Online communities for breast cancer survivors: a review and analysis of their characteristics and levels of use

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Abstract

Purpose Online communities have been heralded as one of the most promising health resources on the Internet. The purpose of this study was to identify the characteristics and levels of use of online communities for breast cancer survivors.

Methods Using Google, we identified websites with a string of computer-mediated communication terms and individual queries of three to five words of online community terms. This was complemented by a review of website resource lists and personal libraries. Two reviewers independently extracted information on their general characteristics and

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number of members and message board posts. A coding scheme guided content analysis.

Results We found 111 websites. Most sites (*n*=64, 65.8 %) had a broad focus (e.g., health, cancer, or general). One third (*n*=38, 34.2 %) were exclusive to breast cancer and 11 catered to specific disease characteristics. The majority were American (*n*=79, 75.2 %), nonprofit (55.0 %), and moderated (69.5 %). Most moderators (85.7 %) were staff or community members; eight sites were moderated by health professionals. Greater than one-third of sites (*n*=40, 36 %) were initiated by breast cancer survivors or loved ones. Breast cancer-specific sites contained a total of 4,186,275 posts. One-third (*n*=10) contained 93.4 % of posts, displaying over 100,000 posts each. As of April 3, 2012, eight sites were discontinued.

Conclusions There is a wide range of online communities available for breast cancer survivors with extensive archives of personal illness experiences. Future efforts should focus on identifying the factors that determine their success and effectiveness.

Keywords Online communities · Breast cancer · Health information · Internet · Social support

Background

The Internet has changed the way people seek and engage with health information. Although health professionals, family, and friends remain the preferred sources of health information, online resources, including patient experiences are a significant source of health information and support [1, 2]. Surveys conducted in 2010 indicate that at least 80 % of North Americans use the Internet regularly, that six in ten

have looked online for health information [1, 3] and that one in four Americans have read about someone else's health experience in an online community [1].

Online communities have been defined as "virtual social space(s) where people come together to get and give information or support, to learn, or to find company" [4]. The terms "online," "virtual," "Internet-mediated-," "web-based-," "group," "community," or "network" are used interchangeably in the literature to refer to the same concept. Initially, online communities were supported by mailing list and message board software. More recently, they have formed around and across blogs, wikis, and social network sites Web 2.0 software applications, which allow the creation and exchange of content by anyone in an open collaborative fashion [5].

Breast cancer survivors have been identified as one of the groups most likely to use online communities as a health resource [6]. Although there is limited empirical evidence concerning their effects [7], numerous descriptive studies indicate that online communities have empowering benefits. Such groups have been shown to provide breast cancer survivor reassurance, a sense of community and hope for the future, reduce feelings of stress and uncertainty, validate concerns ignored by health-care professionals, enable breast cancer survivors to become better informed and able to manage their condition, and prepare breast cancer survivors for their interactions with the health-care professionals [8–13].

However, we know little about the amount and characteristics of online communities for people living with breast cancer, including which ones are most popular and why. A review conducted in 2003 identified a total of 546 online cancer communities but did not characterize them by cancer type or report their levels of activity [14]. Two studies that attempted to evaluate the quality of information in a sample of breast cancer websites [15, 16] documented the type of communication software that the sites provided but also did not report on their levels of use. One study [16] concluded that the most popular breast cancer websites (as determined by Google rank) were correlated with type rather than quality of content and contained message board software. All of these studies were published in the early 2000s, well before the emergence of Web 2.0 and the subsequent social media revolution.

We need to gain a better understanding on the most popular online communities so that we can effectively target our effectiveness research and guide patients to useful resources. One way to assess the popularity of an online community is to determine its activity, as measured by the number of user-generated posts [17]. Therefore, the purpose of this study was to identify websites that provide English language online communities for breast cancer survivors and to synthesize their general characteristics and patterns of use.

Methods

Data sources

Websites were identified through a search of Google (www.google.ca) accessed on December 23, 2009, because it represented the leading search engine used by 85 % of the global market share at that time [18].

Inclusion criteria

Websites were included if they

- Contained communication technology (e.g., mailing list, message board, chat room, blog, wiki) that served as a forum for breast cancer related topics;
- Contained content (including that contributed by users) in English;
- Were active, as defined as having more than one post contributed by members from the date the search was conducted (December 23, 2009) to the date the total number of the members and posts was documented (October 26, 2010); and
- Were publicly available.

Excluded websites

- Single author blogs (as opposed to sites that provided facilities for any visitor to create and sustain a personal blog);
- Websites that contained wikis as the only form of computer-mediated communication if they were not being used for breast cancer-themed discussion; and
- Website aggregators (i.e., websites that pool and publish other websites).

