

# Information seeking and avoidance throughout the cancer patient journey: two sides of the same coin? A synthesis of qualitative studies

Evi Germeni\* and Peter J. Schulz

Institute of Communication and Health, Faculty of Communication Sciences, University of Lugano, Lugano, Switzerland

\*Correspondence to:

Institute of Communication and Health, Faculty of Communication Sciences, University of Lugano, Lugano, Switzerland. E-mail: evdokia.germenii@usi.ch

## Abstract

**Objective:** Understanding what motivates patients to seek or avoid information beyond the medical consultation is essential for effective information provision that will be relevant to patients' needs and preferences. We conducted a synthesis of published qualitative research to provide insight into patients' motivations for cancer information seeking and avoidance.

**Methods:** We searched five electronic databases: Medline, CINAHL, PsycINFO, Communication and Mass Media Complete, and Sociological Abstracts. We complemented this process by reviewing reference lists of relevant articles and searching in Google Scholar. We independently assessed the quality of selected studies and used the technique of meta-ethnography to synthesize available findings.

**Results:** Eighteen articles that reported the information-seeking experiences of 650 patients diagnosed with more than 20 different types of cancer were included. Key concepts were experience of diagnosis, sense of control, trust in medical expertise, hope and fear, and need to resume normality. The synthesis revealed the fluid boundaries existing between information seeking and avoidance throughout the cancer journey and pointed toward the exploration of factors that could influence patients' motivations to engage in information seeking. Patient characteristics, disease characteristics, characteristics of incoming information, and the context of cancer care were found to facilitate or hinder individuals' willingness and potential to assume the role of 'informed patient'.

**Conclusions:** This meta-ethnography suggests that information seeking and avoidance should not be necessarily considered as two distinct behaviors pertaining to different groups of patients; rather, a number of personal and contextual characteristics should be taken into account when evaluating patient desire for information.

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Received: 6 December 2013

Revised: 10 March 2014

Accepted: 18 April 2014

## Introduction

Over the last 30 years, shared decision-making has been increasingly advocated as an ideal model of treatment decision-making in the medical encounter [1,2]. Oncology practice, in particular, has been viewed as a unique setting for the adoption and promotion of shared decision-making, given the wide range of preference-sensitive decisions that need to be made across the cancer care continuum [3]. Nevertheless, patient involvement in decision-making has been based on the *a priori* assumption of an 'informed patient' who is both capable and willing to actively contribute to the long-standing process of making sense of the disease and reaching the best possible solutions regarding treatment and care.

Although the majority of cancer patients in developed countries want to have as much information as possible regarding their disease and actively seek such information from a wide range of medical and nonmedical sources, a considerable proportion of patients, estimated to range from 10% to 30%, prefers not to have information beyond what is offered by the physician [4–7]. Information

avoidance, long considered as an 'anomaly' in human behavior, is growingly legitimized for the same reasons that information seeking has been extensively studied: it may play a critical role in individuals' efforts to cope with stressful illness-related events, such as the shock of diagnosis, the burden of treatment decisions, and the management of side effects [8,9]. Notwithstanding the long history of information management in the communication literature, several questions regarding the motivations, outcomes, and implications associated with information seeking and avoidance in the healthcare context still remain open. For instance, should healthcare professionals recognize and respect the information needs of different groups of patients, grossly divided into those wanting additional information and those rejecting it? Does the health information-seeking behavior of individuals change across the disease trajectory? What are the motivations that drive patients to seek or avoid information regarding their disease?

The purpose of this meta-ethnography was to determine what qualitative research, published within the last two decades, can contribute to the understanding of underlying

factors influencing cancer patients' decisions to actively seek or avoid information beyond the medical consultation. Unlike narrative literature review or quantitative meta-analysis, qualitative synthesis does not rely on the mere description or aggregation of findings from individual studies but rather aims to advance knowledge by accomplishing some degree of conceptual innovation [10]. Hence, the value of synthesizing qualitative research lies in its potential to accumulate and reinterpret understandings gained from often small-scale and context-bound qualitative studies and to provide a means for making these findings accessible and usable for healthcare practice and policy [11].

## Methods

### Inclusion criteria

Given that prior to the 1990s, only a few seminal works had addressed the concept of health information-seeking behavior [12], the study was restricted to original research articles published in peer-reviewed journals between January 1, 1993 and December 31, 2012. We sought to include studies employing qualitative methods of data collection and analysis and reporting findings about cancer information seeking and/or avoidance of adult patients diagnosed with any type of cancer. We excluded studies of screening services, because we considered the moment of diagnosis as the starting point of the cancer patient journey. We also excluded studies that reported healthcare professionals' or caregivers' perspectives on the

