

Virtual navigation in colorectal cancer and melanoma: an exploration of patients' views

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Abstract

Purpose Individuals with cancer frequently report significant gaps in information, support, and health care service navigation at diagnosis and in the survivorship phase. A comprehensive web-based tool called the Oncology Interactive Navigator™ (OIN) appears promising in addressing these gaps. The present qualitative inquiry explores the perceptions of individuals concerning the OIN™, as a complementary resource to support psychosocial adjustment to cancer and guide access to cancer care services.

Method As part of a pilot multi-method multi-site study, 151 individuals newly diagnosed with colorectal cancer or melanoma were offered unrestricted access to the OIN™ for 8 weeks. Qualitative interviews were undertaken with a subset of participants ($n=20$) to explore their experience with the tool. Interviews were digitally audio-recorded and transcribed verbatim.

Results The OIN™ was reported to be instrumental in fulfilling participants' cancer information and supportive care needs, particularly early in the cancer trajectory. More specifically, the tool was seen as a “go to” resource to obtain more detailed information, validate information provided elsewhere, and pace exposure to cancer information. Content also was perceived to be of high quality, practical, and comprehensive. All participants underscored how the tool improved their cancer knowledge, facilitated communication, and prepared them for subsequent medical consultations.

Conclusion Given the rapid proliferation of web-based tools of varying scope, quality, and relevance, the exploration of users' perspectives is key to informing the development, refinement, implementation, and sustainability of promising web-based tools such as the OIN™.

Keywords Virtual navigation · Patient navigation · Cancer education · Health service use · Psychosocial adjustment to cancer · Colorectal cancer · Melanoma

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Background

Cancer remains an important cause of burden, morbidity, and premature death worldwide [1]. A diagnosis of cancer, and subsequent treatment, disrupts many aspects of daily life and is associated with distress, uncertainty, and significant needs for information and support [2]. Individuals with cancer often report dissatisfaction with the type, amount, and nature of information and support provided by health care professionals (HCPs) [3, 4]. This can lead to decreased quality of life, poorer health outcomes, and increased health care costs [5].

Increasingly, individuals are turning to the internet to meet their cancer-related information needs [6, 7]. Several surveys have documented that patients prefer receiving information primarily from their health care providers; however, busy

clinic visits frequently place limitations on time spent addressing concerns and clarifying issues [8, 9]. The internet often becomes the next available solution, but concerns remain about the quality of information retrieved [10]. Checklists have been developed to guide patients in discerning website quality, and new evidence-based, interactive web applications are increasingly being developed [11, 12].

Preliminary evidence documents positive health-related outcomes related to interactive web-based tools, also called virtual navigators, and more research is needed to further document their effects [13, 14]. The Oncology Interactive Educational Series (OIES), an initial CD-ROM version developed by a Canadian firm, Jack Digital Productions Inc., has filled an important information and support gap for individuals with cancer for over 12 years. As a web-based virtual navigator, its more recent version (the OIN™) builds on the OIES to offer comprehensive, easily updated, and readily accessible web-based information and support designed to serve as a complement to professional and peer navigation initiatives. OIN™ modules focus on particular cancer diagnoses. Users are provided with a code to log in and access a large repository of cancer information concerning their diagnosis and treatment, the health care facility where they are being treated, supportive care services offered in their community, and frequently asked survivorship questions. Features include high quality graphics, an introductory section for first-time users, videos of patients and family members describing their experience with cancer, customized hospital and contact information, printable cancer care journals, and links to financial support application forms (Fig. 1).

Patients learn about the virtual navigator through either their physician or nurse, depending on the clinical environment. OIN™ Patient Summary and Support forms (PS form) are completed during the initial consultation and include a unique access code, an outline of the patient's diagnosis, and an individualized "prescription" for medical information and psychosocial resources.

Studies have documented positive outcomes associated with the use of the initial tool by individuals newly diagnosed with cancer. In a quasi-experimental study [5], 250 patients newly diagnosed with breast or prostate cancer were assigned to either access the tool during an 8-week period or receive care as usual. The experimental group showed increased levels of satisfaction with information ($p < 0.001$), higher satisfaction with information provided by oncologists ($p = 0.051$), and no significant decline in quality of life over time ($p = 0.03$), as opposed to the control group. Qualitatively, participants reported feeling better prepared for their consultations with HCPs [15].