Search strategy

We used two complementary search strategies to locate relevant websites (Appendix 2). The first approach, modeled after a typical academic literature search, used Boolean operators (e.g., "AND" and "OR") to connect a string of computer-mediated communication technology terms; all accessible hits were investigated. The second approach, modeled after a typical Google query, which consists of an average of four words [19], included nine separate searches of different types of online communities (e.g., *breast cancer message boards*). The first 100 hits from each of the nine searches were investigated after it was concluded from the first approach that there would likely be about 100 relevant sites in total. Both search strategies were applied to "anywhere on a page." Two of us (JLB and MCJM) independently assessed the eligibility of all search results. One of us (JLB) reviewed the resource lists of retrieved websites, as

well as personal libraries for other potentially eligible websites to include in the review. Disagreements were resolved by consensus in all cases.

Data collection and analysis

Two of us (JLB and MCJM) independently extracted information on the following:

- General characteristics (e.g., URL, launch date, purpose, country of origin, initiator, affiliation, and moderation)
- Number and type of communication technologies (e.g., mailing list, asynchronous message board, chat room, blog, wiki)
- Social networking features (e.g., ability to construct a public profile and view the profiles and networks of other members)
- Total number of registered users and posts as of October 26, 2010, (11 months after the sites were identified and their general characteristics were extracted for analysis)
- Status as of April 3, 2012

We developed a coding scheme to classify the purpose (breast cancer exclusively, cancer, any health issue, or any general topic), affiliation (e.g., for-profit organization, non-profit organization, university or health care organization, or unaffiliated individual or group), and initiator (former cancer survivor/ family caregiver, health professional, health research, charity, or unknown). Sites were classified as moderated if they claimed to be so or contained evidence of moderation from site administrators or suggestive activities in the message board (e.g., posts that welcomed new members, individuals who responded to member requests or questions, or who stimulated discussion).

We contacted site administrators, where possible, to request the total number of registered members, posts, and date of launch, if it was not published on the site. We obtained permission from site owners to publish any publicly unavailable information. The total number of registered members and message board posts is summarized from breast cancer-specific sites only because this information was not consistently available from multipurpose sites. Only 21.9 % of multipurpose sites disclosed the total number of posts, and only 2.7 % disclosed their membership numbers.

We met to review all data extracted and coded. Disagreements were resolved through consensus, including cross-checking the original source and involving a third reviewer when necessary.

Evidence tables were produced to summarize the information extracted from the websites and obtained from the site administrators. We calculated descriptive statistics using the software package SPSS version 17 (IBM Corporation, Somers, NY, USA).

This study was a component of a larger research study for which ethical approval was obtained from our Institution's Research Ethics Board.

Results

The total yield from the two Internet search strategies was 1,714. As shown in Fig. 1, 153 websites were subjected to preliminary analysis and 111 were included in the final analysis. The complete inventory of online communities used in this study is presented in Table 1.

Characteristics of included websites

Purpose

Characteristics of the websites are shown in Table 2. The majority (65.8 %) of sites were multipurpose. These included general health sites (www.mdjunction.com), cancer sites
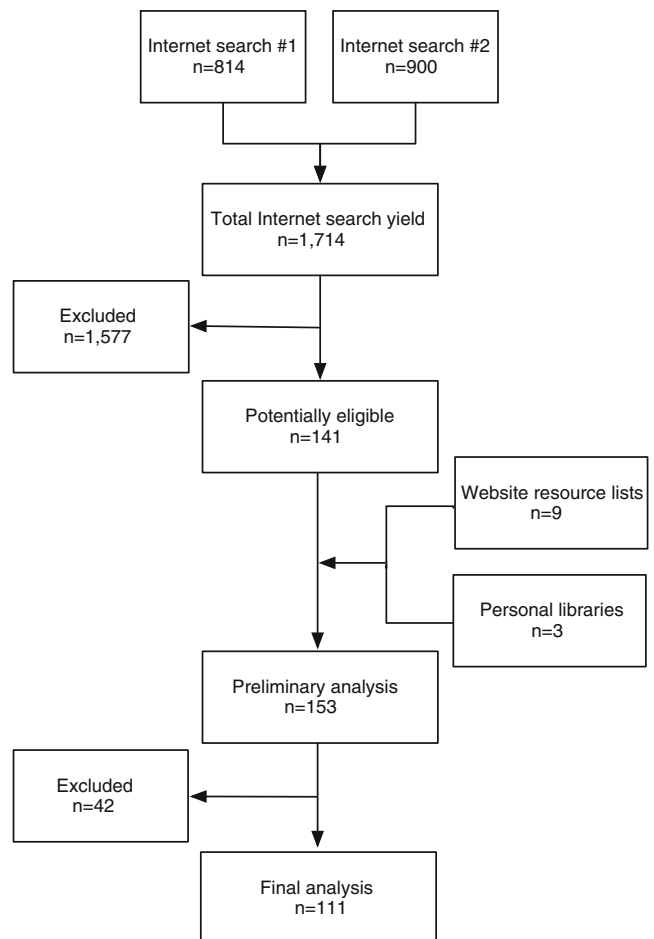

