

# Social media for breast cancer survivors: a literature review

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## Abstract

**Purpose** Social media may offer support to individuals who are navigating the complex and challenging experience of cancer. A growing body of literature has been published over the last decade exploring the ways cancer survivors utilize social media. This study aims to provide a systematic synthesis of the current literature in order to inform cancer health communication practice and cancer survivorship research.

**Methods** Using PRISMA guidelines, four electronic databases were searched to retrieve publications on breast cancer and social media published between 2005 and 2015. The final sample included 98 publications (13 commentaries and reviews, 47 descriptive studies, and 38 intervention studies). Intervention studies were assessed for key features and outcome measures. Studies utilizing content analysis were further evaluated qualitatively.

**Results** Online support groups were the most commonly studied platform, followed by interactive message boards and web forums. Limited research focuses on non-Caucasian populations. Psychosocial well-being was the most commonly measured outcome of interest. While social media engagement was assessed, few standardized measures were identified. Content analyses of social media interactions were prevalent, though few articles linked content to health outcomes.

**Conclusions** The current literature highlights the impact and potential utility of social media for breast cancer survivors.

Future studies should consider connecting social media engagement and content to psychosocial, behavioral, and physical health outcomes.

**Implications for Cancer Survivors** Online groups and communities may improve the well-being of breast cancer survivors by providing opportunities to engage with wider social networks, connect with others navigating similar cancer experiences, and obtain cancer-related information. Researchers should consider the potential role of social media in addressing the unmet needs of breast cancer survivors, and particularly the implications for clinical and public health practice.

**Keywords** Social media · Online support · Social support · Breast cancer · Literature review

## Introduction

Currently, there are more than 15 million cancer survivors living in the USA, 3.1 million of whom are breast cancer survivors [1]. The number of cancer survivors is projected to increase to 20 million by 2026 [1, 2]. Individuals navigating the cancer experience face many challenges, including the long-term physical, psychological, social, and economic consequences of a diagnosis [3–6]; limited information and support services [7, 8]; and care coordination issues (e.g., transitioning out of oncology care) [9]. The Internet can ameliorate some of these challenges, for example, by enabling easy access to information or linking survivors to support [10]. By providing access to this information and support, the Internet can also empower cancer survivors to be actively involved in their care [11, 12].

Within the context of Internet support for cancer survivors, social media (commonly defined as “a set of Internet-based applications that allow users to create

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and exchange user-generated content”) [13] can support cancer survivors in a number of ways. The use of social media for health-related purposes has been well documented in non-survivor populations. Examples of social media use in the context of health include health information seeking [14], social support [15], health promotion and behavior change [16], and disease management [17]. Cancer survivors can also benefit from using social media for these purposes. Cancer survivors commonly use social media to exchange information, gain support, communicate with loved ones, and connect with others facing similar experiences [18]. However, the limitations of social media for health-related purposes should be considered, including concerns about information quality, information overload, user privacy, and the possibility that using social media may deter patients from visiting a health professional [15].

Despite these potential issues, existing research shows the promise of social media to improve health outcomes and the healthcare delivery process throughout the cancer experience [19]. For instance, Wallner and colleagues [20] found that women who communicate online, including through social media, frequently reported a higher level of satisfaction with the treatment recommendation they received from their physicians following a breast cancer diagnosis, compared to women who did not engage in online communication activities. This suggests that online engagement could influence a survivor’s perspectives on their care options.

Social media can also provide access to support when it is not otherwise available to survivors. For example, McLaughlin and colleagues [21] found that during an intervention for young adult cancer survivors, those without adequate offline social support were more likely to be engaged with the social networking features of the intervention compared to those with adequate support. One potential explanation for the impact of social media on health outcomes among survivors is that the support provided through social media can facilitate emotional connections and coping [22]. For example, a recent online survey of cancer patients showed that cancer blogs are an effective tool for emotion management, information sharing, and coping, and can even facilitate better cancer-care decision-making [23].

