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Sifting Through It All: Characterizing Melanoma Patients' Utilization of the Internet as an Information Source

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Abstract This study describes how melanoma patients used the Internet as a melanoma information source and how it impacted their clinical encounter and treatment decision. From 2010 to 2013, melanoma patients were invited to complete a 23-question paper survey with open- and close-ended questions. Thirty-one of the 62 patients approached completed the survey. The majority (90 %) of respondents used the Internet as a melanoma information source. Most (90 %) had used the search engine Google. The most commonly searched topics were melanoma treatment (96 %), screening (64 %), and prevention (64 %). While most respondents (85 %) found the Internet was a useful melanoma information source, over half (54 %) found melanoma websites at least somewhat difficult to understand. Many (78 %) believed it increased their understanding of their diagnosis, 71 % thought it influenced their treatment decision, and 59 % felt it impacted their specialist consultation. This study informs health care professionals that many melanoma patients search the Internet for information regarding their diagnosis and that it may impact their disease understanding and treatment decisions.

Keywords Melanoma · Internet · Skin cancer · Patient education

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Introduction

Over the past two decades, Internet usage has rapidly increased and more individuals are looking online for medical information [1]. In 1998, 50 million American adults were searching the Internet for health-related information, and by 2010, this number had increased to 175 million [1]. In 2011, 74 % of American adults had used the Internet to seek health-related information and 81 % of these individuals had searched once or more in the past month [2]. Many studies have established that patients generally report positive experiences when searching the Internet for medical information and believe it improves their understanding of their diagnosis [3]. Comparable trends in Internet usage are seen in oncology. The First Health Information National Trends Survey reported that 40–50 % of patients ages 18–64 would prefer first obtaining information online about a cancer diagnosis before meeting with their specialist [4].

Despite this enthusiasm, health care websites may be difficult for patients to understand [3]. One study found that all medical websites evaluated required at least high school level reading ability [5]. In another study, 76 % of cancer patients found health care information on websites conflicting and 31 % found it overwhelming [6]. Websites are not always peer reviewed for clarity and accuracy and any individual with Internet access can publish a website. Studies evaluating prostate, cervical, bladder, and breast cancer Internet sources have found substantial heterogeneity in the accuracy, currency, and comprehensiveness of websites [3].

Melanoma is the fifth most common cancer diagnosed in America and is increasing in incidence with an estimated 76,100 new cases and 9,710 deaths in the USA and 6,500 new cases and 1,050 deaths in Canada in 2014 [7, 8]. The most recent Canadian Cancer Statistics estimated that 1 in 59 men and 1 in 73 women will be diagnosed with melanoma in their lifetime and 1 in 290 men and 1 in 395 women will die from melanoma [8]. Despite its prevalence, there is scarce literature available regarding the accuracy of melanoma information available online and melanoma patients' Internet usage patterns. A study published in 2002 analyzed 74 melanoma websites and found the majority lacked basic information and 14 % contained inaccuracies [9]. A survey conducted between 2001 and 2003 found that 39 % of melanoma patients had searched the Internet for information about their diagnosis [10]. Internet usage has nearly doubled in North America and websites have changed substantially since these two studies were performed over a decade ago [1]. The primary purpose of this study was to provide an updated assessment of how melanoma patients use the Internet as a melanoma information source. Previous research has demonstrated that many oncologists have difficulty discussing Internet utilization with patients [6]. Consequently, physicians may underestimate the impact of the Internet on the clinical encounter. Thus, a secondary aim of this study was to determine how the Internet impacted patients interactions with their oncologists and treatment decisions.

Materials and Methods

From 2010 to 2013, patients diagnosed with melanoma who were waiting to see their melanoma specialist at our cancer institution were asked to participate in this study. Patients who were unable to provide voluntary consent were excluded from the study. Patients less than 18 years of age were also excluded, as they could not provide full consent without a legal guardian. Non-English-speaking patients were excluded, as adequate comprehension of the English language was required to understand the study and questionnaire. Responses were anonymous and participation was voluntary with all subjects providing written consent prior to completing the survey. Subjects were provided a paper survey and consent forms along with a stamped envelope so that they would have greater than 24 h to consent and complete the survey. Our institution's Research Ethics Boards approved the study.