Fig. 1 Flow diagram of included websites

Table 1 Inventory of online communities for breast cancer survivors

	Name	URL	Focus
1	Association for Online Cancer Resources (ACOR)	www.acor.org	Cancer
2	Action Breast Cancer Ireland	www.cancer.ie/action/ http://www.cancer.ie/cancer-information/breast-cancer http://forum.cancer.ie/phpBB3/	Breast cancer
3	All About You	www.allaboutyou.com	General purpose
4	AOL	http://messageboards.aol.com	General purpose
5	Aussie Breast Cancer Forum	www.bcaus.org.au/	Breast cancer
6[a]	Avon Crusade	Closed	Breast cancer
7	B-mail	www.bci.org.au	Breast caner
8	BC Advisor	www.bcadvisor.com/	Breast cancer
9	BC Mets	www.bcmets.org	Breast cancer (metastatic)
10	BC Pals	www.bcpals.org.uk	Breast cancer
11	BC Support	www.bcsupport.org	Breast cancer
12	Bebo	www.bebo.com	General purpose
13	Bella Online Forums	www.bellaonline.com	General purpose
14	Be Bright Pink	www.bebrightpink.org	Breast cancer (high risk young women)
15	Bizymoms	www.bizymoms.com	General purpose
16	Blog for a cure	www.blogforacure.com	Cancer
17	Bosom Buddies	http://bosombuddies.cfsites.org/	Breast cancer
18	Breast Buddies	www.breastbuddies.co.za/forum	Breast cancer
19	Breastcancer.org	www.breastcancer.org	Breast cancer
20	Breast Cancer Awareness	www.breastcancerawareness.com	Breast cancer
21	Breast Cancer Care	www.breastcancercare.org.uk	Breast cancer
22	Breast Cancer Mailing List	www.bclist.org	Breast cancer
23[b]	Breast Cancer Network of Strength (Rebranded: Y-Me Breast Cancer Support Today)	http://www.y-me.org/	Breast cancer
24	Breast Cancer Now What	www.breastcancernowwhat.ca	Breast cancer (young women)
25	Breast Cancer Support New Zealand	www.breast.co.nz/	Breast cancer
26	Breast Cancer Support UK	www.breastcancersupport.co.uk	Breast cancer
27[a]	Breast Friends	Closed	Breast cancer
28	Breast Health Online	www.breasthealthonline.org	Breast cancer
29	Breast Reconstruction	www.breastreconstruction.org	Health (breast reconstruction)
30	Cancer Buddies Network	www.cancerbuddiesnetwork.org	Cancer
31	Cancer Survivors Network	http://csn.cancer.org/forum	Cancer
32	Cancer Care	www.cancercare.org	Cancer
33	Cancer Chat UK	www.cancerchat.org.uk	Cancer
34	Cancer Compass	www.cancercompass.com	Health
35	Cancer Connections	www.cancerconnections.com.au	Cancer
36	Cancer Focus	www.cancerfocus.org	Cancer
37	Cancer Forums	www.cancerforums.net	Cancer
38	Cancer Match	www.cancermatch.com/	Cancer
39	Cancer Support	http://cancersupport.aarogya.com	Cancer
40[a]	Cancer Treatment Forums	Closed	Cancer
41	Care Pages	www.carepages.com	Health
42	Caring 4 Cancer	www.caring4cancer.com	Cancer
43	Caring Voices	www.caringvoices.ca	Cancer
44	Cure Today	www.curetoday.com	Cancer

Table 1 (continued)