While there has been a substantial body of research published on social media in the context of cancer survivorship over the past decade, there is little comprehensive understanding of the role that social media, either as organically formed communities or as designed interventions, plays in the lives and experiences of

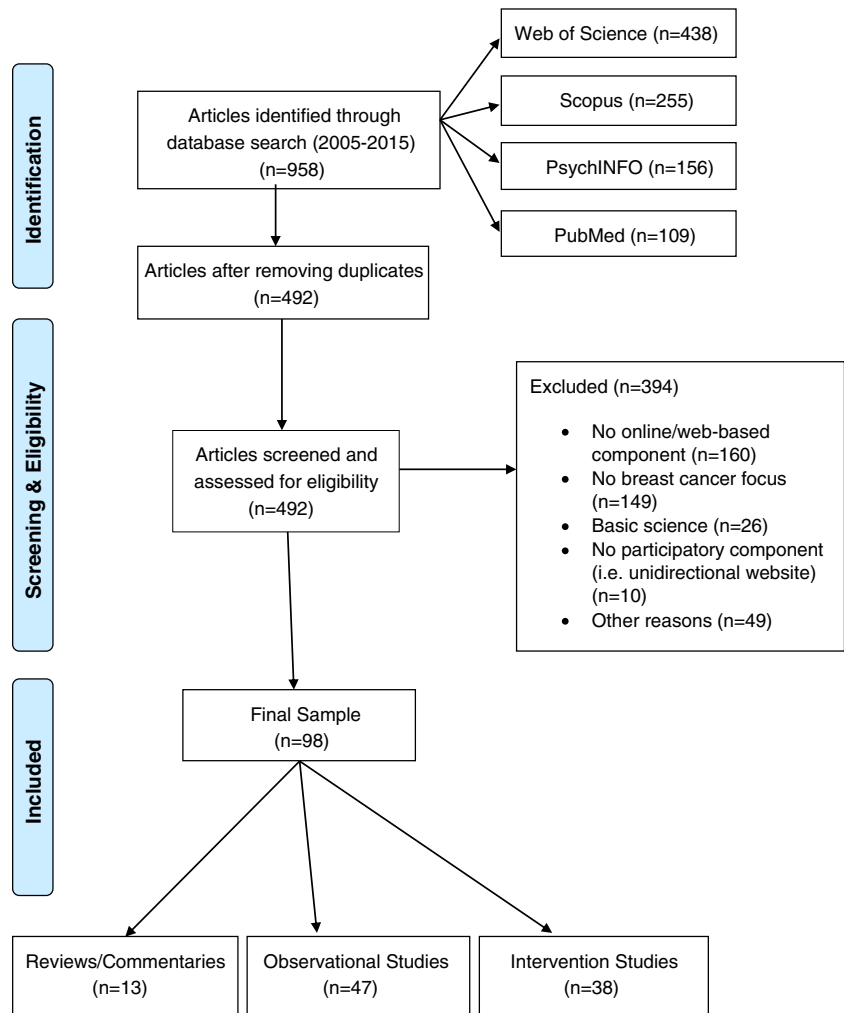
cancer survivors. A systematic review of the existing literature is needed to characterize the current state of the science on social media in cancer survivorship, while identifying opportunities to advance research and practice in this area. Due to the wide range of survivor experiences and needs across cancer types, we chose to focus this review on breast cancer survivors. The high prevalence of breast cancer coupled with the active and well-documented social media presence of breast cancer survivors [2, 18] offers a starting point for a synthesis of the current literature.

## Methods

### Literature search

Standard Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used to guide our systematic literature review of relevant published peer-reviewed articles (Fig. 1). A keyword search spanning the period between January 1, 2005, and November 12, 2015, was executed in four medical and social science databases (Web of Science, Scopus, PsycINFO, and PubMed) to capture approximately a decade of published research related to social media in the context of breast cancer. The terms “breast cancer” AND “social media” OR “online support” OR “social network” OR “social networking site” OR “online social network” were used to search titles and abstracts. The search identified 958 articles. The removal of duplicates left 492 articles that were then manually reviewed for exclusion by members of the research team. In all, 394 articles were excluded for the following reasons: no online or web-based component (e.g., in-person or phone-only), no participatory or interactive features (i.e., unidirectional information or content through a website or text based program), no focus on breast cancer (i.e., focus on other conditions or no indication that breast cancer survivors were included in the sample), basic or bench science studies, conference proceedings, and no focus on *survivors* (e.g., focus on caregivers or providers only, or on prevention rather than survivorship). No exclusions were made based on stage of diagnosis or treatment, as the National Cancer Institute’s definition of “cancer survivor” was used, which considers a person to be a cancer survivor “from the time of diagnosis until the end of life” [1, 24]. Any uncertainties regarding article exclusion were discussed

**Fig. 1** Summary of the eligibility criteria for inclusion into the review



and resolved through consensus. The final sample included 98 articles.