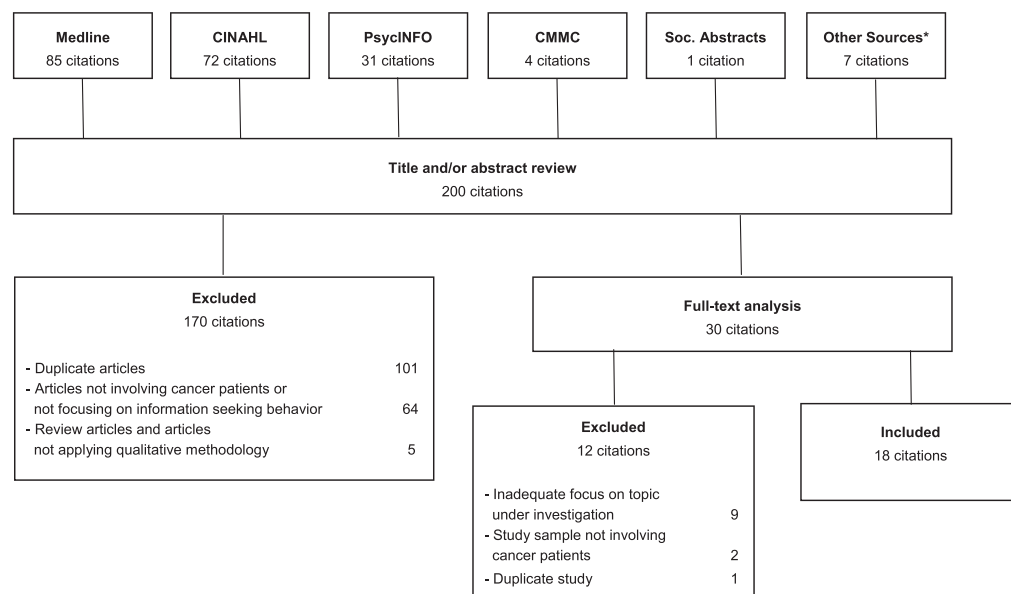
information-seeking behavior of patients. Multiple articles from a single study were included only if they presented unique data or new insights. To prevent cultural and linguistic bias in translations [13], we decided to include only articles published in English. A systematic review protocol was not developed, yet the Preferred Reporting of Items for Systematic Reviews and Meta-Analyses guidelines were used for reporting this review.

### Search strategy and study selection

We searched five electronic databases (Medline, CINAHL, PsycINFO, Communication and Mass Media Complete, and Sociological Abstracts) using the following keywords: ('information seeking' OR 'information avoidance' OR 'information management' OR 'information needs') AND (cancer OR neoplasms OR oncology) AND ('qualitative research' OR 'qualitative study' OR 'qualitative methodology'). We complemented this process by reviewing reference lists of relevant articles and searching in Google Scholar. All searches were conducted between January and February 2013, whereas update searches were undertaken in February 2014. A total of 200 citations were identified, of which 170 were excluded after title and/or abstract review and another 12 after examining the full text. An overview of the selection process is shown in Figure 1.

### Quality assessment

Using an adapted version of the Critical Appraisal Skills Programme criteria, which has been previously developed and tested [14,15], we independently assessed the quality



\* Refers to Google Scholar searching and reference list reviewing

**Figure 1.** Flowchart of study selection process

of the 18 articles considered eligible for inclusion and resolved disagreements by discussion. Given that study details were not provided in the majority of articles (especially those published in medical journals), we opted for a lenient assessment of study reporting quality, taking into account the different reporting requirements and word limits that apply to different journals. For instance, if the data analysis method was explicitly stated and adequately referenced in a paper, we considered that the study met the specific criterion, even if the authors did not provide a detailed description of the steps followed. Although the application of quality criteria to qualitative research is still widely debated [14], we undertook this process for two reasons: first, it enabled us to gain a deeper understanding of available material; second, it allowed us to identify common omissions in the reporting of qualitative studies, which could potentially contribute to improvements in the quality of future reporting. No studies were excluded on the basis of the quality assessment.

### Synthesis of findings

We conducted a synthesis of included studies, drawing on the technique of meta-ethnography developed by Noblit and Hare [16] and on modifications proposed by Pound *et al.* [17] and Campbell *et al.* [18]. We read identified articles repeatedly to familiarize ourselves with the content and details of each study, as well as to gain a good overview of all material. Using a standard Excel form, we extracted basic information on study objectives, context, sample, data collection methods, and main findings from each of the 18 articles. Using Schutz's notion of first-order and second-order constructs [19], we also retrieved patients' quotations on cancer information management (first-order constructs), usually found in the Results Section of an article, as well as authors' interpretations of participant experiences (second-order constructs), usually found in the Discussion Section of an article, and grouped them according to stage of the cancer patient journey, namely, immediate post-diagnosis, between diagnosis and treatment, and post-treatment. We proceeded to construct reciprocal translations of each study into the others, starting from the earliest one. This entailed examining, comparing, and contrasting the key themes of individual studies, a process comparable with the method of constant comparison used in primary qualitative research. Such analysis allowed exploration of third-order constructs that were not overt in individual studies and could provide a further level of interpretation.