More recently, a multi-site pilot study using the OIN™ was conducted among 151 patients newly diagnosed with colorectal cancer (CRC) ($n = 95$) or melanoma (MEL) ($n = 56$). Following an 8-week exposure to

the OIN™, pre/post findings demonstrated statistically significant increases in cancer knowledge ($p = 0.003$), perceived cancer competence ($p = 0.035$), and higher perceived support for autonomy was found to be nearing significance ($p = 0.058$) [16, 17]. A qualitative study with cancer care providers and volunteers ($n = 20$) also found positive assessments of the OIN™ as a useful tool to support and enhance person-centered cancer care [18]. The present paper reports on the qualitative findings in a sample of newly diagnosed CRC and MEL patients drawn from this multi-site study.

Research question

This qualitative study sought to address the following research question: How do newly diagnosed adults with CRC or MEL perceive the OIN™ and its potential role pertaining to their adjustment to cancer when provided with unlimited access for 8 weeks?

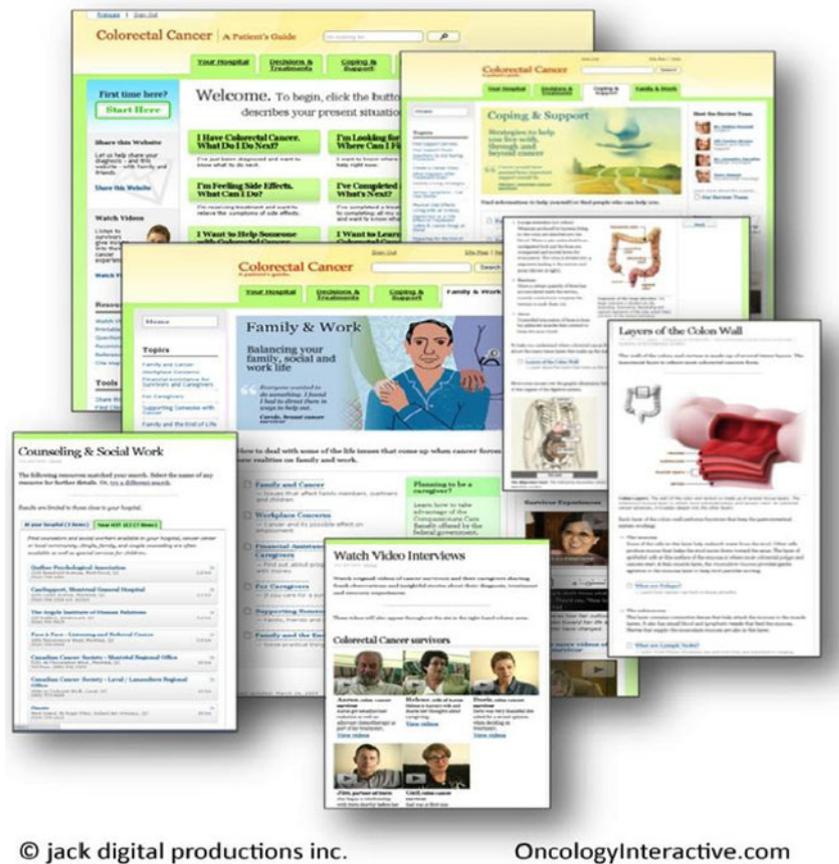
Method

Sample

A convenience sample ($n = 20$) from a larger study [16] was recruited from five Canadian cancer centers. To be eligible for the study, patients had to (1) attend a participating cancer center within approximately 8 to 12 weeks of diagnosis, (2) have a new diagnosis of CRC or MEL, (3) be fluent in English, (4) be at least 18 years of age, and (5) have a readily accessible internet connection. Patients were excluded if they had a concurrent major illness (e.g., severe mental or cognitive problems).