### Coding and review process

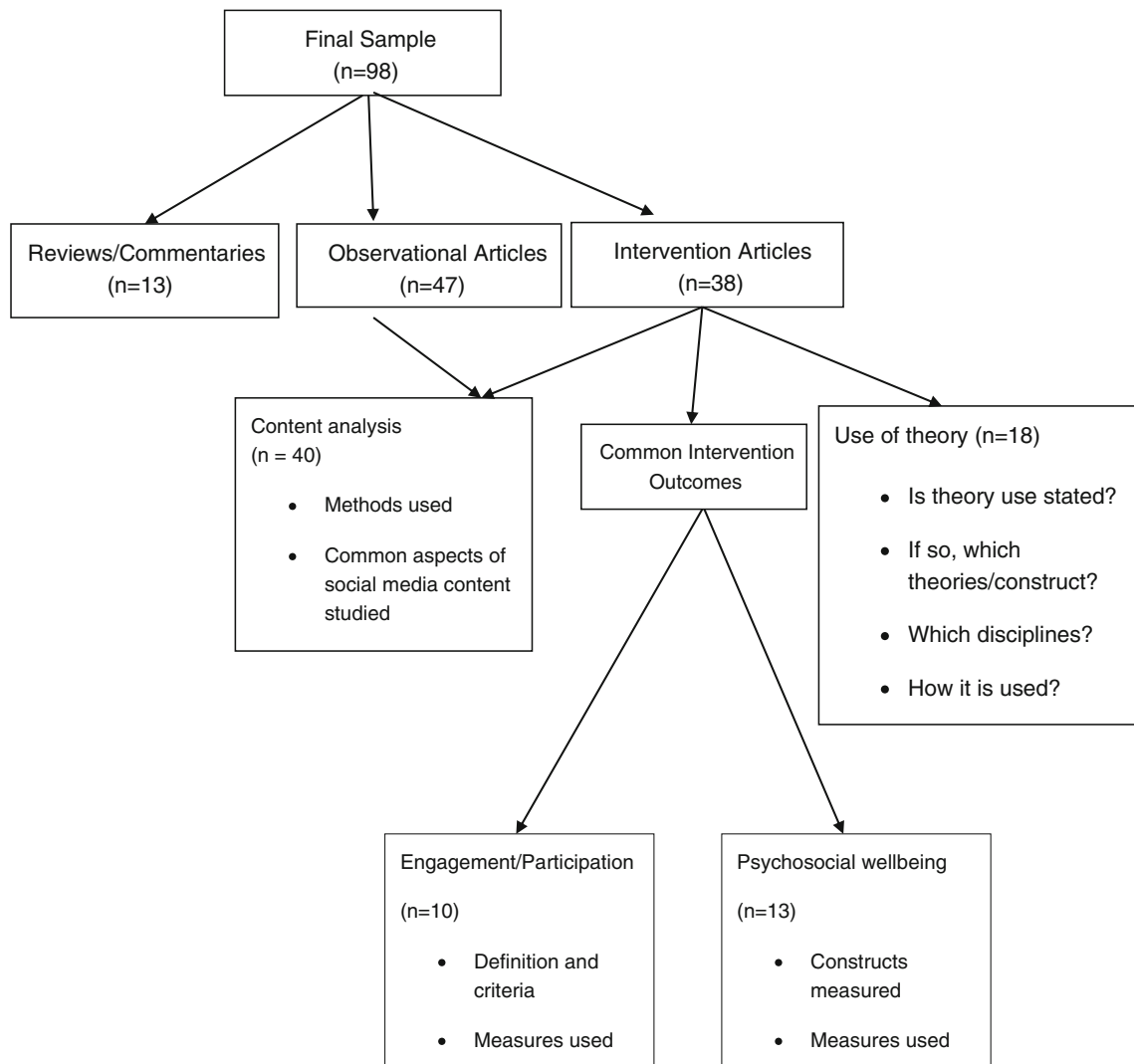
#### Phase I—assessment of general characteristics