## Results

### Study characteristics

Eighteen articles [20–37] that reported the information-seeking experiences of 650 patients diagnosed with more than 20 different types of cancer were included (Table 1).

The articles corresponded to 17 different qualitative studies conducted in the UK (5), the USA (5), Canada (3), Australia and Canada (1), Japan (1), Denmark (1), and Ireland (1). Most articles had been published in oncology-related journals (7) followed by general medicine journals (4), nursing journals (4), informatics journals (2), and health psychology journals (1). The earliest paper was published in 2000.

### Study quality

In this study, 6 out of the 13 criteria used for assessing study quality were met by all included articles. Yet, 61% of included studies did not provide any description of the researcher's role; 28% did not provide sufficient information on the study context; 22% did not clearly describe the method of data collection; 11% did not clearly describe the method of analysis; 11% did not offer adequate justification of the use of a qualitative approach; 6% did not provide a clear description of the sampling method; and, in 6% of included studies, the sampling strategy was judged not to be appropriate for the research question. Figure S1 presents an overview of the criteria used for assessing study quality and the percentage of studies meeting each criterion. A summary of individual quality assessment scores can be found in Figure S2.

### Identification of second-order constructs

Despite differences among studies in terms of geographical context and recruited samples, clear similarities were noted with regard to patients' motivations for information seeking and avoidance. Five second-order constructs were identified: experience of diagnosis, sense of control, trust in medical expertise, hope and fear, and need to resume normality (Table 2).

### Experience of diagnosis

The experience of initial diagnosis was a main theme across studies [21,25,27,31]. Even when expected, the announcement of cancer diagnosis caused a kind of shock reaction, with patients reporting 'breaking down' and 'shutting off from everything' [27,31]. Many patients associated the cancer diagnosis with a death sentence [21]. This limited their ability to take in information provided by medical staff and formulate questions that would reduce their feelings of anxiety and uncertainty [21,27,31]:

As soon as he said 'leukaemia', the first thing I thought was: 'I can't die now, I haven't time for that'. And then I didn't think or hear anymore of what was said. He might have said that some types of leukaemia were possible to cure, but I simply didn't catch it [21].

Yet, the shock of initial diagnosis also appeared to function as a trigger for subsequent information-seeking behavior [25,35].

**Table 1.** Characteristics of studies included in the synthesis

Reference	Year	Country	Participants	Data collection method
Leydon <i>et al.</i> [20]	2000	UK	17 newly diagnosed patients (four with breast cancer; four with lymphoma, two with non-Hodgkin's lymphoma, two with lung cancer; one with colon, one with bladder; one with skin, one with brain, and one with liver cancer)	Interviews
Friis <i>et al.</i> [21]	2003	Denmark	21 acute myeloid leukemia patients	Interviews
Kirk <i>et al.</i> [22]	2004	Australia and Canada	21 patients (16 home-hospice and 5 inpatients) in Perth, Western Australia, and 16 patients (14 home palliative care and 2 inpatients) in Winnipeg, Canada	Interviews
Ziebland <i>et al.</i> [23]	2004	UK	175 patients diagnosed with prostate, testicular, breast, cervical, or bowel cancer	Interviews
Dickerson <i>et al.</i> [24]	2006	USA	20 women diagnosed with breast cancer; gynecologic cancers, gastrointestinal cancer, lymphoma, and hematologic cancers	Narrative stories
Loiselle <i>et al.</i> [25]	2006	Canada	12 women diagnosed with breast cancer	Interviews
Evans <i>et al.</i> [26]	2007	UK	43 male patients diagnosed with colorectal cancer; prostate cancer; lung cancer; thymic cancer; tonsillar cancer; pancreatic cancer; bone cancer; bladder cancer; renal cancer; esophageal cancer; lymphoma, and leukemia	Interviews
McCaughan and McKenna [27]	2007	UK	27 patients (14 female and 13 male) diagnosed with lung, breast, colon, thyroid, prostate, bone, and kidney cancer	Interviews
McCaughan and McKenna [28]	2007	UK	13 men newly diagnosed with cancer	Interviews
Lambert <i>et al.</i> [29]	2009	Canada	62 individuals diagnosed with breast, prostate, or colorectal cancer	Focus groups and interviews
Lambert <i>et al.</i> [30]	2009	Canada	62 individuals diagnosed with breast, prostate, or colorectal cancer	Focus groups and interviews
Nanton <i>et al.</i> [31]	2009	UK	58 prostate cancer patients	Focus groups and interviews
Tsuchiya and Horn [32]	2009	Japan	12 women with breast cancer	Interviews
Balka <i>et al.</i> [33]	2010	Canada	35 women who had been diagnosed with breast cancer prior to age 45 years and were known to use the Internet for health information seeking	Written narratives based on predetermined sentence stems
Nagler <i>et al.</i> [34]	2010	USA	43 breast, prostate, and colorectal cancer patients	Interviews
Dickerson <i>et al.</i> [35]	2011	USA	15 male cancer patients who used the Internet (14 with a diagnosis of prostate cancer and 1 with a diagnosis of leukemia)	Narrative stories
McCaughan <i>et al.</i> [36]	2011	Ireland	38 individuals (24 men and 14 women) with a first diagnosis of colorectal cancer	Interviews
Radina <i>et al.</i> [37]	2011	USA	35 breast cancer survivors	Secondary analysis of data from two separate but compatible data sets based on face-to-face or telephone interviews

