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Avoiding Information during Serious Illness: Insights into the Information Behavior of Cancer Patients

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ABSTRACT
Cancer patients seek information about their health and illness using many different approaches. Some prefer to seek intensively whereas other avoid seeking information. Over the course of the cancer continuum an individual may meet their needs using several different approaches. In this paper, we explore how avoidance can be an approach used as part of information seeking activities and not just as an alternative approach. Interviews with six current and former cancer patients were conducted and audio recorded for transcription. The transcriptions were coded to identify themes and concepts. We identify the different patterns of information seeking among the interviewees ranging from seeking intensively to avoiding information. Furthermore, we find that exposing yourself selectively to information as well as avoiding some information can be strategies to protect the information seeker from information the individual is not able to cope with. This study indicates that information seeking approaches are overlapping.

KEYWORDS
Information seeking; information avoidance; cancer patients; interviews; selective exposure and avoidance.

INTRODUCTION
Cancer is a globally occurring, life-threatening disease, and bearing the prevalence of cancer in mind it is important to consider how and why cancer patients seek information about their illness. Focusing on the information behavior of cancer patients, studies have shown that the information needs of cancer patients are diverse (Abi Nader et al., 2016, Abu Sharour et al., 2020, Ancel, 2012, Arroyo and Tillinghast, 2009, Germeni and Schulz, 2014). Cancer patients seek information about their health and illness and increasingly, the Internet is an essential informational source (Ebel et al., 2017). However, it can be difficult for the patients to navigate the vast amount of information (Perrault et al., 2020, Chua et al., 2020).

Through significant life changes information seeking have lifelong impacts (Huttunen and Kortelainen, 2021). During critical illness both lifestyle and health behaviors can be affected by the patient’s information seeking (Zhang, 2012). Information seeking affects health outcomes (Katavic et al., 2016, Kostagiolas et al., 2020) and can influence illness fatalism (Paige et al., 2020). In addition, seeking information can help the patient gain an increased sense of control (Faller et al., 2016, Persakis and Kostagiolas, 2020). Miller (2014), however, argues that information plays a salient role in the management of uncertainty and can both facilitate as well as complicate the individuals’ management of cancer-related uncertainty. The information needs of cancer patients include coping and information seeking is considered a key coping strategy in health-promotive activities and psychosocial adjustment to illness (Lambert & Loiselle, 2007).

There are variations in the approaches used by patients to seek information. Costello and Veinot (2020) identify five spectrums of approaches to health information: avoiders, who close themselves off from health information; receivers, who encounter information in the dialysis clinic but do not seek it out; askers, who only pose questions about health to their healthcare providers but otherwise do not seek; seekers, who actively look for health information both in and out of the clinic; and verifiers, who seek information and triangulate it among multiple sources. Lambert et al. (2009a,b) identify five patterns for cancer patients:

- intense information seeking looking for as much information as possible
- complementary information seeking adding to what they already know
- fortuitous information seeking consulting other patients for health information
- minimal information seeking where the individual does not look for information on their own
- guarded information seeking where the individual avoids some cancer information.

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The five patterns represent different approaches to addressing the needs of the individual (Sheridan et al., 2020, Germeni and Schulz, 2014). As we can see from the five patterns, some patients avoid information even though avoiding e.g. cancer-related information may have severe health impacts (Chae, 2016). Sweeny et al. (2010, p. 341) define information avoidance:

*We define information avoidance as any behavior intended to prevent or delay the acquisition of available but potentially unwanted information. Information avoidance can entail asking someone not to reveal information, physically leaving a situation to avoid learning information, or simply failing to take the necessary steps to reveal the content of information. That is, information avoidance can be active (e.g., by asking someone not to reveal information) or passive (e.g., by failing to ask someone a question that would reveal the information).*

Loiselle (2019) finds that almost 40% of a large cohort of cancer patients are uninterested or even deliberately avoids information related to their illness. In an earlier study Carlsson (2000) finds that about 30% does not actively seek information regarding their illness. It should be noted that Nelissen et al. (2017) stress that information avoidance is conceptually different from information disinterest. In general, a considerable number of people actively avoid challenging information in their daily lives (Karim et al., 2019).

The cancer information seeking preferences have been used to characterize behavior but also in many cases individuals (Germeni and Schulz, 2014). A recent example is the study by Loiselle (2019) who assesses cancer information seeking preferences by asking participants to characterize their own cancer information seeking preferences. Characterizing individuals has been questioned by e.g. Germeni and Schulz (2014) who argue that information seeking and avoidance are not two distinct behaviors pertaining to different groups of patients. Shim et al. (2016) argue that there is a lack of longitudinal studies examining information seeking behavior of cancer patients throughout their cancer journey or over the course of the cancer continuum. The information seeking behavior can evolve across different stages of the patient journey and thus longitudinal studies are needed (Germeni et al., 2015, Shim et al., 2016).