	Name	URL	Focus
45	Cure Zone	www.curezone.com	Cancer
46	Daily Strength	www.dailystrength.org	Health
47	DIEP Breast Reconstruction	www.diepbreastreconstruction.org/forum/	Breast cancer (post-mastectomy reconstruction)
48	Discovery Health	http://health.discovery.com/conversations/conversations.html	Health
49	eHealth Forums	http://ehealthforums.com	Health
50	EmpowHER	www.empowher.com	Health
51	Everyday Health	www.everydayhealth.com	Health
52	Experience Project	www.experienceproject.com	Health
53	Facebook	www.facebook.com	General
54	Facing Our Risk of Cancer Empowered (FORCE)	www.facingourrisk.org	Breast and Ovarian cancer (hereditary)
55	Friends in Need	www.friendsinneed.com	Breast cancer
56	Friends in Touch	www.friendsintouch.net	Breast cancer
57	Healia Communities	http://communities.healia.com	Health
58	Healing well	www.healingwell.com	Health
59	Health	www.health.com	Health
60	Health Boards	www.healthboards.com	Health
61	Health Central	www.healthcentral.com	Health
62	Health Forums	www.health-forums.com	Health
63	Health Front	www.healthfront.com	Health
64	Health Talk	www.healthtalkonline.org	Health
65	Her 2 Support	www.her2support.org	Breast cancer (Her 2 positive)
66	Hystersisters	www.hystersisters.com	Health (hysterectomy)
67	Inflammatory Breast Cancer Support	www.ibcsupport.org	Breast cancer
68	Imaginis	www.imaginis.com	Health
69[a]	iMedix	Closed	Health
70	Inspire	www.inspire.com	Health
71	iVillage	www.ivillage.com	General
72	Living Beyond Breast Cancer	www.lbbc.org	Breast cancer
73	Lymphedema People	www.lymphedemapeople.com	Health (lymphedema)
74	MD Anderson	www.mdanderson.org/	Cancer
75	MD Junction	www.mdjunction.com	Health
76	MSN Health & Fitness	http://health.msn.com	Health
77	MacMillan	www.macmillan.org.uk	Cancer
78	Make Me Heal	www.makemeheal.com	Health (plastic surgery)
79	Med Help	www.medhelp.org	Health
80	Medpedia	www.medpedia.com	Health
81[a]	Moms Like Me	Closed	General
82	My Lifetime	www.mylifetime.com	General
83	MySpace	www.myspace.com	General
84	National Breast Cancer Foundation	www.nationalbreastcancer.org	Breast Cancer
85	Net Doctor	www.netdoctor.co.uk	Health
86	No Surrender	www.nosurrenderbreastcancersurvivorforum.org	Breast cancer
87	Oncochat	www.oncochat.org	Cancer
88[a]	Oncology Channel – (Rebranded Health Communities)	www.healthcommunities.com (Removed online community)	Cancer/Health
89	Pink Link	www.pink-link.org/	Breast cancer

Table 1 (continued)

	Name	URL	Focus
90	Pink Ribbon	www.pinkribbon.org	Breast cancer
91	Pink Ribbon Girls	www.pinkribbongirls.org	Breast cancer
92	Revolution Health	www.revolutionhealth.com	Health
93[a]	Sharing Strength	www.sharingstrength.ca (archived)	Breast cancer
94	Susan G Komen Breast Cancer Foundation	http://apps.komen.org/Forums/default.aspx	Breast cancer
95	The Breast Cancer Site	http://www.thebreastcaresite.com/tbcs/	Breast cancer
96	Topix	www.topix.com	General
97	Triple Negative Breast Cancer Foundation	www.tnbcfoundation.org	Breast cancer (triple negative)
98	Twitter	www.twitter.com	General
99	Web MD	www.webmd.com	Health
100	Wego Health	www.wegohealth.com	Health
101[b]	Wellness Community (Rebranded: Cancer Support Community)	www.cancersupportcommunity.org/	Cancer
102	Well Sphere	www.wellsphere.com	Health
103	Wiki Cancer	www.wikicancer.org/	Cancer
104[b]	Willow-Talk (Rebranded: Willow Breast Cancer Support)	www.willow.org	Breast cancer
105	Women's Health	www.womens-health.com	Health
106	Women's Health Matters	http://www.womenshealthmatters.ca/ubbthreads7/ubbthreads.php	Health
107[a]	Wrong Diagnosis	Closed	Health
108	Yahoo	http://health.dir.groups.yahoo.com	General
109	Young Survival Coalition	www.youngsurvival.org/	Breast cancer (young women)
110	YouTube	www.youtube.com	General
111	Yuku	www.yuku.com	General

[a] Site has closed down or discontinued its online community

[b] Site has been rebranded

(www.acor.org), or general purpose sites (www.facebook.com). About one-third of sites (34.2 %) were exclusively for people with breast cancer and, of these, 11 catered to certain disease characteristics (e.g., metastatic) or demographics of breast cancer survivors (e.g., young).