**Table 2.** Second-order constructs: key motivations for cancer information seeking and avoidance

Experience of diagnosis
Shock reaction to announcement of initial diagnosis [21,25,27,31]
Blocking effect on medical information provision [21,27,31]
Trigger for subsequent information seeking behavior [25,35]
Sense of control
Seeking information to gain control over the disease [22–27,29,33,35,37]
Seeking information to gain control over the physical and psychological impacts of treatment [22–26,29,31–33,35,37]
Seeking information to enhance power in patient–provider interactions [22–24,29,31,33–35,37]
Trust in medical expertise
Individual perceptions of what constitutes a 'good patient' [20,30,31]
Perceived ability to assimilate medical information [20,25,30,31]
Hope and fear
Hope and fear are intertwined [20,25,26,30,37]
Avoiding information as a strategy to maintain hope [20,21,25,26,30,37]
Seeking 'positive' information as a strategy to maintain hope [22,24–26,30]
Need to resume normality
Seeking information for the resumption of normal life [23,24,27,31,32,35]
Seeking normality through the experiences of other patients [23,24,27,29,31,35,36]
Need to reduce the amount of energy devoted to cancer and 'get back to normal' [28,30,36]

### Sense of control

Soon after diagnosis, the need to regain some sense of control emerged as an important motivator for information seeking [22–27,29,31–35,37]. The belief that 'knowledge is power' was common in patients' accounts and was associated with (a) control over the disease [22–27,29,33,35,37], (b) control over the treatment [22–26,29,31–33,35,37], and (c) control in patient–provider interactions [22–24,29,31,33–35,37]. Patients who actively sought information wanted to understand and conceptualize illness, reduce uncertainty caused by diagnosis, learn about available treatment options, and ensure that the best treatment would be chosen. In many cases, information gathered from secondary sources served as a tool to supplement, clarify, or even validate information provided by healthcare professionals:

I've learnt an awful lot—er, maybe too much time on my hands, maybe not, I don't know—but I needed to know. Knowledge is power, and I needed to know that what was happening to me was the right thing... [23].

Although this sometimes reflected a mistrust of medical sources, most patients felt that they knew best what was



good for them (or what they would be willing to endure) and expressed a need to be advocates for themselves.

### Trust in medical expertise

On the other hand, the belief that ‘the doctor knows best’ was prevalent among patients who avoided further information [20,25,30,31]. Trust in medical expertise was a recurring theme and was associated either with individual perceptions of what constitutes a ‘good patient’ or with ‘ignorance’ and perceived inability to assimilate medical knowledge. In particular, many patients, especially older ones, believed that seeking information from sources outside the healthcare system is opposed to the ideal model of a ‘good’ patient, whereas others recognized the complexity surrounding the cancer diagnosis and felt more contented relying on the ‘experts’:

To be honest, when they said to me it’s cancer I thought I’ll put it in their hands now because sometimes it can be a dangerous thing when you start listening and looking. We only have a certain amount of intellect, and we only have a certain amount of education. There is nothing like an ignorant man trying to learn and know every little thing about it. With regards to medicine and the like, the less you know the better [20].

### Hope and fear

The need to maintain hope—closely intertwined with fear of coming across unwanted, stressful information—interacted with information seeking in a complex way [20,25,26,30,37]. Many patients preferred to avoid information as a strategy to maintain hope [20,21,25,26,30,37]. ‘Not knowing is better’ was the main thought expressed toward cancer information, which was motivated by the tremendous anxiety provoked by diagnosis:

I don’t want to use information lines and things like that at the moment. I’m working on my principle that ignorance is bliss. I am not denying the situation I am in, but I am not speaking to people like that at the moment, I don’t feel I need to. At the moment I get what I want, but not too much detail. Further down the line it may change, depending on which way it goes, if it’s bad [20].

Others, although actively searching for cancer-related information, demonstrated a degree of selectivity and pursued only ‘positive’ or comforting information [22,24–26,30]:

I was overwhelmed by fear... What I needed was ‘anti-fear’ information—information that I could intellectually use, process, and combine, to counterbalance and reduce the fear. I needed information that would elicit hope and contribute to a positive attitude [25].

### Need to resume normality

Yet, in the post-treatment period, patients’ decisions to actively seek or avoid cancer information appeared to be driven by the same need: the need to resume ‘normality’ [23,24,27,31,32,35]. For patients seeking information, the search of normality involved finding ways to cope with symptoms experienced and understanding how to manage treatment side effects [23,24,27,29,31,35,36]. By comparison, for those not engaged in information seeking, normality was associated with trying to reduce the amount of energy devoted to cancer and go on with their lives [28,30,36]. Thus, although having access to experiential knowledge from other patients was of paramount importance for information seekers, information avoiders wanted to minimize any reverberating effects of the disease and focus on other aspects of their lives [30].

