

# Why People Living With and Beyond Cancer Use the Internet

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## Abstract

People living with and beyond cancer suffer with a wide range of physical and psychological symptoms. To manage the challenges associated with cancer, patients use a variety of self-management resources, including the Internet. People living with and beyond cancer use the Internet to make decisions regarding their self-care, through information provision, online communities, and support groups. Using the Internet may empower patients, enabling them to feel they have the required knowledge to discuss complementary and alternative treatment options with their health care team. Patients use the Internet because of its practicality; however, there are also several barriers affecting patients with cancer using the Internet, such as lack of information technology skills, lack of computer access, and concerns over the quality of information. Health care professionals need to be aware that the information available on the Internet plays a factor in the decision-making processes regarding using complementary and alternative medicine for self-management. With the use of the Internet as a tool for self-management continuing to grow, it is recommended that more emphasis is placed on health care professionals discussing the role the Internet plays in the decision-making process, to further support their patients regarding self-management for living with and beyond cancer.

## Keywords

Internet, self-management, oncology, information seeking behavior, review, cancer survivor

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As of 2012, an estimated 32 million people globally are living with or beyond cancer,<sup>1</sup> who use a wide range of self-care techniques and self-management resources to manage the complicated disease trajectory.<sup>2,3</sup> Self-management includes actions taken by individuals to control health and cope living with an illness. This can include visiting health care professionals and using health care services, support networks, spiritual practice, complementary and alternative medicine (CAM), and using the Internet to search for information.<sup>2,4-7</sup> Results of a questionnaire in Sweden in 2008 exploring information sources for cancer patients found that 61% of participants (total  $n = 135$ ) used the Internet as a source of information, a 45% increase over 10 years.<sup>8</sup> The percentage of survivors who reported cancer information seeking increased over time from 66.8% in 2003 to 80.8% in 2013.<sup>9</sup> However, there are concerns over the information provided on the Internet including issues with the quality and reliability of website content.<sup>10-12</sup>

A recent study explored breast cancer survivors' use of the Internet to find information on complementary medicine.<sup>13</sup> Participants completed a short cross-sectional survey and took part in a qualitative interview exploring their

use of the Internet. The results indicated that the information available on the Internet plays a role in the decision-making process to use CAM. Participants' use of the Internet to find information on CAM was inherently connected to their experiences of trying to self-manage the consequences of cancer and its treatment. Some participants did not disclose their use of the Internet to their health care team. Therefore, health care professionals need to be aware that the information available on the Internet factors into the decision-making processes regarding self-management for the consequences of cancer and its treatment.

Several studies have explored why people living with and beyond cancer use the Internet, summarized in Table 1. This research has included participants with cancer diagnoses including brain, breast, gastrointestinal, gynecologic, head and neck, hematologic, leukemia, lung, lymphoma,

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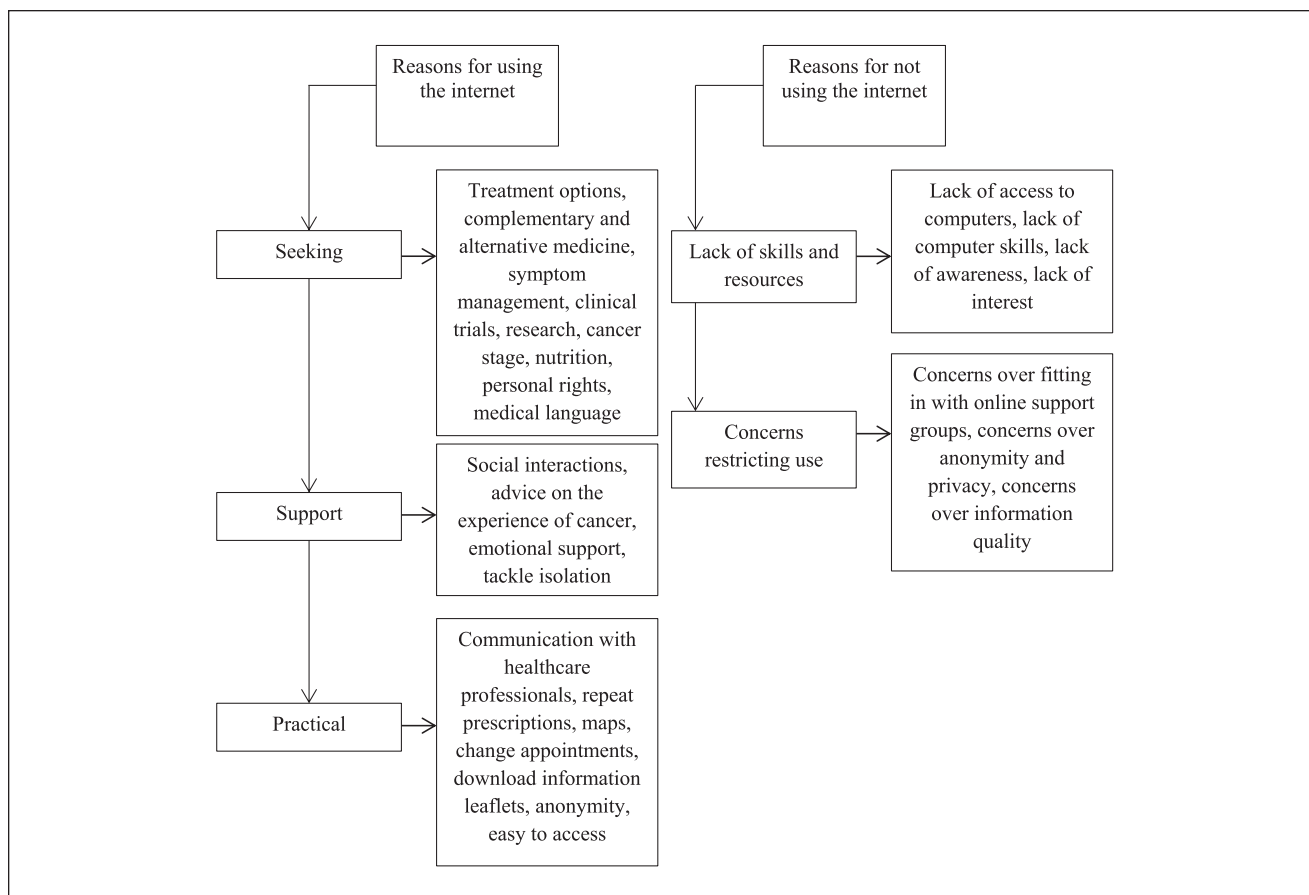
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**Table 1 . Study Characteristics.**