Procedures

Following ethics approval, a research assistant approached eligible individuals to take part in the larger study. Those agreeing to participate signed the consent form and were asked to consent to an optional follow-up interview. Participants were invited to use the OIN™ based on their own needs for a period of 8 weeks. After this period, one of the authors (O.P.) contacted the participants who had agreed to a follow-up interview and arranged a convenient time and format (i.e., face-to-face or telephone) for the interviews. A semi-structured interview guide was developed to guide the interviews (Supplemental material: Box 1). The interviews, conducted in 2009, lasted between 45 and 60 min and were digitally audio-recorded and transcribed verbatim. The interviewing of new participants ceased when further data collection yielded no new emerging themes [19].

Fig. 1 Oncology Interactive Navigator (OIN™)

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Data analysis

Data were analyzed by thematic content analysis [20]. Transcripts were read line by line, and statements deemed pertinent to the research question were highlighted and then coded. Clusters of codes referring to similar concepts formed the basis for creating themes and sub-themes. Data analysis was on going, beginning during data collection and continuing after all interviews were completed [19]. Themes and concepts that emerged early in the analytic process were explored through generating new questions that were subsequently integrated into the interview guide. Data, codes, and themes were reviewed by a separate researcher (KH), who listened to the audio recordings, reviewed the transcripts, and confirmed relevance of the themes.

Results

Of the 20 participants recruited, 11 had CRC (7 men and 4 women; mean age=60.2 years) and 9 had MEL (5 men and 4 women; mean age=58.9 years). All reported having attained at least a high school level of education (Table 1).

Three face-to-face ($n=3$) and 17 telephone interviews ($n=17$) were completed. Analysis of data revealed three main themes with respective sub-themes depicting participants' impressions of the OIN™ (Fig. 2). These included viewing the OIN™ as (1) a valuable comprehensive, readily accessible, and reliable source of cancer information and support; (2) a useful means to control/pace exposure to cancer information; and (3) a catalyst for cancer knowledge acquisition and understanding among patients and family members.

The virtual navigator as a valuable source of cancer information and support

Participants perceived the OIN™ to be a comprehensive, complementary, and timely source of cancer information and support. This theme encompasses individuals' enthusiasm for 24/7 access to cancer information and support.

Comprehensive

All participants perceived the tool to be a self-standing informational and supportive resource that can readily be accessed when needed. One participant with CRC commented, "It had everything there that I needed... there