### Identification of third-order constructs

We subsequently grouped identified second-order constructs into four interrelated themes (shock of initial diagnosis, knowledge is power, ignorance is bliss, and in search of normality) and developed a ‘map’ indicating the relationships between them. This process brought out the fluid boundaries existing between information seeking and avoidance and pointed toward the exploration of factors that could play a role in individuals’ motivations to engage in cancer information seeking. Four third-order constructs were identified: patient characteristics, disease characteristics, characteristics of incoming information, and context of cancer care (Table 3).

#### Patient characteristics

Patient characteristics were most frequently discussed in the studies considered and included the following: (a) demographic characteristics (older patients and men did not usually access additional information sources) [20,21,28,30,31], (b) medical history and concurrent life events (patients with complex medical histories or concur-

**Table 3.** Third-order constructs: personal and contextual characteristics influencing patients’ motivations to seek or avoid cancer information

Patient characteristics
Demographic characteristics [20,21,28,30,31]
Medical history and concurrent life events [30,31]
Coping strategies [21,29,32,37]
Previous experience in seeking information [29,37]
Disease characteristics
Severity of illness [21,22]
Time since diagnosis [23,26]
Characteristics of information
Type of incoming information [25,27,29,30,33]
Amount of incoming information [27,29,33]
Context of cancer care
Delegation of treatment decision making to the patient [29,31,35]

rent life events typically relied on the healthcare team for information) [30,31], (c) coping strategies (patients' preferences for information derived from the coping strategies they adopted to manage their cancer) [21,29,32,37], and (d) previous experience in seeking information (individuals who described themselves as attentive consumers of information prior to the disease sought cancer-related information after their diagnosis) [29,37].

**Disease characteristics**

Disease characteristics focused on the severity of illness and the time elapsed from the moment of diagnosis [21–23,26]. Although, on the basis of included studies, we were not able to differentiate between types or stages of cancer, it was evident that physically very ill patients tended to rely mostly on information provided by the medical staff. Furthermore, there was evidence that patients' preferences for information changed over time:

It's been helpful knowing where to look and being able to sort of follow the evidence and so on, but now I've reached the stage where I'm not looking any more. It kind of comes and goes; to begin with I wanted a whole lot of information, now I feel perhaps I don't want to know too much and I just want to try and keep going and not think too closely about what might happen [23].

**Characteristics of incoming information**

The type and amount of incoming information also appeared to play an important role in patients' motivations to engage in information seeking [25,27,29,30,33]. Cancer information judged by individuals to be too distressing, too difficult, or too confusing to make sense of, resulted in 'blocking' their efforts to obtain further information. Similarly, information that was considered as overwhelming or inadequate, especially in the post-diagnosis period, contributed to limiting their desire of information seeking:

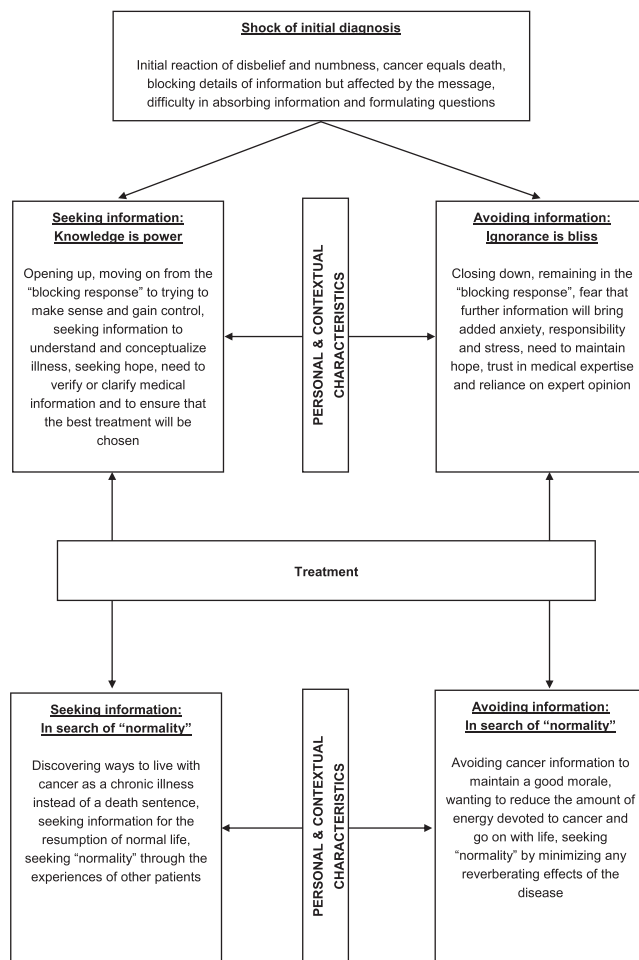
I was overwhelmed by the information. I was frightened and stopped searching [33].

