Online information seeking behaviors of breast cancer patients before and after diagnosis: From website discovery to improving website information

A R T I C L E   I N F O

A B S T R A C T

Despite the internet being a common place breast cancer patients seek information, navigating this Wild West of content can be challenging. The present study analyzed open-ended data from breast cancer survivors ($n = 77$) regarding their online information seeking behaviors when looking for breast cancer information to help inform the creation of improved online educational materials. Participants were asked what prompted them to seek information, which websites and search terms they used both before and after diagnosis, what information was useful, what misinformation was found, and what they would like to see improved. Results indicated symptoms, tests, or diagnoses prompt women to seek breast cancer information online, and that many different search terms and websites are used. More search terms and websites were utilized after diagnosis compared to before diagnosis, but the most common search terms and websites did not change much from before to after diagnosis. Cancer specific and general medical websites were the most popular. The most useful information related to treatment, obtaining information from other breast cancer survivors, statistics, and positively-valenced information. Though misinformation was not reported by many participants, some mentioned outdated survival rates, inaccurate information about alternative treatments, and other breast cancer patients' experiences that did not align with their own. Participants desired improvements in treatment information, more factual information, a guide, and information that is easy to understand. Creation of a guide and use of search engine optimization to help breast cancer patients navigate this online information could be beneficial.

Introduction

In the U.S., breast cancer (BC) accounts for almost one-third of new cancer cases, and in 2019, 268,600 new female BC cases were estimated to be diagnosed [1]. When people want cancer information, they often go to the internet first [2]. Thus, it is important to understand why and how BC patients start seeking online information, and if they perceive the information as accurate, useful, and accessible.

Triggers prompting BC information seeking

Cancer patients can use the internet to understand symptoms before seeing providers. After diagnosis they can also seek information to cope, enhance confidence, and guide decisions [3]. Understanding what triggers lead women to seek information about BC online could therefore help educators develop more useful web content.

RQ1: What prompted BC patients to initially search for BC information online?

Search terms used in seeking BC information

Investigating search terms is essential because many people do not click beyond the first page of search results [5]. Common BC search terms used by the general population include "prognosis," treatment options (e.g., "radiation" or "mastectomy"), and "prevention," [6]. However, little research has examined what terms *BC patients* use, and if there are differences at different points in their disease trajectories.

RQ2: What search terms do BC patients use to seek out BC information online before and after diagnosis?

Websites used for information seeking

To obtain cancer information, people visit a variety of websites [2]; BC information is spread across multiple websites, making it difficult to find information [6]. BC patients commonly seek BC information from cancer organization websites or WebMD [4]. Yet, little research has examined if women seek out different websites before and after diagnosis.

RQ3: Which websites do BC patients use to seek out BC information before and after diagnosis?

Usefulness and misinformation of online information

The quality of information BC patients find online varies substantially [[8],[9],[10]], with over one-third of the information unrelated to the search [7]. Few recent sources examine the accuracy of online BC information and BC patients' perceptions of misinformation.

RQ4: What online information is most useful for BC patients, and on which websites is this information found?
RQ5: What misinformation about BC exists online?
RQ6: How can online BC information be improved?

Materials and methods

Data collection occurred in November-December 2017. Recruitment messages were posted on the ACS Facebook page seeking BC survivors to take an online Qualtrics survey about online information seeking ($n = 43$). Additionally, the Inflammatory Breast Cancer (IBC) Research Foundation sent a message to their listserv to recruit participants ($n = 34$). For each woman who took the survey, $1 was donated to the organization where they saw the recruitment prompt. The study was approved by the university's institutional review board.

Participants

Seventy-seven female BC patients' open-ended responses were analyzed. Ages ranged from 28 to 77 ($M = 39.04$, $SD = 10.87$). The sample was 82.4% Caucasian, 13.3% African American, and 4.4% indicated Other. Approximately 60% of respondents resided in Indiana, 35.8% resided in one of 20 other U.S. states, and 4.5% resided outside the U.S. Participants were diagnosed with BC between 1981–2017. Nine participants did not provide demographic information.

Survey items

Open-ended questions were asked regarding what prompted participants to seek information online, which websites they sought information from, and which search terms they used before and after diagnosis with BC. Participants were also asked to indicate the most useful information they found, where they found it, what misinformation they found, and what they would like to see improved regarding online BC information.