Summing up, information seeking and avoidance are approaches to meeting a need. We can identify the behavior in an individual, and over the course of the cancer continuum an individual may meet their needs using several different approaches. According to Germeni and Schulz (2014, p 1371) information seeking and avoidance are two sides of the same coin. In this paper, we take a step further and explore how avoidance can be an approach used as part of seeking activities and not as an alternative approach to seeking. Information can be avoided while seeking if particular sources are disregarded (Festinger, 1957). Kwanya (2016) characterizes this shortcut to satisfying an information need as an echo chamber. Based on an analysis of social media (Malinen et al., 2018) labels the behavior in which a person actively seeks information that supports their views and avoids information as selective exposure and selective avoidance. Case et al. (2005) argues that selective exposure, which relates to behaviors aimed at preventing confrontation with specific information, is an early characterization of avoidance.

In this study, we explore how cancer patients actively seek information while cautiously and consciously avoiding information that may be relevant, but does not meet their needs.

**METHODS**

In order to further our understanding of the information-seeking behavior of cancer patients with special attention to selective avoidance interviews with six current and former cancer patients were conducted. Meeting current and former patients naturally requires a number of considerations, because the interviewees can be both vulnerable and fragile. Prior to the interview, all interviewees signed a written consent that allows the interview to be recorded and used for research purposes. It was stressed that the transcript would be anonymized. The names of the interviewees were changed to IP1-IP6 in the data and other personal information was excluded.

The interviewees were located through the Danish Cancer Society in which one of the authors is actively involved. The interviewees did not receive any financial or material payment for their participation. To reduce potential bias an author unrelated to the interviewees performed the interview without the presence of the other authors. The interviewees were 25 to 58 years old. Although one of the interviewees’ native language was not Danish, all interviewees speak Danish fluently and are residing in Denmark. Therefore, the interviews are conducted in Danish and translated to English for the purpose of this publication.

Four interviewees are former cancer patients whereas two are current cancer patients. Two men and four women participated in the interviews. Each interview interaction starts with an introduction to the process which is not recorded or transcribed. The interviewee is introduced to the study and is being informed that the interview can be paused or interrupted if the person so wishes. Before the recorder is started the interviewee is given the chance to ask questions. The interview then begins and concludes with any comments or remarks the interviewee would like to add.
The in-depth interviews used a semi-structured interview protocol and each lasted approximately an hour. Most of the participants preferred a telephone interview because of the lockdown caused by the COVID-19 pandemic during the time period of conducting the interviews and because it was easier to organize. The interviews were audio recorded and later transcribed. The transcriptions were coded to identify themes and concepts. The transcripts were coded individually by two of the authors. The individual coding was then compared and discussed until agreement was reached. The focus of the coding was on information avoidance and information seeking during serious illness. No categories or theoretical framework formed the coding and the study utilized an inductive content analysis.

**FINDINGS**

In the analysis we identify the different patterns of information seeking among the interviewees. We identify intense information seeking as one pattern of information seeking behavior among the cancer patients interviewed in this study. Some of the interviewees are interested in knowing as much as possible and they seek information intensively. Some of the interviewees clearly state that they seek intensively and prefer having as many answers as possible to satisfy their information needs.

> I am realistic, if one is to die, then one might as well find some information about it. I was hoping I would not find anything of that kind but I have not avoided anything because I wanted answers (IP4).

> The thing about closing your eyes to something.... and prognoses, it does not matter at all, because it does not mean that it is something that will affect me. So no, the more information, the better (IP6).

However, even though a cancer patient is interested in knowing as much as possible, it can be difficult to navigate the overwhelming amounts of information, and some of the information may even distress the cancer patient. One of the interviewees reflect on the need to know as much as possible and maybe not having the mental resources for handling the answers.

> But in the beginning, I just swallowed everything raw. But it didn't really do me anything particularly good. It was the information I got primarily from my friend who is a doctor and the information I got in general from my network who has had cancer. Now, I don’t know that many people who has had cancer. But I don’t think searching the Internet was good for me in the beginning. Since I also had to know what to look for and how to sort it. I did not have those mental resources. I only had those [mental resources] later. So in hindsight I should probably have saved the Internet for a later use (IP1).