**Context of cancer care**

In addition, the context of cancer care was a major factor influencing patients' decisions to actively seek or avoid further information [29,31,35]. Specifically, delegation of treatment decision-making to the patient appeared to 'force' individuals to undertake the role of information seeker, even though in many cases they felt that they were not prepared for this or did not have the skills and abilities required for the role:

I felt like I was having to make a really important decision which I didn't know a lot about and in a way I was feeling that they weren't like... how can I put it? I felt like all the onus was on me to do everything [31].

Figure 2 displays the close inter-relationships among identified second-order and third-order constructs while providing an overarching theoretical framework that illustrates key motivations and factors influencing information seeking and avoidance throughout the cancer patient journey. The framework is based on findings from all studies and attempts to advance knowledge by presenting how patients may deliberately move across different information roles to meet their changing emotional and cognitive needs. Taking as a starting point the shock of initial diagnosis, individuals may either gradually open up to cancer information, in an effort to make sense of the disease and gain control, or remain in the initial 'blocking response' and try to maintain hope by delegating decision-making to the oncologist and intentionally avoiding any additional information. The period after treatment, whereas for some, bringing new information



**Figure 2.** Model of information seeking and avoidance throughout the cancer patient journey

needs to light, for others is associated with the end of an extremely intense (physically and psychologically) period and a need to 'get back to normal'. Although the search of normality seems to motivate both information seeking and avoidance during this period, normality is construed differently by different patients. Yet, information seeking is not a linear process but rather an iterative one, with patients moving back and forth or switching information roles to better address their needs. A number of personal and contextual characteristics may facilitate or hinder individuals' willingness and potential to undertake a certain role.

## Discussion

Against a background of debate on what constitutes good evidence to support clinical decision-making [38–41], we have sought to demonstrate that meta-ethnography can successfully accumulate understandings gained from diverse qualitative studies and can provide clinically relevant information about patient needs, by drawing attention to subjugated, experiential knowledge [42]. We have identified five key motivations for cancer information seeking and avoidance, notably the shock of initial diagnosis, the need to regain control, the trust in medical expertise, the need to maintain hope, and the need to resume normality, as well as a variety of intrinsic and extrinsic factors that influence individual's willingness and potential to assume the role of informed patient. In an effort to address the reality of clinical practice, we have also developed a conceptual model to help practitioners understand the reasons that patients may deliberately move across different information roles throughout their cancer journey.

Our synthesis of published qualitative research offered several new insights. First, by constructing reciprocal translations of each study into the others, we identified motivations for cancer information seeking and avoidance that were common across patients diagnosed with different types of cancer and treated in different healthcare contexts. Similarly, Smith *et al.* [43], in their meta-ethnography of patients' help-seeking experiences and delay in cancer presentation, found strong similarities in patients with different cancer types. It could therefore be assumed that although available quantitative findings point toward significant differences in the health information-seeking patterns of patients diagnosed with different types and stages of cancer [5,44,45], these differences may apply only to measurable outcomes of the patient information-seeking behavior (e.g., breadth and depth of search, time spent in searching, and type of information sought) and not to the underlying motivations that lie at the core of the human experience.

Second, by grouping identified first-order and second-order constructs according to stage of the cancer patient journey, we were able to elicit a patterning of information seeking across the disease trajectory that was not evident in individual studies. Yet, given the paucity of published

qualitative evidence on survivorship and end of life, this patterning was restricted to a broad categorization of stages, namely, immediate post-diagnosis, between diagnosis and treatment, and post-treatment. Indeed, results from an earlier systematic review also showed that published cancer research has focused almost exclusively on investigating patients' information needs during the diagnosis and treatment phase, neglecting other stages of the cancer care continuum [46]. Hence, the patterning of information seeking that emerged from our analysis could be especially useful, considering both the growing evidence suggesting that patients' information-seeking behaviors change over the course of the disease and the noticeable scarcity of longitudinal evaluations [6,46–48].

Finally, our analysis allowed exploration of third-order constructs, as well as the development of a conceptual model encompassing all data, while being—as Noblit and Hare initially suggested [16]—'open-ended' enough to allow consideration of new data and new comparisons. This 'integrating scheme', bringing out the fluid boundaries existing between information seeking and avoidance, could inform future research directions in cancer information management and could serve as a valuable tool for healthcare practitioners. Results of this meta-ethnography suggest that cancer information seeking and avoidance should not be necessarily considered as two distinct behaviors pertaining to different groups of patients; rather, a number of personal and contextual characteristics should be taken into account when evaluating patient desire for information. Considering that effective use of cancer information is a prerequisite for successfully implementing shared decision-making in oncology practice, doctors need to accurately assess patients' changing preferences for information and help them navigate the medical information labyrinth.