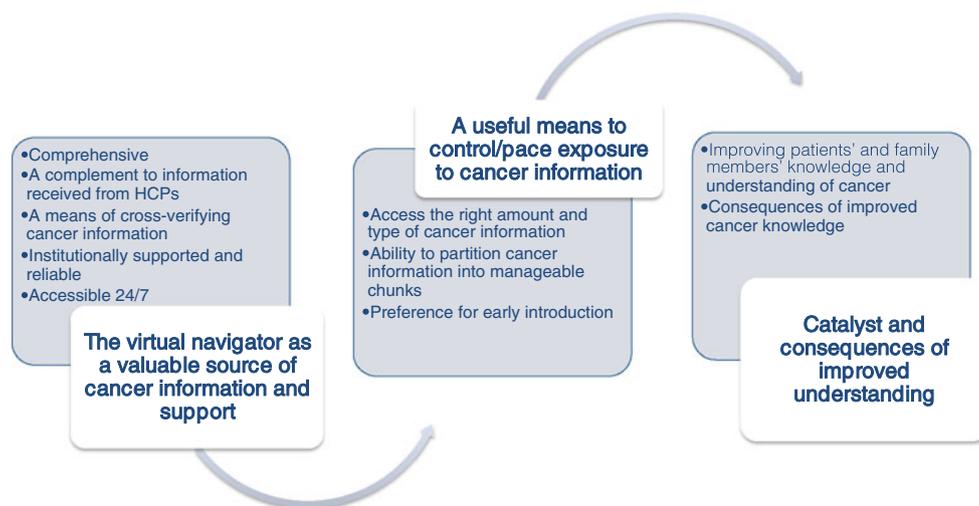
Table 1 Participant characteristics

Participants	Sociodemographic information			
	Age	Gender	Income (Canadian dollars)	Highest educational attainment
Participants with colorectal cancer	51	M	>120,000	University
	51	M	>120,000	High school
	51	F	80,000–99,000	Post-secondary
	58	F	50,000–79,000	Post-secondary
	62	M	>120,000	University
	64	M	Not reported	University
	64	M	50,000–79,000	Post-secondary
	64	M	30,000–49,000	University
	66	F	10,000–29,000	High school
	66	F	10,000–29,000	University
Participants with melanoma	71	M	30,000–49,000	Post-secondary
	42	F	30,000–49,000	University
	45	M	>120,000	University
	52	M	30,000–49,000	University
	54	F	50,000–79,000	High school
	60	F	30,000–49,000	Post-secondary
	63	M	110,000–119,000	Not reported
	66	M	50,000–79,000	High school
	72	F	>120,000	University
	76	M	>120,000	University

didn't seem to be anything missing in terms of information.” Another added, “I didn't need to go anywhere else to look for information once I got on the website.”

A few perceived the virtual navigator to be somewhat overwhelming in terms of the amount of information provided. A CRC participant found it difficult to identify specific information: “You're trying to search through for

something that's relevant to me and there's just so much other stuff... you do get lost.” One individual with MEL misconstrued the purpose of the tool and was under the impression that the entire content had to be viewed. He stated: “There was more than I wanted to know... I don't know how you can rule down [the information on the OIN] to [the] optimal level people have accepted and stop there.”

**Fig. 2** Findings

A complement to information received from HCPs

Most participants used the virtual navigator as a complement to information received from their healthcare team. An individual with CRC said, “The doctor’s time is limited...he can’t provide you with all the information that you might want because you’d be there with him for two hours [and] he doesn’t have that time. So you need to go and augment that information somehow.” Similarly, a MEL participant mentioned, “...[clinicians] are so extremely busy; I just didn’t think they have the time to physically sit down and walk you through the process.”

Most participants appraised the tool as one of the most complete and useful sources of information that went beyond what clinicians, Internet sites, pamphlets, brochures, newspapers, family members, and other patients with cancer communicated to them.

A means of cross-verifying cancer information

CRC participants reported using the virtual navigator to corroborate information received from their healthcare team. As one participant noted: “The doctor...basically filled me up with all these stories of how awful chemo was going to be... that’s when I went to the [OIN™] website to see if there was information about chemotherapy, which of course there is, and just to...fact check what the doctor told me.”

Institutionally supported and reliable

The virtual navigator was perceived by most as a reliable and accessible information source. One participant with CRC said, “When I am searching the website [the OIN™] ...I have a better idea of who it is prepared by... you have confidence in the information... when you are looking up [information] on the general internet you aren’t as sure of the source”. Supporting this viewpoint, another added, “I think it was reassuring to know I was getting reliable information to the questions that I was seeking answers to.” Likewise, another participant noted: “On the Internet you don’t know whether to believe half of what you read or not ... you don’t know how much truth there is in it. Whereas the OIN™ ... it’s something you can rely on.”

Accessible 24/7

Participants stated that following their diagnosis and discussion of treatment options with clinicians, more questions often arose. A participant with CRC stated “I didn’t want to bug [clinicians] every time I thought of something” and instead relied on the tool to address his questions. As well, a MEL participant indicated that a key benefit was its availability for repeated use.

A useful means to control/pace exposure to cancer information

Participants underscored that the navigator served as a useful platform to control their exposure to information depending on their emotional state, readiness, and preferences. Participants also emphasized the importance of having access to various types of cancer information early in their illness trajectory. The OIN™ was depicted as a key resource to incrementally adjust to a diagnosis of cancer.

Access to the right amount and type of cancer information

Participants described wanting different amounts and types of cancer information. Although many “want[ed] to know everything about cancer”, a few described accessing “sufficient information”: “As soon as I had enough [information] ... that I needed for my [treatment] decision, I didn’t need more information [and discontinued use of the OIN™].” Some also used the virtual navigator to obtain the “right type” of information they were seeking. One individual with MEL commented, “I wanted to learn more...[about] the effects of radiation, the side effects of radiation, and what radiation is all about.” Another CRC participant described limiting his exposure to positive and encouraging information: “Most of the time it’s the negative side [of CRC] you’re thinking [about]...what I want to read is only the good part.”