We categorized the 98 included publications into 3 distinct types (reviews, observational studies, and intervention studies), and analyzed the studies through a mixed-methods evaluation process (adapted from Chou et al. [25]). In Phase I, each article was independently coded by two research team members for key article features. The extraction form included article type (review/commentary, observational, intervention), year of publication, health condition (breast cancer only vs. breast cancer included among other conditions),

race/ethnicity of study population, and social media platform utilized (e.g., online support group, web forum, Facebook, Twitter, blog, etc.). Discrepancies between coders were resolved using team discussion.

#### Phase II—assessment of intervention articles

Phase II of the review focused on the 38 articles categorized as intervention studies. The team reviewed these articles in full to identify (1) key features of the intervention, (2) time/duration of the intervention and assessments, (3) outcomes measured (e.g., physical health, psychosocial well-being, information-seeking behavior, engagement/participation), and (4) method of analysis (i.e., quantitative evaluation, content analysis, or other method) (Appendix 1). An in-depth qualitative assessment of intervention articles was then performed to identify



**Fig. 2** Phase II and Phase III analysis: in-depth assessment of intervention and observational articles

the specific measures of engagement/participation, measures of psychosocial well-being, and theoretical frameworks used in the articles. Figure 2 includes the criteria used to assess each of the articles in these three areas.

*Phase III—assessment of articles with a content analysis component*

The final phase consisted of a qualitative assessment of all intervention and observational articles that used content analysis (n = 40). This part of the review was guided by the following questions: (1) *What methods were used to perform the content analysis?* (2) *What aspects of social media content are commonly analyzed (e.g., linguistic features, topics of discussion, etc.)?* (3) *What connections are made between social media content and health outcomes?* (Fig. 2).

**Findings**

**Phase I—assessment of general characteristics**

Reviews/commentaries (n = 13), intervention articles (n = 38), and observational articles (n = 47) were identified. The majority (71%) of the 85 observational and intervention articles were published in 2011 or later, and the total numbers of publications increased each year from 2011 to 2015 (Table 1). Roughly half of the articles (52%) focused exclusively on breast cancer. Twenty-eight articles (35%) reported the race or ethnicity of the study population. Of those, 18 (64%) included non-white participants, and two articles [26, 27] included samples of exclusively non-white participants. The first of these explored the feasibility and acceptability of online support groups among immigrant Latina women, while the second assessed the preferences for physical

**Table 1** General characteristics of observational and intervention articles ( $n = 85$ )

	Number of articles (%)
Published during or after 2011	60 (71%)
Focused exclusively on breast cancer	44 (52%)
Reported information about participant race	28 (33%)
Included non-white participants (among those that reported race)	18 (64%)
Included only non-white participants (among those that reported race)	2 (7%)
Type of social media platform used/studied <sup>a</sup>	
Online support group/community	52 (61%)
Message board/web forum	20 (24%)
Twitter	5 (6%)
Facebook	4 (5%)
Blog	3 (4%)
YouTube	1 (1%)
Online mailing lists	1 (1%)

<sup>a</sup> Groups are not mutually exclusive; some articles included multiple platforms

activity interventions among African American breast cancer survivors' engaged in an online social network [26, 27]. Online support groups were the most commonly studied social media platforms ( $n = 52$ ), followed by message boards and web forums ( $n = 20$ ), and commercial sites (Twitter,  $n = 5$ ; Facebook,  $n = 4$ ).

## Phase II—assessment of intervention articles

Twelve of the 38 intervention articles (32%) were publications related to the Comprehensive Health Enhancement Support System (CHESS) intervention (Appendix 1). CHESS is a “computer-based system of integrated services designed to help individuals cope with a health crisis or medical concern” [28]. The articles focused specifically on the “Living with Breast Cancer” program and the computer-mediated social support group component within CHESS. Taken together, these 12 articles assessed how engagement, expression, and communication with peers through CHESS affects breast cancer-related concerns, perceived social support, and other psychosocial outcomes (e.g., Han et al. [29]; Kim et al. [30]). The remaining 26 intervention articles examined other web-based programs and online support groups. Several ( $n = 4$ ) explored the impact of support group format and structure on participant mental health outcomes, including depressive symptoms (e.g., Klemm [31], Lepore et al. [32]). The interventions included in this review addressed a variety of patient experiences from the time of diagnosis to post-treatment survivorship and end of life. For example, the CHESS program targets any person diagnosed with cancer regardless of their treatment trajectory. On the other hand, the

Surviving and Thriving with Cancer Intervention [33] focuses on survivors who are post-treatment.