Affiliation and initiator

Forty-five percent of the online communities were for-profit commercial sites (e.g., affiliated with a pharmaceutical company or product manufacturer). Only seven sites were affiliated with a university or health care institution and, of these, two were affiliated with a cancer treatment center, namely Princess Margaret Hospital in Toronto, Canada, and MD Anderson Cancer Centre in Houston, USA. Fifty-eight percent of sites included information on the individual or group that spearheaded its creation. The majority of these sites (69.0 %) were initiated by, or on behalf of, a breast cancer survivor or an informal caregiver (e.g., spouse, partner, child, or friend).

Launch dates

Forty-three of the multipurpose sites (58.9 %) provided their launch date. Of these, roughly 37 % were launched between 1994 and 1999, 25.5 % between 2000 and 2004, and the remaining 37 % between 2005 and 2009 (data not shown).

Twenty-two of the breast cancer-specific sites (57.9 %) provided their launch date. The majority of these sites (60.6 %) were launched between 2004 and 2008 (Fig. 2).

Communication technology

The majority of websites contained message boards as their main communication tool (91.9 %) and provided their users with the ability to construct a public or semipublic profile (82.7 %). Nearly half (44.8 %) allowed their users to make visible their social networks and thus could be classified as a social network sites.

Table 2 Characteristics of included websites

Characteristics	Number (%)
Purpose (*n*=111)	
Breast cancer exclusively	38 (34.2)
Breast cancer forum on a health site	36 (32.4)
Breast cancer forum on a cancer site	21 (18.9)
Breast cancer forum on a general site	16 (14.4)
Niche breast cancer communities (*n*=11)	
Young women	4
Breast reconstruction	2
Hereditary breast cancer	1
Her2 positive breast cancer	1
Inflammatory breast cancer	1
Metastatic breast cancer	1
Triple negative breast cancer	1
Country of origin (*n*=105)	
USA	79 (75.2)
UK	9 (7.6)
Canada	8 (7.6)
Australia	4 (3.6)
South Africa	2 (1.9)
India	1 (0.9)
Ireland	1 (0.9)
New Zealand	1 (0.9)
Affiliation (*n*=108)	
Commercial	50 (45.0)
Nonprofit organization	32 (29.6)
Individual or Group	19 (17.6)
University or health care institution	7 (6.5)
Initiator (*n*=58)	
Former patient or caregiver	40 (69.0)
Health care professional	10 (17.2)
National Charity	6 (10.3)
Patient and health care professional	1 (1.7)
Health researcher	1 (1.7)
Communication Features (*n*=111)	
Message boards (asynchronous)	102 (91.9)
Blogs (multiuser)	42 (37.8)
Chat rooms (synchronous)	21 (18.9)
Mailing lists	5 (4.5)
Wikis	3 (2.7)
Social networking features	
Profiles (*n*=110)	91 (82.7)
Create and view friend lists (*n*=105)	47 (44.8)
Moderation (*n*=111)	
Yes	77 (69.4)
Moderator (*n*=77)	
Website staff or volunteers exclusively	66 (85.7)
Website staff and health care professionals	8 (10.4)
Health Care professionals exclusively	3 (3.9)

Moderation

The majority of websites (69.4 %) were moderated. Most sites (85.7 %) were moderated by site staff alone or in combination with community members. Only eight sites were moderated by health-care professionals alone, or in combination with website staff. Fifteen sites contained additional features that were moderated by health professionals such as an "Ask the Expert" message board service. Three sites employed a "notice and take down" policy, also known as "reactive moderation" relying on the site members to alert the site administrators of inappropriate use. Only one website (Cancer Chat UK) stated that they screened the message board post accuracy before posting them.

