, $p = 0.02$, with males being more likely to report being *minimal* or *guarded*. Reports of being an *Intense seeker* were significantly related to being **less** satisfied with cancer care (on all AOPSS care domains) when compared to other CISP. Although all CISP groups were dissatisfied with the support (lack of) received on possible changes in their relationship with a spouse or partner, *intense seekers* were the most dissatisfied, $\chi^{2\ as}$ (4, N = 1,328) = 34.36, $p < 0.001$. In addition, when asked if they knew whom they could talk to if they had questions or concerns, four of the CISP groups reported "yes" (98–100% of the time) whereas only 57% of *intense seekers said "yes."* As such, these are examples of how divergent CISP can predict differential cancer-related experiences and satisfaction. Next, the CISP measure is presented in more detail.

Figure 1

Patient Cancer Information-Seeking Profiles (CISP)



Source: Adapted from Loiselle, C. G. (2019). Cancer information-seeking preferences linked to distinct patient experiences and differential satisfaction with cancer care. *PEC, 102,* 1187-1193. https://doi.org/10.1016/j.pec.2019.01.009

THE CANCER INFORMATION-SEEKING PROFILES (CISP) MEASURE

The CISP (available in English and French) consists of asking participants to choose one of five statements that best characterizes their own information-seeking preferences related to their cancer (Appendix 1). Individuals are prompted by the following instructions: "*Which of the following statements best describes how you go about getting information about your cancer (choose only the statement that describes you best)*." Each of the five profiles represents a specific motive (in brackets below) as per the theorizing offered by SET.

1. Intense seeker (accurate self-assessment): "*I seek as much information as possible about my cancer*";
2. Complementary seeker (self-improvement): "*I seek information about my cancer that adds to what I was told*";
3. Peer-focused (self-verification): "*I seek cancer information from others diagnosed with the same cancer*";
4. Minimal (amotivational): "*I do not seek information about my cancer*";
5. Guarded (self-protection/self-enhancement) "*Cancer is stressful enough; I only seek information about my cancer that is hopeful*".

In line with SET and the evidence gathered to date, profiles one to three are considered proactive information seekers, whereas profiles four and five are construed as information avoiders.

A word on single-item (multiple choice) measures

Researchers have had mixed opinions on the use of single-item measures. Some have suggested that a single-item is most appropriate for constructs that are well delineated or narrow in scope (Wanous et al., 1997) with single-item measures not being inferior to multi-item ones (Allen et al., 2022). Key benefits of a single-item scale include theoretical parsimony, shorter administration time, and more appealing nature to respondents – the latter most important in busy clinics or when responders are vulnerable (e.g., have a serious illness) (Allen et al., 2022). Moreover, Allen et al. (2022) report that most published reports on single-item measures demonstrate similar validity and reliability coefficients to multi-item measures. To establish adequate psychometric properties, single-item scales must have face validity (i.e., in terms of relevance, easy to answer, lack of ambiguity, not distressing). Test-retest reliability (i.e., score stability over repeated measures ranging from one week to a few months apart) is also important and can be computed for relatively stable constructs (whereas Cronbach alpha testing requires at least two items). Prior work, briefly reviewed herein, with the CISP has documented strong face and convergent validity. An advantage of the CISP over other single-item measures is the inclusion of multiple choices based on prior solid evidence. To add to the CISP's psychometric properties, future work would determine reliability through test-retest within short intervals (e.g., two weeks), as CISP may change over longer periods.

DISCUSSION

In an era of person-centred and value-based care, healthcare professionals must move beyond approaches that consider the "average" patient's needs. Providing normative or "standard" care no longer addresses the highly diverse cancer care landscape. Cancer care increasingly plays a key role in inviting patients to be actively engaged in their care and the decisions that affect their health – and this is supported by mounting evidence that more engaged patients have better outcomes. Because significant numbers of individuals report some form of cancer information avoidance (higher than previously thought, e.g., Carlsson, 2000; Cassileth et al., 1980; Rutten et al, 2005), oncology nurses must promote patient engagement in this group through adapting their informational interventions to the information seekers' profiles, but also encouraging more proactive behaviours. Likewise, the finding that few patients report being intense seekers (3.8%) means that we cannot assume that all patients are eager to receive as much cancer information as possible. In sum, such CISP diversity calls for more user-centric, as opposed to system-centric, cancer care delivery (Canadian Partnership Against Cancer, 2018; Loiselle & Brown, 2020).

Future work would explore further the role of CISP in relation to patient-reported experience measures (PREMS) and patient-reported outcome measures (PROMS). Reliance on brief measures such as the CISP can serve to swiftly inform healthcare professionals of patients' specific preferences and care needs, so that patient experiences and outcomes continue to be optimized.

DECLARATION OF CONFLICT OF INTEREST

None.

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Appendix 1

Single-Item, Multiple Choice Cancer Information-Seeking Profiles (CISP) English and French Versions

"Which of the following statements best describes how you go about getting information about your cancer (choose only the statement that describes you best)":
i. I seek as much information as possible about my cancer. (intense)
ii. I seek information about my cancer that adds to what I was told. (complementary)
iii. I seek cancer information from others diagnosed with the same cancer. (peer-focused)
iv. I do not seek information about my cancer. (minimal)
v. Cancer is stressful enough; I only seek information about my cancer that is hopeful. (guarded)

« Lequel des énoncés suivants décrit le mieux vos démarches afin d'obtenir de l'information concernant votre cancer (cocher seulement l'énoncé qui vous décrit le mieux) » :
i. Je cherche le plus d'information possible sur mon cancer. (intense)
ii. Je cherche de l'information sur mon cancer qui ajoute à ce qui m'a été communiqué. (complémentaire)
iii. Je cherche de l'information sur le cancer qui provient des personnes diagnostiquées avec le même cancer que moi. (axé sur les pairs)
iv. Je ne cherche pas d'information sur mon cancer.(minimal)
v. Être atteint d'un cancer est suffisamment pénible; Je cherche seulement de l'information sur mon cancer qui est encourageante. (gardé)

Source: Adapted from Loiselle, C. G. (2019). Cancer information-seeking preferences linked to distinct patient experiences and differential satisfaction with cancer care. Patient Education and Counseling, 102(6), 1187–1193.