## Intervention study outcomes

The most commonly measured outcomes in the intervention articles were related to the participants' psychosocial well-being ( $n = 13$ ), such as depression, mood, quality of life, and social support. Most articles that assessed psychosocial outcomes utilized standard, validated measures to assess these constructs, including breast cancer-related concerns (BCC), depression (CES-D), quality of life (MILQ, FACT-B), and social support (MOS-social). BCC was the most common scale used. In comparison to psychosocial well-being, other health outcomes were evaluated infrequently in the intervention articles reviewed. Of note, one randomized controlled trial study assessed physical health and health behavior (e.g., diet, exercise, sleep) outcomes to measure the effect of a social media-based intervention for breast cancer survivors [33]. Few studies included general measures of functional well-being and physical well-being (e.g., Shaw [34], Lieberman [35]).

Ten intervention articles (26%) measured engagement with the intervention. Across these 10 articles, the definition of engagement differed and disparate measures for evaluating engagement were used. Authors chose a variety of approaches to quantify engagement, such as the number of posts written or read by participants, number of words per post, number of website users, number of website visits, total time spent on the website, and number of pages viewed per website visit.

**Table 2** Application of theory among intervention studies

	Theory	Application
Chen et al. [36]	Self-efficacy Theory; Salient Belief Theory	Intervention development Hypothesis/research question
Han et al. [52]	Comprehensive Model of Information Seeking (CMIS) Social Enhancement Model; Social Compensation Model	Hypothesis/research question
Han et al. [29]	CMIS; Social Enhancement Model; Social Compensation Model	Hypothesis/research question
Han et al. [29]	Equity Theory	Hypothesis/research question
Han et al. [53]	Broaden and Build Theory	Hypothesis/research question
Kim et al. [30]	Social Exchange Theory; Equity Theory	Hypothesis/research question
Kim et al. [54]	Social Comparison Theory	Hypothesis/research question
Lepore et al. [32]	Helper Theory Principle	Intervention development
Lieberman et al. [35]	Social Cognitive Processing Model	Hypothesis/research question
Lieberman et al. [55]	Disease Psycho-Social Model	Hypothesis/research question
Lieberman and Goldstein [49]	Theory of “Type C” personality	Hypothesis/research question
Namkoong et al. [22]	Self-Perception Theory	Illustration of findings
Radin et al. [56]	Medium Theory; Social Capital Theory	Hypothesis/research question
Rimer et al. [57]	Problem-Focused and Emotion-Focused Coping	Intervention development
Shaw et al. [38]	Constructivist Theory Social Learning Theory	Hypothesis/research question
Shaw et al. [38]	Self-in-Relation Theory	Illustration of findings
Shim et al. [58]	Cognitive Adaptation Model; Emotional Exposure Habituation Model	Hypothesis/research question
Stephen et al. [40]	Model of Hyper Personal Communication	Illustration of findings

Number of posts written was the most common criteria used to measure engagement (e.g., Chen et al. [36]; Grau et al. [37]). Five articles categorized engagement based on level of participation (e.g., Shaw et al. [38]; Owen et al. [39]); however, criteria for evaluating level of participation differed between articles.

*Use of theoretical frameworks*

Approximately half ( $n = 18$ ) of the intervention articles referenced a theoretical framework or construct (Table 2). A majority of the articles ( $n = 13$ ) used theory to test a hypothesis or motivate a research question (e.g., Lieberman et al. [35]); fewer articles used theory to inform intervention design (e.g., Lepore et al. [32]), and to explain findings (e.g., Stephen et al. [40]). The theories and constructs used came from a diverse range of academic disciplines, including psychology (e.g., Social Comparison Theory), communication (e.g., Model of Hyperpersonal Communication),

education (e.g., Constructivist Theory), and behavioral science (e.g., self-efficacy, Theory of Planned Behavior). The remaining intervention articles ( $n = 20$ ) did not explicitly reference any theoretical constructs or frameworks.