However, not all cancer patients are interested in knowing as much as possible about their disease. We also find examples of minimal or guarded information seeking where the individual does not look for information on their own or avoids some cancer information. One of the interviewees did not feel a need for seeking information regarding the illness and primarily relied on the health professionals because the interviewee did not feel a need for further information:

> No, not so much. Now, of course, it is a few years ago, but it was all very overwhelming, and I was only 21-22 [years old] at the time ... so in the beginning it went mega fast and you already get a lot of information. So in the first 2-3 weeks I could not keep up. Not mentally either, because it went so fast. But when I have had questions, I have just asked [the health professionals]. But otherwise, I think they were reasonably good to inform [the patient] (IP2).

Some cancer patients may feel need for information although they do not seek it actively. Some consciously choose not to seek information regarding their illness. They are aware that information seeking can result in finding information that is difficult to cope with. One of the interviewees actively chose early in the process to avoid searching on his/her own:

> I chose from the beginning not to [...] read online. That was probably to avoid.... I'm generally critical in regard to online information, of course I googled some things. But it is very minimal. Otherwise, I have actually relied heavily on the healthcare staff. Both regarding surgery and radiation therapy, yes... (IP3).

Exposing yourself selectively to information as well as avoiding some information during the process of information seeking can be strategies to protect the information seeker from information the individual is not able to cope with. An example is IP5 who asks a close relative to seek information regarding the illness and only provide the patient with a minimum of information:

> I avoided all that was uncomfortable to hear, but luckily, I felt I was well-informed from the start that my diagnosis was not so bad or what to say. So if I heard anything about someone who had been severely ill I could not cope with that [...] It's a lot about getting something that made sense to me. So I could cope with being in [a situation] which was so difficult (IP5).
Then [my mother] passed on the information to me in a gentle way because I could not bear to have in-depth information about the illness at all (IP5).

The interviewee thus gets information filtered by a relative to protect him/her from information that would cause distress. Another example of selective exposure and avoidance is to select the sources carefully and thus avoid specific sources of information that can upset the patient. One of the interviewees reflects on the choice of resources when seeking information:

"There were many guesses ... Many asked "now I have these symptoms, what could it be?" and then there were hundreds of suggestions, and I think that could worsen my condition. [...] I would get more upset. [...] then I would rather ask a doctor who knows my specific situation (IP3)."

To avoid getting upset the interviewee carefully selected the resources to rely on. However, the resources relied on depends on the information need and is therefore not necessarily constant. IP3 also states that seeking information on personal experience is of value:

"Well, Wikipedia and something like that I avoid ... but otherwise I searched for [information from] previous cancer patients and their experiences with, e.g. bras - it was not the disease I searched for, because it is different from one person to another. I'm probably also critical, as no one has the same case as me (IP3)."

A cancer patient can also select a resource because they expect it to give them a specific answer to their question and thus fulfill their information need and it may not necessarily be authoritative or quality approved information. One of the interviewees needed to be assured that treatment would cause serious side effects in his/her case and as the health professionals could not give him/her any guarantees she went to a different source of information.

"It was worse when I googled the prognoses for facial paralysis, so I actually completely stopped googling it. Then I went to a healer instead, and I do not believe in such a thing at all. But just to give [the interviewer] a picture of how far out you can get. Well, it did [give positivity]. That's the worst part. I wish I could say no (IP1)."

Even though the interviewee does not trust healers in general, a healer is asked about a crucial aspect of the patient’s prognosis. First and foremost, the interviewee needs a positive answer to the question regarding prognosis and if internet searching cannot provide that then an alternative source is identified. Therefore, selective exposure and avoidance is used in order for the patient to be able to fulfill their information needs.

CONCLUSION

During serious and even life-threatening illness patients have many different information needs and fulfilling unmet information needs can improve their health-related quality of life as well as optimizing their health care. Cancer patients use a variety of approaches to satisfy their information needs. The role of information seeking during serious illness includes information seeking as a coping-strategy. Different information seeking approaches can be identified in an individual and over time a patient may use several different approaches.

However, seeking and avoidance can be considered two sides of the same coin, and in this study, we have explored if they can be used simultaneously. We have found that the approaches can overlap, and this seems to be tied to coping. In order to cope with the information found several approaches are used simultaneously. The patients seek information while avoiding otherwise relevant information regarding their illness. Therefore, cancer patients can actively seek information while cautiously and consciously avoiding information that is relevant but does not meet their need and support them in coping with a serious and potentially fatal illness.

More research is needed to confirm our findings and elaborate on how avoiding information can be part of an active information seeking process during periods of significant life changes such as serious illness.

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