## Study limitations

We used a systematic and rigorous approach to locate all potentially relevant articles. We conducted electronic searches of five databases covering a wide range of disciplinary areas, we reviewed reference lists of retrieved articles, and we searched Google Scholar for studies we might have missed. Given, however, the well-known challenges in the identification of qualitative studies [43,49,50], we cannot exclude the possibility that some were missed. Yet, because the purpose of meta-ethnography is interpretative explanation and not prediction (as is the case in statistical meta-analysis), we have managed to locate and include a purposive sample of studies that allowed for conceptual saturation.

Furthermore, although almost half of the criteria used for assessing methodological quality were met by all included articles, more than half of the studies (61%) failed to provide a clear description of the researcher's role in the qualitative process. This finding is in accordance with other meta-ethnographies applying the Critical Appraisal

Skills Programme criteria to assess study quality [14,15], and while it has not been previously highlighted, we believe that it requires special consideration. Qualitative studies are prone to a degree of subjectivity, as the researcher acts as the data gathering instrument and interpretation of collected data are influenced by the researcher's values, beliefs, interests, and experiences. Reflexivity, that is, awareness and transparent reporting of the reciprocal influence of participants and researcher on the process and outcome, could ensure rigor in qualitative research.

## Conclusions

Understanding what motivates patients to seek or avoid information beyond the medical consultation is essential for effective information provision that will be relevant to the patients' needs and preferences. The results of this study suggest that information avoidance is not necessarily a 'trait' of a specific patient group, as it has been mostly viewed up to now, but may also constitute a behavioral response, on the one hand, to patients' changing emotional needs and ways of coping with the disease and, on the other hand, to external events, such as the type and amount of incoming information and the context of cancer care. Both quantitative and qualitative longitudinal

studies are needed to confirm our findings and to further evaluate whether patients avoiding information, especially at the initial stages of their disease, are in a position to fully comprehend the risks and benefits of available treatment options and provide valid informed consent.

## Acknowledgement

No funding was received for this work.

## Ethics approval

An ethics statement was not required for this work.

## Author contributions

E. G. conceived the study and wrote the initial draft. P. J. S edited the manuscript. Both authors undertook publication searches, identified and assessed the papers to be included in the study, and synthesized the data.

## Conflict of interest

The authors have declared no conflicts of interest.

## References

- Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997;**44**:681–692.
- Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. *Am J Prev Med* 1999; **17**:285–294.
- Politi MC, Studts JL, Hayslip JW. Shared decision making in oncology practice: what do oncologists need to know? *Oncologist* 2012; **17**:91–100.
- Jefford M, Tattersall MH. Informing and involving cancer patients in their own care. *Lancet Oncol* 2002;**3**:629–637.
- Nagler RH, Gray SW, Romantan A *et al*. Differences in information seeking among breast, prostate, and colorectal cancer patients: results from a population-based survey. *Patient Educ Couns* 2010;**81**(Suppl):S54–S62.
- Eheman CR, Berkowitz Z, Lee J *et al*. Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources. *J Health Commun* 2009;**14**:487–502.
- Ramanadhan S, Viswanath K. Health and the information nonseeker: a profile. *Health Commun* 2006;**20**:131–139.
- Case DO, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *J Med Libr Assoc* 2005;**93**:353–362.
- Brashers D, Goldsmith, DJ, Hsieh, E. Information seeking and avoiding in health contexts. *Hum Commun Res* 2002;**28**:258–271.
- Britten N, Campbell R, Pope C, Donovan J, Morgan M, Pill R. Using meta ethnography to synthesise qualitative research: a worked example. *J Health Serv Res Policy* 2002;**7**:209–215.
- Sandelowski M, Docherty S, Emden C. Focus on qualitative methods. Qualitative metasynthesis: issues and techniques. *Res Nurs Health* 1997;**20**:365–371.
- Lambert SD, Loiselle CG. Health information seeking behavior. *Qual Health Res* 2007;**17**:1006–1019.
- Tong A, Lowe A, Sainsbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systematic review of qualitative studies. *Pediatrics* 2008;**121**:349–360.
- Atkins S, Lewin S, Smith H, Engel M, Fretheim A, Volmink J. Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC Med Res Methodol* 2008;**8**:21.
- Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, Volmink J. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. *PLoS Med* 2007;**4**:e238.
- Noblit G, Hare, RD. *Meta-Ethnography: Synthesizing Qualitative Studies*. Sage Publications: London, 1988.
- Pound P, Britten N, Morgan M *et al*. Resisting medicines: a synthesis of qualitative studies of medicine taking. *Soc Sci Med* 2005;**61**:133–155.
- Campbell R, Pound P, Pope C *et al*. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. *Soc Sci Med* 2003;**56**:671–684.
- Schutz A. *Collected Papers*, Vol. 1. The Hague: Nijhoff, 1962.
- Leydon GM, Boulton M, Moynihan C *et al*. Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ* 2000;**320**:909–913.
- Friis LS, Elverdam B, Schmidt KG. The patient's perspective: a qualitative study of acute myeloid leukaemia patients' need for information and their information-seeking behaviour. *Support Care Cancer* 2003;**11**:162–170.
- Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ* 2004; **328**:1343.
- Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L. How the internet affects patients' experience of cancer: a qualitative study. *BMJ* 2004; **328**:564.
- Dickerson SS, Boehmke M, Ogle C, Brown JK. Seeking and managing hope: patients' experiences using the Internet for cancer care. *Oncol Nurs Forum* 2006; **33**:E8–E17.