**Phase III—assessment of content analyses**

Two main methods for conducting content analyses were identified in the included articles: computer-assisted ( $n = 24$ ) and manual ( $n = 13$ ) coding of content, with a few articles using a combination of these two approaches ( $n = 3$ ). Computer-assisted techniques enabled much larger data sets to be analyzed compared to manual coding techniques. For instance, Huang and colleagues [41] manually coded the content of 2053 posts downloaded from breast and prostate cancer discussion boards, categorizing the type of “social support” or “companionship activity” contained in each post. In contrast, Wang and colleagues [42] used machine



learning techniques to classify the major types of social support present in 2.8 million posts pulled from discussion boards for breast cancer survivors.

Methods for computer-assisted coding and analysis differed depending on the year of the study. Specifically, prior to 2011, the Linguistic Inquiry and Word Count (LIWC) text analysis program, which counts the number of specified keywords that appear in a text, was the most frequently used method for computer-assisted content analysis among the articles included in this review. Although LIWC continued to be used after 2011, more complex methods and programs, such as Infotrend ( $n = 4$ ) and latent Dirichlet allocation (LDA) ( $n = 4$ ), were increasingly used.

Three articles performed in-depth, immersive content analyses. For example, Rubenstein [43] analyzed cancer blogs written by young women and identified emerging themes (e.g., “new normal,” “transition into the unknown,” etc.), in order to shed light on the lived experiences of these women through their social media expressions. Most content analyses, however, were exploratory descriptive analyses ( $n = 37$ ). Identifying common topics of discussion ( $n = 10$ ) and analyzing patterns or frequencies of social support exchange ( $n = 9$ ) were the most common objectives among these types of content analysis articles. Analysis of specific linguistic features (e.g., pronoun use) or communication behaviors other than social support exchange was less common. A few articles also focused on identifying and analyzing symptoms and side effects reported in social media discussions ( $n = 4$ ). While most content analysis articles focused on one community or patient population, several comparison articles ( $n = 3$ ) were also conducted to explore differences in communication based on gender or disease type.

None of the content analysis articles attempted to link the content of the users’ posts to physical health outcomes. However, a few of the intervention articles ( $n = 11$ ) that surveyed participants in addition to analyzing their posts were able to explore the link between certain content features (e.g., level of religious expression) and psychosocial outcomes like depression. For example, Harris and colleagues [44] used LIWC to calculate the percentage of positive emotion words (e.g., “joy”), negative emotion words (e.g., “angry”), and cognitive processing words (e.g., “realized”) used in the blog posts of participants taking part in an Internet-based intervention for women with breast cancer, and explored the relationships between these types of words and various self-reported psychosocial outcomes assessed via online questionnaire. The study found that while writing about positive and negative emotions was associated with improved psychosocial outcomes, cognitive processing word use was not significantly associated with any of the outcomes analyzed.

## Discussion

This review summarizes the existing literature related to social media use among breast cancer survivors. Our results highlight several key themes that suggest important directions for future research at the intersection of social media and cancer survivorship. The discussion will focus primarily on issues relevant to a research audience, with consideration also paid to the ways that advancing research in this area can help inform clinical and public health practice.

This review highlights the incremental methodological developments in studying social media that have occurred over the last decade. For instance, as machine learning techniques became more widely adopted, content analyses of social media interactions shifted from counting keywords to utilizing sophisticated, automated techniques such as topic modeling. On the other hand, there remains value in examining social media content through qualitative approaches in order to explore the richness of the conversations occurring on these platforms and to better understand the survivors’ motivations for sharing their cancer experience online. Specifically, a number of the content analyses analyzed for this review offer insight into the survivors’ reasons for participating in social media-based activities, namely, for offering and receiving support and for sharing personal experiences (e.g., Huang et al. [41], Rubenstein [43]).