Data analysis

Four coding schemes were developed for the questions asking what prompted participants to search, what information was useful, what misinformation was found, and what information participants would like to see improved. One researcher conducted a thematic analysis and open coded the data to look for emergent themes [11]. The researcher developed a coding scheme for the open-ended content questions and trained two other researchers in the scheme. For all questions, all responses were coded because of the small number of responses. After all coding was completed (coding agreement was high among all categories [85–100%], $\kappa = 0.81$ overall), the researchers then talked through each disagreement and came to a consensus about which category(ies) it fit into until 100% agreement was obtained.

Results

Research question 1

Research question 1 sought to understand what prompted women with BC to seek information online. Four primary themes emerged: symptom, test, after diagnosis, and family (see Table 1).

Research question 2

The second research question examined which search terms BC patients used to look up BC information online before and after diagnosis. Separate frequency counts were conducted for the search terms used before and after diagnosis (see Table 2). The top three search terms were "breast cancer," "mastectomy," and "IBC."

Research question 3

The third research question sought to examine which websites BC patients used to look for BC information before and after diagnosis.

Separate frequency counts were conducted for websites used before and after diagnosis (see Table 2). The most common websites were American Cancer Society, WebMD, Mayo Clinic, and Breastcancer.org.

Research question 4

The fourth research question asked what useful information BC patients found when searching for information online, and on which sites it was found. Six relevant themes emerged: treatment, others' experiences, statistics, positive, symptoms, and questions (see Tables 1 and 2).

Research question 5

Research question 5 asked what misinformation was found when looking online for BC information. Seven themes emerged: old rates, holistic/cure, worse experience, lack of information, pain, causes, or none (see Table 1).

Research question 6

The final research question sought to understand what online BC information participants believed could be improved. Eleven themes emerged: treatment, accuracy, guide/navigation, health literacy, good as is, symptom/diagnosis, IBC, negative, culture, age, and selling things (see Table 3).

Conclusions

Many BC patients seek information online about BC before and after diagnosis. Symptoms initially prompt women to seek online information on BC. BC patients desire information that is up-to-date, accurate, and easy to comprehend, and appreciate health sites related to their *specific* health issues such as IBC. Because women use so many search terms, cancer educators who update these websites should ensure their websites are search engine optimized by placing key search terms into the titles, urls, and website overview text that appears on search results pages [12]. Limitations from this study include recall bias, as participants were asked to recall which sites/search terms were visited and when, and the results may overrepresent perspectives of IBC patients.

A guide for navigating online BC information would be helpful for BC patients, listing common websites, search terms, useful information, and misinformation. This guide could be organized by topic based on the most common search terms, and could link to specific helpful websites related to each topic, or organized by type of website (e.g., government site, support group, etc.). Compiling all of this information into one place would allow for BC survivors to guide new BC patients with lessons learned from their own information seeking experiences, and help newly diagnosed patients navigate this complex information environment.

Ethics approval

This research was approved as exempt by the Purdue University Institutional Review Board.

Author contributions

Evan K. Perrault, Ph.D. helped conceptualize the study, supervised research assistants, co-wrote the manuscript and edited the revision.

Grace M. Hildenbrand, supervised data coding, formally analyzed the data, and co-wrote the manuscript and edited the revision.

Seth P. McCullock, assisted in data coding and writing the original manuscript.

Katie J. Schmitz, assisted in data coding and writing the original manuscript.

Table 1
Themes arising from open-ended responses.

What Prompted Online Information Seeking? (N = 77; κ=0.86; 96.10% agreement) – RQ1

	Symptoms	Test Results	After Diagnosis	No Online Search	Family	Other
n (%)	35 (45.45)	18 (23.38)	14 (18.18)	8 (10.39)	3 (3.90)	2 (2.60)
Examples	"My nipple started to invert"; "I felt the lump"	"Abnormal screen in mammogram"; "Called back to clinic for suspicious mammogram"	"I didn't do online research until I was diagnosed with Inflammatory Breast Cancer"; "After being diagnosed with breast cancer and I wanted to learn more"	"Didn't search at this time"; "Had no 'on line' back in 1991, saw info in Preventive magazine"	"Family history of breast cancer"; "Since breast cancer runs in my family - I immediately wondered if there was a connection"	"Good to know information to pass on to someone who needs it"; "I was suspicious that I could have breast cancer, even though my surgeon did not think I had cancer"