Many reported using the tool intermittently to access the right amount and type of information according to their needs and preferences. Individuals’ readiness to seek information was an important factor in the pacing of their use. Some immediately sought information from the tool, whereas others waited: “At the beginning I was afraid to look at the information and I preferred to wait [until] I was ready... few days later I was okay and I decided in the morning to visit the site from the beginning to the end.”

Ability to partition cancer information into manageable chunks

Most participants reported accessing the navigator at least twice (nine CRC and six MEL participants). The number of independent times that the OIN™ was accessed by the participants ranged between 1 and 17 for CRC and between 1 and 22 for MEL. Participants returned to the tool because “it’s hard to retain all that [information] at once”, and therefore, used it as a means to partition information into manageable and assimilated blocks. As a participant with MEL noted, “It’s interesting because we can go there [referring to the OIN™] when we are ready to go for this information or if I don’t have enough time at one time I can continue [using the OIN™] the next day or the next week.”

Preference for early introduction

Although participants were exposed to the virtual navigator within 8 to 12 weeks of their cancer diagnosis, many would have preferred being introduced even earlier. Some believed that having more information at the time of diagnosis would have left them in a better position to ask clinicians more pertinent questions; otherwise, emotional distress associated with the disclosure of cancer was perceived to be an impediment to information seeking and retention during the clinical encounter. This was clearly articulated by a participant who said, “When you are visiting with the doctor, you know like the first time, you don’t know everything you want to say ... you think of a lot of questions later, and you’re probably most concerned with the question: am I going to live? ... you just really don’t have a clue what to ask at first.”

Another MEL participant expressed a preference for introducing the navigator prior to meeting the dermatologist/oncologist to be used as a first-line informational source upon which physicians can expand. A participant clearly articulated, “It’s easier if we have [the OIN™] information first; we [can] understand a little bit and if we need specific information, [we can] ask the doctor.”

Preference for early introduction was corroborated by a participant with CRC, who was recruited later in his cancer treatment trajectory. During chemotherapy, he stated: “most of your questions occur when you are diagnosed... I think the information comes too late for most people.”

Catalyst and consequences of improved understanding

The third theme centers on individuals’ impressions of the tool as a contributing factor in enhancing the ability of the patient and family to manage their cancer experience.

Improving patients’ and family members’ knowledge and understanding of cancer

By accessing the navigator, participants learned about many facets of life with a cancer diagnosis. One participant commented, “[the OIN™] gave me context in terms of... here’s the big picture and here you are in the big picture, and here’s how this thing works, and here’s what’s available to you.”

Information retrieved through the tool also helped improve participants’ understanding of what to expect of cancer treatment and care. One participant used the navigator successively in anticipation of upcoming events: “As the treatments grew, I wanted to see where things were going [so I used the OIN™].” Another participant relied on the tool because “I wanted as much information as I possibly could...[to] really understand what was going on [and] what to expect.”

Many of the participants reported providing family members with access to the navigator to help them understand the experience with cancer. One CRC participant offered the OIN™ to his wife: “I just let her see a few things so that she could have a better understanding of what I had.” Another paraphrased her daughter’s statement: “Mom, it’s really interesting to go check it out [the OIN™] and find out what you really have.” Thus, the tool was seen as a means of informing both patients and family members about cancer.

Consequences of improved cancer knowledge

Participants described having greater cancer knowledge resulting from OIN™ use, which prompted subsequent reactions and behaviors. For example, participants reported that the tool assisted in reducing distress and uncertainty, normalizing the cancer experience, facilitating treatment decision-making, and encouraging loved ones to get screened for CRC or MEL.

Improved understanding of cancer helped to appease distress of one CRC participant: “When you use that [OIN™], it’s less scary. You understand what’s going on in your body.” A MEL participant added, “The unknown can quite often...create a certain amount of fear and anxiety and by being able to go onto the website... [it] alleviated a lot of those concerns.”

Participants also described how the information in the navigator could assist in the decision-making process. Illustrating this, one person with CRC stated “if you take the standard [radiation] treatment, all your organs can be affected... brachytherapy will not affect other organs. [on the OIN™] I can see some positive and negative sides to each [one] and that helped me to take my decision”.