Level of activity of breast cancer-specific sites

Information on membership and total number of posts was available for 57.9 and 78.9 % of breast cancer-specific sites, respectively. As shown in Table 3, these sites reported a total of 140,162 registered members and 4,186,275 posts. One third of breast cancer-specific sites contained the majority of posts (Fig. 3). The top ten most active breast cancer-specific sites (Table 4) each reported more than 100,000 posts. Four of them catered to a specific type or experience of breast cancer.
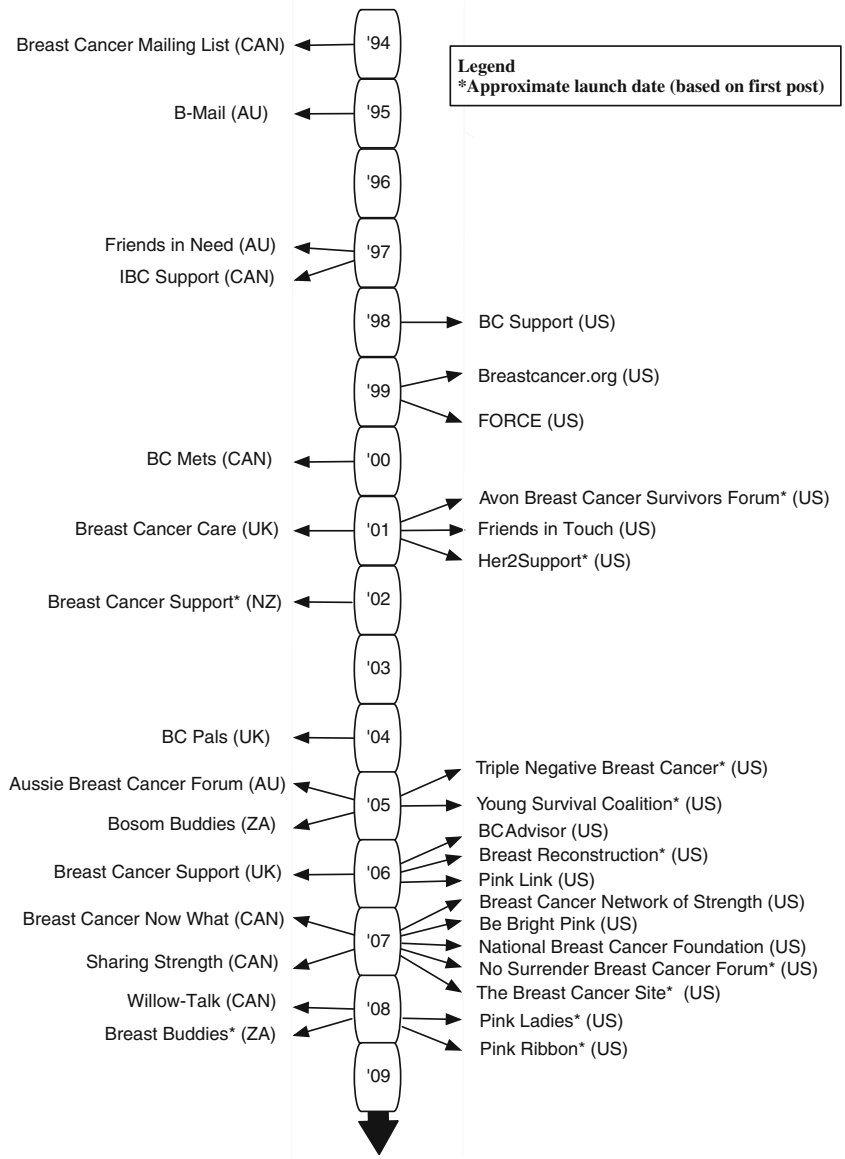
Status

As of April 3, 2012 eight online communities were discontinued—six had shut down, one removed its online community, and another disabled its community functions but archived its content. We successfully contacted two of these sites to inquire about their closure. One site reported that their online community was discontinued because of inactivity and spam. The other site cited changes in the leadership and strategic focus of the funding organization, along with funding pressures and a perceived need to keep pace with the rapidly changing social media landscape.

Discussion

This study has generated the first known systematic review and characterization of online resources for cancer survivors. In doing so, it has revealed that breast cancer survivors have a wide range of Internet-based peer support options. The number of online communities identified in this review is an underestimation of the total number that exists for breast cancer survivors, given that we analyzed websites as whole entities. Many websites have multiple communities. In a separate study, we identified over 600 breast cancer groups on Facebook alone [20]. Likewise, the review conducted in 2003 that identified 546 online cancer

Fig. 2 Launch dates of breast cancer-specific online communities (*N*=33)

Legend
*Approximate launch date (based on first post)

Breast Cancer Mailing List (CAN) ← '94
B-Mail (AU) ← '95
'96
Friends in Need (AU) ← '97
IBC Support (CAN) ← '97
'98 → BC Support (US)
'99 → Breastcancer.org (US)
'99 → FORCE (US)
BC Mets (CAN) ← '00
'01 → Avon Breast Cancer Survivors Forum* (US)
Breast Cancer Care (UK) ← '01 → Friends in Touch (US)
'01 → Her2Support* (US)
Breast Cancer Support* (NZ) ← '02
'03
BC Pals (UK) ← '04
Aussie Breast Cancer Forum (AU) ← '05 → Triple Negative Breast Cancer* (US)
'05 → Young Survival Coalition* (US)
Bosom Buddies (ZA) ← '05 → BCAdvisor (US)
'06 → Breast Reconstruction* (US)
Breast Cancer Support (UK) ← '06 → Pink Link (US)
'06 → Breast Cancer Network of Strength (US)
Breast Cancer Now What (CAN) ← '07 → Be Bright Pink (US)
'07 → National Breast Cancer Foundation (US)
Sharing Strength (CAN) ← '07 → No Surrender Breast Cancer Forum* (US)
'07 → The Breast Cancer Site* (US)
Willow-Talk (CAN) ← '08 → Pink Ladies* (US)
Breast Buddies* (ZA) ← '08 → Pink Ribbon* (US)
'09

communities reported all of the 150 mailing lists offered by the Association of Online Cancer Resources at that time [14], a website included in our review. That 2003 review, although important, did not report the names or URLS of all the websites included in their sample, which limits further comparisons.