The survey consisted of 23 open- and closed-ended questions. Questions were asked to elicit patient demographics. Subjects' Internet use including the frequency, location, and use as a melanoma information source was evaluated. Specific questions were asked regarding subjects' melanoma search patterns including search engines and search terms used, information sought, websites accessed, and method of source evaluation. The impact of the Internet on their treatment decision, understanding of their diagnosis, and specialist consultation was determined.

Descriptive statistics were used to interpret quantitative data. The narrative data and open-ended questions were analyzed with qualitative methods using a grounded theory approach [11]. The responses were read and re-read and themes were identified by two authors (S.H. and P.I.) utilizing constant comparative analysis. Exemplary quotes were used to provide examples of content included in the themes.

Results

Sixty-two subjects were approached and agreed to participate in the study. A total of 31 questionnaires were completed and returned for a 50 % response rate. Table 1 demonstrates subjects' demographic characteristics.

The vast majority (93 %, $n=29$) of subjects used the Internet. These subjects will be referred to as the Internet user cohort. Sixty-eight percent of Internet users reported using the Internet one to four times per day. Almost all Internet users (97 %) accessed the Internet at home and 55 % accessed at work. Most respondents (90 %, $n=28$) had used the Internet as a melanoma information source. All respondents in the Internet user group accessed the Internet themselves and 21 % also had friends or family members access the Internet for them. Those that did not use the Internet to search for melanoma information cited that they were satisfied by the information provided by health professionals ($n=3$), confused/overwhelmed by the information available ($n=2$), or were not Internet users ($n=1$).

The most common search engine used was Google (90 %), followed by Yahoo (11 %), Bing (7 %), and Microsoft Network (4 %); some subjects used multiple search engines. In order to select websites for review, just over two thirds (69 %) chose melanoma websites based on the top hits returned from Internet searches. Almost half (42 %) chose specific web pages from a known reputable source, while 15 % selected websites based on recommendations from their doctor or other health care providers. Over half (54 %) viewed 1–5 melanoma websites, 39 % viewed 6–10 websites, and 8 %

Table 1 Subjects demographic characteristics

Variable	Number	Percentage
Age		
19–39	8	26
40–59	9	29
60–79	14	45
Sex		
Male	19	61
Female	12	39
Year of first melanoma diagnosis		
1980–1985	2	6
2006–2008	8	26
2009–2011	15	49
2012–2013	4	13
Unknown	2	7

viewed greater than 10 websites. Many Internet users (46 %) visited specific hospital/cancer institution-specific websites (e.g., British Columbia Cancer Agency, Mayo Clinic) while 15 % reported viewing commercial health or general knowledge websites (e.g., WebMD, Wikipedia) for melanoma information. The remaining 38 % could not recall the websites they had visited. Table 2 displays the melanoma websites subjects recalled visiting.

With respect to search patterns, the majority of Internet users sought out information regarding melanoma treatment (96 %), prevention (64 %), and screening (64 %). Over half (54 %) searched for information concerning symptom management and treatment toxicity. Additional topics queried included clinical trials (18 %), support groups (18 %), and alternative/complementary treatment (14 %). The most common search terms used were “melanoma” (75 %) and “skin cancer” (36 %). A quarter (25 %) also used search terms specific to melanoma treatments, 11 % searched for terms relating to melanoma symptoms, and 11 % for melanoma staging.

To evaluate the quality of information on the websites, almost two thirds (64 %) compared data from several websites and the same proportion (64 %) evaluated quality by discussion with their family doctor or oncologist. A third (32 %) reported selecting information from academic or government websites. Only 14 % referred to the credentials of the website authors and 11 % examined the references that were cited on websites.

The Internet was found to be a useful source of melanoma information for 85 % of Internet users, 78 % of users reported that the Internet improved their understanding of their melanoma diagnosis, and 71 % found the Internet somewhat or very influential on their treatment decision. Over half (52 %) found the Internet affected their specialist consultation by helping their decision making, while 37 % found it did not influence their decision making and 7 % found it made their decision more difficult. The most common cited strength of the Internet over other melanoma resources was ease of access (74 %), followed by the volume and detail of information available (52 %), the discussion of different perspectives/options (37 %), and anonymity (7 %).