25. Loiselle CG, Lambert SD, Cooke A. The searching, processing, and sharing of breast cancer information by women diagnosed with the illness. *Can J Nurs Res* 2006;**38**:82–104.
26. Evans M, Shaw A, Thompson EA *et al*. Decisions to use complementary and alternative medicine (CAM) by male cancer patients: information-seeking roles and types of evidence used. *BMC Complement Altern Med* 2007;**7**:25.
27. McCaughan E, McKenna H. Never-ending making sense: towards a substantive theory of the information-seeking behaviour of newly diagnosed cancer patients. *J Clin Nurs* 2007;**16**:2096–2104.
28. McCaughan E, McKenna H. Information-seeking behaviour of men newly diagnosed with cancer: a qualitative study. *J Clin Nurs* 2007;**16**:2105–2113.
29. Lambert SD, Loiselle CG, Macdonald ME. An in-depth exploration of information-seeking behavior among individuals with cancer: part 1: understanding differential patterns of active information seeking. *Cancer Nurs* 2009;**32**:11–23; quiz 4–5.
30. Lambert SD, Loiselle CG, Macdonald ME. An in-depth exploration of information-seeking behavior among individuals with cancer: part 2: understanding patterns of information disinterest and avoidance. *Cancer Nurs* 2009;**32**:26–36.
31. Nanton V, Docherty A, Meystre C, Dale J. Finding a pathway: information and uncertainty along the prostate cancer patient journey. *Br J Health Psychol* 2009;**14**:437–458.
32. Tsuchiya M, Horn SA. An exploration of unmet information needs among breast cancer patients in Japan: a qualitative study. *Eur J Cancer Care (Engl)* 2009;**18**:149–155.
33. Balka E KG, Holmes BJ, Stephen JE. Situating Internet use: information-seeking among young women with breast cancer. *J Comput-Mediat Comm* 2010;**15**:389–411.
34. Nagler RH, Romantan A, Kelly BJ *et al*. How do cancer patients navigate the public information environment? Understanding patterns and motivations for movement among information sources. *J Cancer Educ* 2010;**25**:360–370.
35. Dickerson SS, Reinhart A, Boehmke M, Akhu-Zaheya L. Cancer as a problem to be solved: Internet use and provider communication by men with cancer. *Comput Inform Nurs* 2011;**29**:388–395.
36. McCaughan E, Parahoo K, Prue G. Comparing cancer experiences among people with colorectal cancer: a qualitative study. *J Adv Nurs* 2011;**67**:1365–2648.
37. Radina ME, Ginter AC, Brandt J, Swaney J, Longo DR. Breast cancer patients' use of health information in decision making and coping. *Cancer Nurs* 2011;**34**:E1–E12.
38. Green J, Britten N. Qualitative research and evidence based medicine. *BMJ* 1998;**316**:1230–1232.
39. Wiart L, Burwash S. Qualitative research is evidence, too. *Aust J Physiother* 2007;**53**:215–216.
40. Audrey S. Qualitative research in evidence-based medicine: improving decision-making and participation in randomized controlled trials of cancer treatments. *Palliat Med* 2011;**25**:758–765.
41. Grace J. Qualitative research: using 'soft' evidence to solve hard clinical problems. *AACN Adv Crit Care* 2011;**22**:89–92.
42. Adams E, McCann L, Armes J *et al*. The experiences, needs and concerns of younger women with breast cancer: a meta-ethnography. *Psycho-Oncology* 2011;**20**:851–861.
43. Smith LK, Pope C, Botha JL. Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *Lancet* 2005;**366**:825–831.
44. Ofra Y, Paltiel O, Pelleg D, Rowe JM, Yom-Tov E. Patterns of information-seeking for cancer on the internet: an analysis of real world data. *PLoS One* 2012;**7**:e45921.
45. Smith-McLallen A, Fishbein M, Hornik RC. Psychosocial determinants of cancer-related information seeking among cancer patients. *J Health Commun* 2011;**16**:212–225.
46. Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient Educ Couns* 2005;**57**:250–261.
47. Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol* 1997;**8**:857–863.
48. Mistry A, Wilson S, Priestman T, Damery S, Haque M. How do the information needs of cancer patients differ at different stages of the cancer journey? A cross-sectional survey. *JRSM Short Rep* 2010; **1**:30.
49. Shaw RL, Booth A, Sutton AJ *et al*. Finding qualitative research: an evaluation of search strategies. *BMC Med Res Methodol* 2004;**4**:5.
50. Bunn F, Goodman C, Sworn K *et al*. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. *PLoS Med* 2012;**9**:e1001331.

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