Our study found that the participation levels in online breast cancer communities varied from very high (e.g., more than one million posts) to very low (less than 15 posts). Ten sites accounted for 93.4 % of the total number of message board posts in the breast cancer-specific websites sampled, each of which reported more than 100,000 posts. Interestingly,
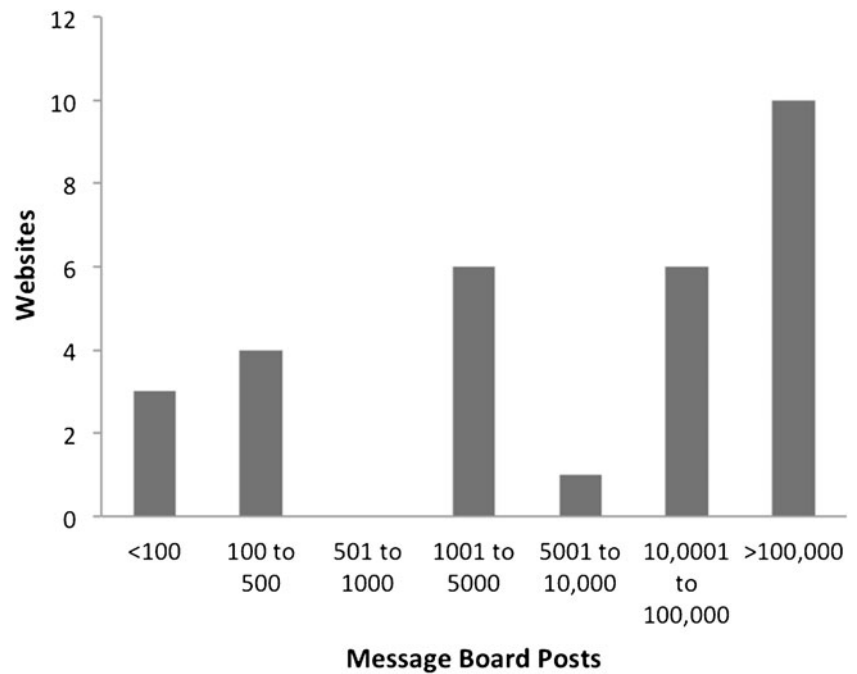
Table 3 Activity level of breast cancer-specific online communities

	Number (websites)	Total	Min	Max	Median	IQR
Total members	22	140,162	10	78,931	1,118.5	3,930.2
Total posts	30	4,186,275	14	1,502,508	19,669.5	144,827.7

Data on membership size were available from 22 of the 38 breast cancer online communities, and data on site usage were available from 30 of the 38 breast cancer-specific online communities. All activity data were extracted on October 26, 2010

IQR interquartile range

four of the top ten sites catered to a less common type of breast cancer (e.g., hereditary) or characteristic of breast cancer survivor (e.g., young), demonstrating the potential of the Internet to leverage the "long-tail" [21]. The long-tail in health represents the numerous individuals with less common conditions that are poorly served by traditional support systems because they do not fit the model of the "average" patient [22]. Online communities enable these individuals to more easily connect, develop a critical mass, and build a shared knowledge base related to their condition [5].

Inadequate usage statistics prevented us from examining why these top ten sites were more popular than others. However, it is worthwhile to note that all top ten sites were initiated by a nonprofit organization, breast cancer survivor, or affected family caregiver as opposed to a commercial company, university, or health care institution. In fact, the majority of sites

sampled that were exclusive to breast cancer were initiated by a breast cancer survivor or affected loved one (68 %), confirming anecdotal reports that have suggested that patients, and their loved ones, are taking a major role in creating health resources on the Internet [1, 23, 24]. According to a qualitative study with 23 webmasters of patient-initiated breast, fibromyalgia, and arthritis online communities, patients create such resources because of a desire to help others, promote awareness of the disease, or because existing resources do not meet their needs [25]. The personal motivation of the individual behind the online community may be a key success factor.