Few of the articles included in the review attempted to link social media content with psychosocial and physical health outcomes, which limits our ability to draw connections between social media engagement and any improvement in the cancer survivorship experience. Future research should consider linking data from multiple sources (content of posts, survey data, clinical records, etc.) to develop a more comprehensive picture of a survivor’s experience. This type of research could also help improve our understanding of the motivations behind the survivors’ use of social media. Another issue that limits our ability to draw conclusions regarding the impact of social media use on the cancer survivors’ health outcomes is that engagement and participation in online groups and interventions are not defined or measured consistently across studies in this field. This review highlights the fact that engagement and participation in online groups or interventions are defined and measured in varied ways. Before conclusions can be drawn regarding whether online, social media-based interventions are effective, the operationalization of these

constructs across studies will need to be more systematic.

As illustrated in this review, while many social media-based interventions have been developed and tested, there is limited published literature on extant popular online networks that are often used by patients and survivors (e.g., *PatientsLikeMe*, independent Facebook groups, private Twitter groups, etc.) in the context of breast cancer. According to a 2010 Pew Research Center report, one in five Internet users go online to find others with similar health concerns [45]. Specifically, more than half of the patients with a chronic disease refer to online user-generated health information, and of those, more than one third have read about another person's health-related experience or issue in an online group, website, or blog [45]. With so many individuals turning to the Internet and social media to get information and support for their health issues, it is important to understand the potential differences between groups or communities that are organically formed and those that are intentionally created for an intervention. For instance, Abramson et al. [46] conducted a qualitative assessment of the functions and uses of a popular Facebook page focused on breast cancer and found that while much of the content centered around self-expression and sharing of information, many posts on the page also encouraged fundraising and making purchases to support breast cancer survivors and research was also observed on the site. Additionally, they found that there was often an unpredictable evolution to many conversations observed on the page, such that subsequent comments had very little to do with the original post. In contrast, the interventions identified in this review included content or topics that were more directed in nature. For instance, the studies based on the CHES Living with Breast Cancer intervention frequently explored how constructs such as engagement, expression, and communication with peers influenced various psychosocial outcomes.

Participation in some online support networks is high [47]; however, membership in these communities is not easily captured by traditional sampling methods. One reason why naturally existing groups are less frequently studied may be due to the intentionally private nature of some of these groups. It is possible that in some cases, researchers simply do not have access to these groups, whether due to privacy settings (e.g., on Twitter) or an inability to retrieve the data (e.g., from Facebook). Despite these challenges, research on naturally occurring groups could offer unique insights into the value of these naturally occurring networks and increase our

understanding of the functions they serve. Moreover, organically formed groups likely reach a wider and more diverse audience than typical interventions. Building trust and developing partnerships with gatekeepers of closed groups could facilitate access to these private networks in order to uncover valuable information on how survivors utilize and benefit from social media-based networks.

Health behavior theories play a key role in helping researchers assess the effectiveness of public health and health promotion interventions [48]. The diversity of theoretical frameworks used in the intervention studies included in this review highlights the multidisciplinary nature and complexity of social media and health-related research. This diversity in thought offers researchers the opportunity to work collaboratively with others in complementary fields to create a more holistic understanding of social media-focused health research. However, the diversity of theoretical frameworks used may also indicate that the available health behavior theories are not sufficient for social media and Internet intervention research, suggesting that available theoretical models need to be adapted to better suit the features of social media interventions, or that entirely new frameworks are needed to properly understand the functions and processes that occur on social media platforms.

### Implications for clinical and public health practice

Online communities and social media interventions offer an opportunity to gain an in-depth understanding of the cancer survivors' experiences, preferences, and even health-related outcomes. However, it should be noted that none of the articles included in this review provided information about clinical outcomes as they relate to involvement in online groups or communities. While it is known that in-person support groups prolong survival among women with breast cancer [47], the relationship between online support and longer term clinical outcomes, including survivorship, is not well established. Research in this area could offer important insight about the clinical impact of a patient's health-related online activities. Furthermore, though most of the articles in this review identified self-driven or peer-led groups, there may be value in future research that explores the impact of having an expert presence in online communities to serve as a resource or guide.