Interestingly, a participant learned through the navigator that family members could also be affected by CRC, consulted her physician to verify this, and became a cancer screening advocate. Another participant was able to normalize her situation through exposure to the experiences of others who shared their stories through the videos. “It’s difficult to talk about this [MEL] to other people. To tell them that I’m sick, for me it was not normal...[After using the OIN™] I [came] to understand that I’m not the only person who lives this experience.”

Discussion

Participants emphasized that the virtual navigator filled an important gap by offering accessible and reliable information that could be tailored to their needs and preferences. As such, the OIN™ was seen as a key source of information to learn more about the cancer trajectory. Participants found it more comprehensive and easily accessible than HCPs input

and other common sources of information, such as pamphlets. This supports previous findings among 619 cancer survivors, who found the Internet to be a better source of information than HCPs because it was more convenient and comprehensive [21]. Similarly, Cumbo and colleagues [22] found that 68 % of 150 CRC patients considered easily accessible Internet-based information to be more useful than any other source of CRC information.

However, patients often report feeling overwhelmed with the vast reams of information available on the Internet. In a study of 50 adults with CRC, only 8 % reported using the Internet to access information, but 36 % claimed they would use it if a site had been recommended [23]. A comprehensive web-based tool, such as the one investigated herein, could be offered to patients by HCPs to help address their complex informational and support needs and rule out the potential for misinformation arising from unassisted information seeking on the Internet.

Individuals with cancer often perceive a loss of control as they deal with the uncertainty of cancer progression and treatment efficacy [24, 25]. Participants described using the navigator as a means to exert control over the type and amount of information provided, according to the cancer trajectory as well as individual readiness. Although many preferred to learn as much as possible about their diagnosis and treatment, others were deliberate in their information seeking behavior, relying on the tool to incrementally expose themselves to reliable MEL or CRC information—an observation corroborated by several studies [3, 24, 26, 27].

It was anticipated that the virtual navigator would be most valuable if introduced early in the cancer care trajectory. However, it was surprising that some participants would have preferred to access the OIN™ even *prior* to confirmation of their cancer diagnosis, believing this would position them to ask more pertinent questions to the clinician and participate more actively in treatment decision making. Participants' impression that the emotional distress associated with a new cancer diagnosis is an impediment to information retention during the clinical encounter has been well documented [28, 29], but offering the tool when a cancer diagnosis is not yet confirmed is a sensitive issue with potential ethical and legal ramifications. However, early exposure to the OIN™ could address commonly reported findings that (1) patients are often unable to effectively retain key information provided immediately following disclosure of diagnosis [28, 29], and (2) patients often report dissatisfaction with communication patterns and time spent with HCPs [30].

Many participants in this study indicated that the tool might reduce burden on HCPs. This is corroborated in the

literature, where evidence suggests that the use of computer-based health information systems results in shorter visits because patients have clearer expectations, are better prepared, and bring less erroneous information requiring explanation or clarification [31]. Participants in this study also emphasized that the virtual navigator would serve to augment, rather than replace, teaching received in clinical consultations. HCPs' support for patients who seek cancer knowledge both prior to and after clinical encounters remains of utmost importance. However, HCPs must readily accept that many patients have shifted from traditionally passive recipients of health information to engaged participants in their own care [32, 33].

Limitations

In this study, few interviews were conducted face-to-face, and most were done over the telephone due to the distant geographic location of participants. This may have impacted the depth and richness of the data generated; however, some have documented that telephone interviews can lead to more open disclosure given the “social distance” achieved [34]. Social desirability with its associated tendency to want to please the interviewer by providing more positive assessments of the virtual navigator is also a potential limitation.

Conclusion and implications

The main contributions of virtual navigation tools lie in their potential to improve cancer knowledge and support for individuals with cancer. In this study, participants reported that the OIN™ was a very positive addition to their care as it allowed them access to high-quality evidence-based cancer information. Research to date suggests that HCPs must rely on multiple strategies to provide timely psychosocial and informational support to patients for optimal illness management [7, 35]. Interactive web-based applications can play important roles in achieving these goals.

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