What Online Information was Useful? (N = 53; κ=0.82; 94.58% agreement) – RQ4

	Treatments	Others' Experiences	General	Statistics	Positive	Symptoms	Questions	Other
n (%)	24 (45.28)	11 (20.75)	10 (18.87)	10 (18.87)	6 (11.32)	4 (7.55)	3 (5.66)	13 (24.53)
Examples	"Info about breast cancer treatments"; "Drug sites with side effect information"	"I'm not alone, and my reaction/emotions/outbursts/feeling of despair are normal"; "The most useful was from actual survivors"	"General info about breast cancer"; "The explanation of the different types you can have"	"For stats"; "It was information regarding survival rates"	"It was good to see that it wasn't just a death sentence and that women beat cancer"; "They provided hope and realistic expectations"	"That my clear discharge meant cancer. Oh great!!!!"; "Pictures of my symptoms"	"Questions to ask doctors"; "Questions to ask every step of the way"	"I don't remember"; "Nothing stands out"

What Misinformation did Patients Find? (N = 60; κ=0.88; 97.08% agreement) – RQ5

	No Misinformation	Old Rates	Holistic/Cures	Worse Experiences	Lack of Information	Causes	Pain	Other
n (%)	27 (45.00)	10 (16.67)	7 (11.67)	6 (10.00)	5 (8.33)	2 (3.33)	3 (5.00)	8 (13.33)
Examples	"I don't recall any misinformation"; "None"	"Survival stats were outdated"; "Lots of information that seemed accurate was woefully out of date"	"There are a lot of 'miracle cures' out there"; "Stuff about what to eat, not eat, alternative meds and treatments"	"Usually reported much worse side effects"; "Lots of fear and negative complaining stuff out there about not drinking, reconstruction gone wrong etc."	"Specific information about Inflammatory Breast Cancer was scarce"; "There is too little understanding about the potential health benefits of nutritional supplements"	"Coffee causes it, sugar causes it"; "Information that states there is a definite [link] between sugar and meat and tumor growth"	"That pain in the breast would not be cancer. Mine was"; "That breast pain is not a cancer symptom"	"Komen gives back to the community at the grassroots level"; "People not understanding about IBC or Breast cancer in young women"

Table 2
Frequencies of search terms, websites consulted, and most useful websites.

Search Terms- Before (N = 72); 151 terms	n (%)	Search Terms- After (N = 60); 208 terms	n (%)	Websites- Before (N = 74); 41 websites	n (%)	Websites- After (N = 66); 60 websites	n (%)	Useful (N = 63); 22 websites	n (%)
Breast cancer	26 (36.11)	Breast cancer	15 (25.00)	American Cancer Society	21 (28.38)	American Cancer Society	26 (39.39)	IBCresearch.org	11 (17.46)
Mastectomy	8 (11.11)	Inflammatory breast cancer	13 (21.67)	WebMD	14 (18.92)	Mayo Clinic	15 (22.73)	Breastcancer.org	8 (12.70)
Inflammatory breast cancer	7 (9.72)	Mastectomy	6 (10.00)	Mayo Clinic	12 (16.22)	Breastcancer.org	13 (19.70)	Online support groups	3 (4.76)
Chemotherapy	6 (8.33)	Chemotherapy	4 (6.67)	Breastcancer.org	10 (13.51)	IBCresearch.org	12 (18.18)	American Cancer Society	2 (3.17)
Inverted nipple	5 (6.94)	IBC	4 (6.67)	Susan G. Komen	10 (13.51)	Susan G. Komen	11 (16.67)	Dr. Susan Love	2 (3.17)
Radiation	4 (5.56)	Adriamycin	3 (5.00)	IBCresearch.org	7 (9.46)	WebMD	9 (13.64)	Mayo Clinic	2 (3.17)
Swollen breast	4 (5.56)	Breast reconstruction	3 (5.00)	Dr. Susan Love	3 (4.05)	MD Anderson	6 (9.09)	NIH	2 (3.17)
Symptoms of breast cancer	4 (5.56)	Invasive Ductal Carcinoma	3 (5.00)	NIH	3 (4.05)	NIH	5 (7.58)	Pub Med	2 (3.17)
Breast	3 (4.17)	Survival rates	3 (5.00)	Breast Cancer Association	2 (2.70)	Doctor's office website	4 (6.06)	Susan G. Komen	2 (3.17)
IBC	3 (4.17)	Breast cancer research	2 (3.33)	Facebook	2 (2.70)	Dr. Susan Love	3 (4.55)	bcmets	1 (1.59)
Mammogram	3 (4.17)	Breast implants	2 (3.33)	Live Strong	2 (2.70)	Facebook	3 (4.55)	Breastcancer.com	1 (1.59)
Metastatic breast cancer	3 (4.17)	Chemotherapy side effects	2 (3.33)	NCI	2 (2.70)	IBCsupport.org	3 (4.55)	Cancer.org	1 (1.59)
Triple negative	3 (4.17)	Clinical trials	2 (3.33)	Simon Cancer Center	2 (2.70)	Pub Med	3 (4.55)	Chemo Care	1 (1.59)
Biopsy	2 (2.78)	Grade 2 breast cancer	2 (3.33)			Cleveland Clinic	2 (3.03)	DOD breast cancer program	1 (1.59)
Breast cancer staging	2 (2.78)	Hair loss	2 (3.33)			Clinicaltrials.gov	2 (3.03)	Facebook group	1 (1.59)
Breast cancer support	2 (2.78)	HER 2+ breast cancer	2 (3.33)			Dana Farber website	2 (3.03)	IBC app	1 (1.59)
Breast itching	2 (2.78)	Herceptin	2 (3.33)			Johns Hopkins	2 (3.03)	ibcsupport.org	1 (1.59)
Breast pain	2 (2.78)	Inflammatory breast cancer prognosis	2 (3.33)			Live Strong	2 (3.03)	Medical journals	1 (1.59)
DCIS	2 (2.78)	Lumpectomy	2 (3.33)			NCI website	2 (3.03)	NCI	1 (1.59)
Lumpectomy	2 (2.78)	Mammogram	2 (3.33)					Norton's Resource Center website	1 (1.59)
Rash	2 (2.78)	Mayo Clinic	2 (3.33)					Research hospital site	1 (1.59)
Reconstruction	2 (2.78)	Metastatic breast cancer	2 (3.33)					YouTube	1 (1.59)
Survival rates	2 (2.78)	Radiation	2 (3.33)						
Treatment	2 (2.78)	Taxol	2 (3.33)						
		Taxotere	2 (3.33)						
		Triple negative	2 (3.33)						
		Triple negative breast cancer	2 (3.33)						