Citation	Country	Aim	Study Design and Method	Sample and Sampling Strategy
Ziebland et al <sup>30</sup>	UK	To explore the extent people diagnosed with cancer used cancer information on the Internet	Qualitative interviews	n = 175 Cancer diagnosis: breast, bowel, cervix, prostate, and testes Mean age = 48.6
Helft et al <sup>26</sup>	USA	To evaluate Internet use by cancer patients to obtain cancer information	Structured face-to-face interviews with a quantitative survey	n = 200 Cancer patients Mean age = 57
Dickerson et al <sup>23</sup>	USA	To describe cancer patients' experiences using the Internet for care	Qualitative analysis of interviews	n = 20 Cancer patients and survivors Mean age = 52.3
Im et al <sup>33</sup>	USA	To explore attitudes toward Internet cancer support groups	Qualitative analysis of data obtained from an online forum	n = 16 Cancer patients Mean age = 51.19
Sandaunet <sup>37</sup>	Norway	To examine nonparticipation and withdrawal from a breast cancer online self-help group	Qualitative interviews and participant observation	n = 25 Cancer diagnosis: breast
Im et al <sup>35</sup>	USA	To explore Asian Americans living with cancer views and participation on Internet cancer support groups	Qualitative analysis of data obtained from an online forum	n = 18 Asian Americans living with cancer Mean age = 39.89
Dickerson et al <sup>25</sup>	USA	To understand the experiences of using the Internet for men with cancer	Qualitative interviews	n = 15 Men with cancer Mean age = 63.3
Elwell et al <sup>31</sup>	USA	Explore types of social support teenagers with cancer seek out on computer support groups	Qualitative analysis of data obtained from an online forum	n = 151 Unique sender: names of patients currently with or who previously had cancer
Bender et al <sup>24</sup>	Canada	Examining supportive care needs and Internet use as a source of support	Questionnaire—quantitative	n = 204 Testicular cancer survivors Mean age = 35.6
Rogers et al <sup>28</sup>	UK	To report Internet access and Internet use of survivors of head and neck cancer	Survey—quantitative	n = 482 Head and neck cancer survivors n = 56
Nguyen and Ingledew <sup>20</sup>	Canada	To evaluate Internet use by breast cancer patients	Questionnaire—quantitative	Breast cancer patients n = 74
Yli-Uotila et al <sup>22</sup>	Finland	To describe the reasons, cancer patients seek support from the Internet	Online questionnaire with open-ended questions analyzed qualitatively	Cancer patients Mean age = 53
Stephen et al <sup>34</sup>	Canada	To describe Internet experiences and understand its benefits	Qualitative interviews	n = 102 Cancer patients, survivors, and caregivers Mean age = 49
Valero-Aguilera et al <sup>21</sup>	Spain	To describe information needs of cancer patients	Questionnaire-based semistructured interviews—quantitative	n = 169 urological cancer patients n = 100 breast cancer patients Mean age = 48
Yli-Uotila et al <sup>29</sup>	Finland	To describe the social support patients with cancer receive from the Internet	Online questionnaire with open-ended questions analyzed qualitatively	n = 74 Cancer patients Mean age = 53
Ebel et al <sup>17</sup>	Germany	To evaluate the Internet usage and information needs of cancer patients	Questionnaire—quantitative	n = 255 Cancer patients Mean age = 63.5
Girault et al <sup>36</sup>	France	To understand the use of information technology for health	Questionnaire—quantitative	n = 1072 Mean age = 53
Lobchuk et al <sup>18</sup>	USA	To explore conversations of lung cancer patients in an online support group	Qualitative analysis of online blogs	n = 268 Cancer patients n = 70
Maloney et al <sup>27</sup>	USA	To identify the information needs and information use of breast cancer patients	Questionnaire—quantitative	Breast cancer patients Mean age = 52.5
Moody et al <sup>19</sup>	UK	To explore the support needs of young adult cancer survivors	Mixed methods questionnaire—quantitative, qualitative focus groups, and interviews	Online survey n = 24; focus group and interview n = 7 Young adult cancer survivors Mean age = 21