In our study, 7 % of the online communities sampled were discontinued. Reasons cited for closure include changes in the strategic focus of the organization, inactivity, and spam (unsolicited messages that contain advertisements). Building successful, sustainable, and scalable online communities is

Table 4 Top ten most active breast cancer-specific online communities

Rank	Online community (URL)	Total posts[a]
1	Breastcancer.org (www.breastcancer.org)	1,502,508
2	Young Survival Coalition (www.youngsurvival.org)	522,804
3	Breast Cancer Care UK (www.breastcancercare.org.uk)	440,860
4	Susan G. Komen Foundation	317,620
5	Breast Cancer Mailing List (www.bclist.org)	308,160
6	FORCE-Facing Our Risk of Cancer Empowered (www.facingourrisk.org)	276,091
7	Her2Support (www.her2support.org)	185,302
8	BC Mets Mailing List (www.bcmets.org)	132,609
9	Aussie Breast Cancer Forum (www.bcaus.org.au)	119,679
10	BC Pals (www.bcpals.org/uk)	105,594

[a] As of October 26, 2010

challenging, as we know little about the factors that determine their success [26]. Important sociotechnical attributes that warrant attention include anonymity, *homophily* (similarity of user experiences), *presence* (computer-simulated physical presence of others), *interaction management* (ability to control how one participates), and the *sociability* (ability to support social interactions) of the site [17, 24]. In addition, our study suggests that the success of online communities may depend on structural and sociopolitical factors such as the priorities of the organization, allocation of appropriate resources, and effective moderation.

Contrary to reports describing online communities as "ad hoc, self-organizing, organic discussions with no particular oversight or administration" [24], the majority of online communities in our sample were described as moderated or contained evidence of moderation by site administrators or volunteer community members. However, the extent and quality of the moderation appeared to vary with some sites suffering from a considerable amount of spam. Promoting the group, facilitating participation, responding to messages and removing spam are key to ensuring the success of an online community but are onerous activities consuming on average 10–15 h per week [25, 27]. We need a better understanding on the role of moderation on the success and effectiveness of online communities and the resources required to support moderators in their roles.

Health professionals and patients have expressed concern about the potential for deception and misinformation on the Internet [28, 29], particularly in consumer-led online communities [30]. This study may serve as a further cause for concern, given that only one community sampled said they screened for accuracy before posting, and only a handful of sites engaged health-care professionals as moderators. However, there is evidence to suggest that online communities can effectively self-regulate content [31]. Content analysis of the un-moderated Breast Cancer Mailing List (which was included in our study) revealed that of 4,600 postings, only ten were found to be misleading or false, and seven of those were corrected by the community within 5 h of the original posting [32].

Overall, our study highlights a need for more well-designed studies that investigate the factors associated with the success and effectiveness of unstructured, consumer-led online communities. Most of the effectiveness research to date has focused on online communities that are professionally led [7]. The only known RCT of an unstructured, un-moderated mailing list produced conflicting results and is limited by small sample and effect sizes. Participants, who were newly diagnosed breast cancer survivors, experienced a nonstatistically significant increase in distress over time. Paradoxically, 60 % of participants reported high levels of satisfaction with the intervention, a subgroup of whom created their own mailing list at the end of the study [33]. These findings indicate a need for more exploratory research designs, as suggested by Greenhalgh and Russell [34], which take into account the complex array of personal, social, political, and ideological factors that determine the success of eHealth interventions.

This inventory of online communities could serve as a guide for health-care professionals and a resource for breast cancer survivors. Surveys of breast and testicular cancer patients indicate that at least 20–35 % do not know of any online communities [35, 36], and a survey of oncologists and rheumatologists revealed that most found it challenging to provide up-to-date Internet sites to patients [37]. In the time elapsed since our last search, more resources for breast cancer survivors have emerged. Some of the most prominent are www.patientslikeme.org, www.ihadcancer.com, www.cancerconnection.ca, and www.planetcancer.org. As no printed article would be able to provide an up-to-date inventory of sites, we have created an article on Wikipedia to complement this report. We invite interested researchers, developers, and survivors to edit it on an ongoing basis, thus co-creating the most accurate collection of breast cancer online communities.

Limitations

The search results are dependent on the terms included in the strategy and on the search engine used. We attempted to overcome this limitation by choosing common terms, two complementary strategies and the search engine with the greatest market share. A significant proportion of the online communities included in this review did not provide information on the date the site was launched or the usage statistics. Moreover, the launch dates reported in this paper should be regarded as estimates, given that it was not clear in all cases whether the communication feature (e.g., message board) was included on the site when it was first launched or if it was an add-on feature.

Conclusions

There is a wide range of online communities available for breast cancer survivors with extensive archives of personal illness experiences. The scope of online peer support options will inevitably increase due to the growing popularity of social media applications that provide the public with the tools to create the support resources that they need. Future efforts should focus on identifying the factors that determine their success and effectiveness.

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