Note. For some questions, several participants indicated they did not seek information online. For "search terms- before" n = 13, 18.06%; for "search terms- after" n = 7, 11.67%; for "websites- before" n = 6, 8.11%; for "websites- after" n = 14, 18.92%; for "websites-after" n = 3, 4.55%.

Note. For the website questions, several participants indicated that they did a general internet search using a search engine rather than listing specific websites. For "websites- before" n = 14, 18.92%; for "websites- after" n = 5, 7.58%.

Note. For the website questions, several participants commented in a way that did not represent a website, forming an "Other" category, with responses such as "NA," "don't know," or "various." For "websites- before" n = 14, 18.92%; for "websites- after" n = 7, 10.61%; for "useful" n = 9, 14.29%.

Note. For the sake of saving space, for all questions except for "useful," only the frequencies with two or more participants listing the website or search term are listed.

4

Table 3
What improvements could be made to online information? ($N = 55$; $\kappa = 0.70$; 93.48% agreement).

Themes	n (%)	Examples
Treatment Information	15 (27.27)	"Treatment research & meds"
		"Show pictures of…chemo rooms and set ups (they are pretty universal), what going to radiation is like"
Accuracy of Content	14 (23.33)	"I'd like to see more accurate information about various types, and subtypes of breast cancer"
		"More factual information"
Guide/Navigation	11 (20.00)	"A navigation site for all breast cancer sites"
		"I would like to see it all in one place"
Health Literacy Considerations	8 (14.55)	"Explain pathology terms so that non-medical people understand"
		"Easier way to access for different types of bc"
Good as is	7 (12.73)	"Quite frankly, the IBC site was so thorough I can't think of any improvement"
		"I had no problems finding qualified information"
Symptom/Diagnosis	7 (12.73)	"Show pictures of different symptoms"
		"More information regarding the variety of symptoms which could indicate breast cancer"
Inflammatory Breast Cancer (IBC)	6 (10.91)	"Consistent information about IBC"
		"IBC recognized as a real threat"
Less Negative Information	5 (9.10)	"Easier to find information on inflammatory BC that is not so negative"
		"More about not the worst case scenario"
Culture Specific Information	3 (5.45)	"Additional information/statistics regarding Hispanic/Latino/African American and other races"
		"More culturally sensitive information"
Age	2 (3.64)	"Information relative to all ages and stages"
		"More for young people"
Remove Commercialization of Content	2 (3.64)	"I prefer sites that are not seeking $, patients or selling something and base their information on facts"
		"Serious inquires only not for salespeople"
Answers Lacking Specificity / Other	13 (23.64)	"Just more of it"

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5