**Figure 1.** Internet use by cancer patients.

prostate, skin, testicular, and thyroid. Synthesizing the findings of these studies identified that people living with and beyond cancer use the Internet to seek information, to enlist support of their peers, and for practical reasons. Internet use was restricted by patients' concerns as well as a lack of skills and resources. A diagram depicting Internet use by people living with and beyond cancer is shown in Figure 1.

## Information

The use of the Internet as a source for health-related information is well documented within the literature; it is a commonly reported method to seek information surrounding cancer.<sup>14-16</sup> Information is a necessary self-management resource; literature suggests that information resources need to be provided to support self-care activities.<sup>7</sup>

People living with and beyond cancer use the Internet as a form of informational support.<sup>17-22</sup> Some patients feel their information needs are not met, during their interactions with health care professionals.<sup>22</sup> This experience is common across exchanges with several professions including oncologists, doctors, and nurses. Patients use the Internet to seek information that was not provided during their time with

their health care team, which leaves patients feeling that they do not have enough information, or enough time for discussion, and that they are not able to get information if needed after their health care appointment.<sup>22</sup> Nguyen and Ingledew<sup>20</sup> found that patients who used the Internet felt it allowed them to access a great volume of information that was highly detailed compared with other information resources.

The information topics that are most frequently reported were treatment options and CAM, this was followed by searching for information on symptom management.<sup>18,20,23,24</sup> Patients use the Internet after their diagnosis to find information on treatment options; patients want to understand their doctor's treatment plan, identify alternatives, and explore the side effects and consequences of all options.<sup>18,20,21,23-31</sup> People living with and beyond cancer want the best possible care and use the Internet as an information resource to support them when making a treatment decision.<sup>25</sup> Using the Internet in this way empowers patients, enabling them to feel they have the required knowledge to discuss their treatment and treatment options with their health care team.<sup>23</sup>

Other information topics searched by people living with and beyond cancer include identifying clinical trials,<sup>20,24,30</sup> research,<sup>24,26,30</sup> information on specific cancers and disease

stages,<sup>24,26,30</sup> and nutrition for cancer.<sup>17,26,30</sup> Qualitative findings suggested participants also used the Internet to find information on personal rights<sup>25,29,30</sup> and to understand medical language.<sup>23,30</sup>

## Support

The Internet is thought to enable patients to seek and share their experiences; this use of the Internet provides personalized advice on self-management approaches that people living with and beyond cancer have been unaware of.<sup>32</sup> People living with and beyond cancer use the Internet to access online support groups, via social media and online forums.<sup>20,30</sup> Support groups are used for both social interactions with peers who are living with or beyond cancer<sup>21,24,28-30,33</sup> and to seek advice and information on the experience of cancer.<sup>19,20,24,29-31,34</sup>

One reason for seeking the interaction with peers online is to get emotional support<sup>17-19,22,23,29,31,33-35</sup>; discussions with peers enable patients to express their feelings and talk about their experiences, allowing patients to validate their emotions and regain a feeling of control over their lives.<sup>23,29</sup> Patients often feel that only someone who had also been diagnosed with cancer can understand their experiences, perceiving that those in their immediate social network would not understand the issues they faced with cancer.<sup>22,31,34,35</sup> Patients may also not want to burden their family and friends with stories of their suffering, especially if they feel their families would not be able to help.<sup>19,22,29,34,35</sup> Online support groups are also used by people living with and beyond cancer who want to give advice to others, sharing their experiences for the benefit of others.<sup>30</sup>

Through using the Internet as a resource for connecting with others, patients feel they are tackling the isolation they experience with cancer.<sup>19,30,34</sup> Online support groups are suggested to be a place where meaningful interactions can take place, reducing the isolation from being unable to participate in certain activities and feeling unable to discuss issues with friends and family.<sup>22,33</sup>

Online support groups may be convenient and allow for flexible usage and anonymity.<sup>33,35</sup> As cancer can significantly limit a person's physical ability, this may restrict them from attending conventional support groups, information centers, and events<sup>22</sup>; online support groups, therefore, could be more beneficial than conventional gatherings.