Table 2 Melanoma websites survey respondents recalled viewing

Website	Number
Bccancer.bc.ca	5
Wikipedia.org	2
Mayoclinic.org	2
Cancer.ca	2
Cancer.gov	2
Acscan.org	1
Melanoma.org	1
Ehealthcare.ca	1
Nlm.nih.gov/medlineplus	1
Dermnetnz.org	1
Webmd.com	1
Lifescript.com	1
Ask.com	1

While most users reported the Internet increased their knowledge and impacted decision-making, over half (54 %) of Internet users reported that the available Internet melanoma information was somewhat hard or hard to understand. Thematic analysis demonstrated that subjects who did not feel the Internet was a useful melanoma information source found the information was very negative, difficult to understand, and/or was overwhelming. As one respondent summarized there were “too many websites, vast amounts of info, sources were hard to verify and too much information can be unsettling.”

Discussion

This study examined how melanoma patients use the Internet to search for melanoma information and its influence on their understanding, treatment decision, and clinical encounter.

Almost all of the melanoma patients who participated in our study had used the Internet. Our findings are comparable to the Canadian Commercial Monitoring Report, which found that 88 % of English-speaking Canadian adults used the Internet in 2012 [12]. Not surprisingly, we found a greater proportion of melanoma patients were online relative to the survey of Sabel et al. performed a decade ago which found that 73 % of melanoma patients surveyed had Internet access [10]. The majority of respondents in our study had used the Internet to research melanoma, compared to 39 % in Sabel’s study [10]. The age range of respondents was similar between the studies [10]. It is interesting to note that that our results show greater Internet usage among melanoma patients when compared to our parallel survey of breast cancer patients also done at our institution [13]. In our parallel study conducted among our breast cancer patients, 71 % of respondents had searched for information online about their diagnosis [13]. We hypothesize that this difference may be partially due to the relative lack of written resources, patient support groups, and educational materials available for melanoma patients, which is less common than breast cancer. In addition, melanoma is often diagnosed at more advanced stages than breast cancer, so patients may be more motivated to seek out further information and may more readily search the Internet.

Similar to our study, Sabel’s survey of melanoma patients found that 94 % of Internet users found the Internet was a useful melanoma resource [10]. A study by Hessen et al. found that 65 % of 6,369 patients surveyed had a lot or some trust in the Internet as a source of cancer information [4]. Other studies have had comparable findings with most patients believing that the Internet is a helpful health information resource and that it permits patients to be more involved in their own medical care [3].

While many patients are using the Internet as an information source, a considerable amount of information is unfiltered and unedited. Information may be inaccurate, out of date, and irrelevant, and careful selection of search terms and search engines is prudent. Most respondents in our study used the search engine Google and selected melanoma websites to view based on the top search engine hits. However, the most popular websites are not always the most reliable sources [14]. A study looking at breast cancer Internet information quality assessed the top 100 Google web pages per breast cancer topic and found 42 % were inapplicable to the question asked [14]. The accuracy of information on these websites ranged from 78 to 91 % depending on the topic [14]. Another breast cancer study found that of the top 10 Google search results for aromatase inhibitors, only 30 % were considered to be high quality sources [15]. A study performed in 2002 looking at the quality of the first 30 unique websites from eight search engine queries for “melanoma” found that 14 % of websites had inaccuracies and the majority did not include complete information on risk factors, diagnosis, treatment, prevention, and prognosis [9]. A large systemic review of Internet health information found that 70 % of 79 studies included in the analysis found deficiencies in medical information quality online [16].

Only one third of respondents in our study reported visiting academic or government websites. Many studies analyzing website quality have established that commercial breast, gastric, and colorectal websites have higher rates of inaccuracies compared to government and academic websites [14, 17–19]. To verify the quality of the information on the Internet, few respondents in our study assessed website authorship and references. These criteria are often included in tools aimed at assessing the quality of Internet-based information including the Information Quality Tool, Quality Scale, and DICERN [20, 21]. Similar to our findings, Eysenbech et al. found that most patients could not recall which websites they had visited [22].