## Practical Uses

Practicality is one of several reasons why people living with and beyond cancer choose to use the Internet. Patients feel the Internet is an easy and practical way to access information.<sup>20,22,34,36</sup> The Internet is a flexible resource that can be used when convenient for individuals.<sup>33,35</sup> People living with and beyond cancer who use online groups also expressed that it is an easy way to communicate with peers,<sup>22</sup>

as well as being able to communicate anonymously to ask questions and seek answers.<sup>20,34,35</sup>

There are also several practical purposes for using the Internet. Rogers et al<sup>28</sup> determined that people with head and neck cancer in the United Kingdom used the Internet to make or change appointments, order repeat prescriptions, download information leaflets, and see pictures and maps of the hospital and clinics. In another study, patients reported they would like to be able to access personal health information online.<sup>24</sup> "To find out what to take to the hospital" was also reported as a practical use of the Internet.<sup>30</sup> Several studies also reported that people living with and beyond cancer used or would like to use the Internet to contact health care professionals.<sup>21,24,25,28,29</sup>

## Reasons for Not Using the Internet

There are several barriers that influence individuals using the Internet. Patients may lack the knowledge or skills to use a computer and/or the Internet, dislike using computer, or not feel comfortable using a computer.<sup>24,26,28</sup> Access to a computer and cost can also be a significant barrier.<sup>26,28</sup> People living with and beyond cancer may also have a lack of awareness about the information and resources available.<sup>24,26</sup> In a study of patients with breast cancer, a few participants who had access to a computer and were aware of the available resources expressed they did not know where to look for information and felt overwhelmed by the information available.<sup>20</sup>

In several studies people voiced apprehensions with using the Internet, suggesting that they restricted their use of the Internet due to their concerns.<sup>19,34,35,37</sup> One study investigating nonparticipation in online support groups for cancer found people had issues with fitting in and thus dropped out of an online group, feeling that their story was too positive or not wanting to post depressing messages to the group.<sup>37</sup> This left individuals feeling they did not have a position in the group and stopped their participation. Some participants wanted to avoid painful details of cancer stories and did not want to read accounts of recurrence and problems associated with cancer and its treatment. Patients may feel wary about using the Internet due to concerns over the anonymity and confidentiality of online groups and are unsure about the privacy of their postings to online groups.<sup>19,33</sup> Patients may also have concerns surrounding the quality of information found online and may feel wary about accessing online information.<sup>20,28</sup>

## Implications for Practice

People living with and beyond cancer use the Internet to seek information and support, as well as for practical applications. Research has shown that patients feel there is significant time pressure on clinicians and this impacts heavily on the amount of information they can provide, leading patients to seek information elsewhere.<sup>22</sup> Online peer discussions and communities

are also thought to play a significant role in the decision-making process regarding self-management.<sup>22,32</sup> Online social networks, such as Twitter, Facebook, and Instagram, therefore may be a useful resource for health care professionals. These networks are suggested to have a potential role in patient care, disseminating information on management of symptoms, and increasing patient knowledge.<sup>38</sup> Providing education for cancer survivors is thought to reduce patient anxiety and empower patients' self-management of their symptoms.<sup>38</sup>

The health care community must acknowledge the role the Internet plays as a self-management resource during patients' experience of cancer. There is a shift in focus to developing digital self-management interventions for cancer survivors.<sup>39</sup> In a review identifying nonpharmacological interventions to improve the quality of life of cancer survivors, interventions were found to be delivered online or with a combined approach of online and face-to-face.<sup>40</sup> With more emphasis being placed on self-management, it can be suggested that the use of the Internet as a tool for self-management may continue to grow.<sup>41</sup> Health care professionals must be aware of their patients using the Internet, with a need to educate patients on assessing website quality.<sup>10-12</sup> Health literacy is a major concern when advocating the use of the Internet. Previous studies have shown that people lack the basic skills needed to understand the information available to them online.<sup>42-44</sup> This could have a considerable impact on self-management approaches if people living with and beyond cancer are unable to dismiss disreputable and unreliable claims regarding treatment options, leading patients to make misinformed decisions about their health.<sup>45</sup>

More studies are recommended to explore the resources available to people living with and beyond cancer and identify how people evaluate and make decisions based on Internet use. As people living with and beyond cancer continue to use the Internet, the implications suggested here for self-management, further research can only help inform future action aimed at improving the decision-making and self-management choices of people living with and beyond cancer.

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