Almost all of the Internet users in our study searched for melanoma treatment information. The next most common search topics were melanoma prevention and screening. To our knowledge, the study of Bichakjian et al. is the only published study assessing the quality of data available on melanoma websites [9]. They found only 53 % of websites provided information on local treatment, 43 % regional surgery, 23 % sentinel lymph node biopsy, 51 % distant treatment, and 34 % interferon [9]. Approximately a third of websites discussed preventative techniques and 38 % had reviewed screening [9]. Our recent research examined the quality of 100 melanoma websites. Only 36 % of websites described treatment specific to stage [23]. Taken together with Bichakjian’s study, it appears that the majority of top melanoma websites do not contain the type of information melanoma patients are seeking [9].

Although most respondents felt the Internet increased their understanding of their diagnosis, more than half found melanoma Internet resources at least somewhat difficult to understand. This may be due to many Internet resources being written at a grade level higher than the average patient [5]. Indeed, a systemic review found that most studies which assessed health website readability reported reading levels higher than the average grade level of the health consumers [16]. Interestingly, physicians are aware that many Internet resources are not written in an understandable manner. A survey of oncologists found that 90 % believed it was difficult for patients to interpret Internet medical information correctly [24]. Additional factors may impact comprehension such as cultural sensitivity and the tone of websites; however, we did not assess the impact of these factors in our study [16].

A commonly cited reason for not finding the Internet useful in our study was the overwhelming amount and the negativity of information presented. Similarly, Sabel’s study found that one third of melanoma cancer patients surveyed found searching the Internet increased their anxiety [10]. This is not unexpected as melanoma outcomes vary greatly by stage with 97 % 10-year survival for stage I disease compared to 14 % for stage IV [25]. Depending on the stage and other disease variables, treatment can vary from surgical excision alone to radiation and systemic therapy [25]. Patients may lack the ability to sort out what information regarding management and prognosis applies to their specific diagnosis and may incorrectly assume their cancer prognosis is poor.

A large percentage of Internet users in our study identified that the Internet influenced their treatment decision, similar to our breast cancer study [13]. Likewise, over half found it impacted their clinical encounter with their melanoma specialist which was again comparable to our breast cancer study [13]. This is echoed to some extent in other studies. A survey of Canadian patients found that 29 % requested specific treatments and 6 % declined treatments recommended by their physician as a result of their media and Internet information search [24]. This study also reported that 63 % of patients and 76 % of oncologists believed patients’ information searches did not adversely affect the physician–patient relationship [24].

This study has several limitations. Our sample size was relatively small and the survey was conducted at one institution so the findings may not be generalizable to all melanoma patients. All surveys suffer from selection bias; those who do not use the Internet or do not feeling strongly about the survey topics may have been less likely to participate in this survey. In addition, there may be recall bias, as patients who were diagnosed with melanoma many years ago may not have remembered the details of their Internet search patterns.

Our study makes a meaningful contribution to the literature by characterizing the Internet search patterns of melanoma patients and the impact of the Internet on their encounters with physicians. The incidence of melanoma is increasing and the most recent Canadian Cancer Statistics update chose to highlight the rising incidence of skin cancer [26]. Additionally, there has been an influx of novel systemic treatments for melanoma [27]. As a result, it is expected that there will be a similar influx of Internet-based melanoma resources in the near future. Our study found that the majority of survey respondents searched online for melanoma information. While most found the Internet to be a useful source of melanoma information, some found it overwhelming and difficult to understand and few patients critically evaluated websites by assessing author credentials and references. Physicians should acknowledge that many melanoma patients are searching the Internet for information regarding their cancer and that it may impact their disease understanding and treatment decisions. Perhaps, a standard part of any oncologic history should be to ask patients if have looked online for information regarding their diagnosis. This would help assess patients' background knowledge about their diagnosis. Ultimately, physicians and patients must work together to share information and a more complete understanding of the resources patients use may positively impact the patient and physician relationship and improve communication.

Conflicts of Interest None

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