Few of the content analysis studies in this review focused specifically on between-group comparisons, and given the advanced methodological techniques available to study online interventions, there is opportunity to move past descriptive work and begin to explore how and which aspects of a given intervention may be most effective for individuals, given their



backgrounds (i.e., literacy level, language, location, race/ethnicity, etc.). Social media-based interventions have the capacity to be uniquely tailored to an individual, while reaching a wide audience, which could be a particularly valuable tool that public health practitioners can use to better serve typically harder to reach populations. However, to make social media-based networks more practically useful for survivors and practitioners, there is a need to gain a better understanding of individual needs and preferences. This highlights the importance of including more diverse samples in studies of online networks. For instance, only two articles identified in the review focused exclusively on non-Caucasian survivors (specifically, African-American women and immigrant Latinas) [26, 27]. Aside from race/ethnicity, this review did not directly assess the inclusion of special populations, in terms of age, socio-economic status, or other demographic variables. However, given the dearth of literature focused specifically on non-white populations, there is ample opportunity for future research to consider the role that social media plays in the lives of diverse populations. Further, since this review was guided by the NCI definition of “survivor,” distinctions based on cancer stage, treatment type, etc., were not highlighted, thus offering an opportunity for future work to explore the use of social media-based resources by individuals at different points along the cancer continuum.

### Study limitations

While this systematic review represents an exhaustive examination of the available peer-reviewed literature published over the past decade, there are limitations to our study which need to be considered. For example, the reliance on peer-reviewed literature might have led to an overrepresentation of large-scale, federally funded intervention programs (such as CHES) in our pool of reviewed articles. However, the qualitative analysis of the intervention articles took into account publications that were derived from the same parent study. Additionally, opinion-sharing platforms and publications outside of academic venues (e.g., blogs, new articles, commentaries by non-academic thought leaders, etc.) were not captured in the current review. Lastly, this review focused specifically on breast cancer survivors. Although many identified articles included breast cancer as one of multiple cancers or conditions studied, using “breast cancer” as a required search term may have affected the population of articles screened for inclusion in the review. Although breast cancer was chosen as the focus of this review due to the established presence of breast cancer survivors on social media and online networks [18], additional research evaluating the utility and effectiveness of social media for survivors of other cancers is needed in order to generate a more comprehensive understanding of social media in the context of cancer survivorship.

### Conclusions

Through a mixed-methods approach, this literature review synthesized the body of research focused on social media for breast cancer survivors. Despite the well-documented and active online presence of breast cancer survivors [18], research about social media use in this population remains fairly nascent. The majority of the studies we have reviewed do not ascertain the impact of social media interactions and interventions on health outcomes. While a few studies measured association between involvement in interventions and psychosocial well-being (e.g., Kim et al. [30], Lieberman [49]), they are correlational at best. Opportunities exist to design experimental and longitudinal studies that examine the impact of social media participation on outcomes relevant to cancer survivorship, such as quality of life, physical activity, and perceived social support. Research that aims to link data from multiple sources (content of posts, survey data, clinical records, etc.) can help to develop a more refined picture of a survivor’s experience.

An important finding from this review is that significant advances can be made by exploring popular platforms like Facebook and Twitter. In addition, research on diverse populations is needed. The currently available research has been overwhelmingly focused on Caucasian survivors, but non-Caucasian survivors have poorer psychosocial and health outcomes [50, 51]; thus, it remains unknown how online platforms might assist survivors who are most in need of support.

In addition to exploring the platforms and interventions themselves, there is opportunity for research that aims to better understand the theoretical underpinnings of the survivors’ online experiences and relevant outcomes. As it currently stands, there do not appear to be exemplary frameworks or models to guide research in this field. Further research in these areas promises to increase our understanding of how breast cancer survivors leverage and expand their online social networks to navigate the cancer experience, which can, in turn, inform the development of future interventions and resources that may supplement, or complement, traditional care.

### Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Statement on the welfare of animals** This article does not contain any studies with human participants or animals performed by any of the authors.

**Informed consent** Not applicable; this manuscript does not include any studies with human participants performed by the authors.

## Appendix 1

**Table 3** Summary of intervention articles

First author—title	Intervention (duration and follow-up, if applicable)	Key features of the intervention, including constructs of interest	Main outcomes of interest
Bantum—Surviving and Thriving With Cancer Using a Web Based Health Behavior Change Intervention: Randomized Controlled Trial [33]	Six-week program	Structured self-directed behavior change: Discussion Center, My Tools, Post Office, Help Center	Diet, exercise, depression, fatigue
Changrani—Online cancer support groups: Experiences with underserved immigrant Latinas [27]	Ninety-minute session once a week for 30 weeks	Led by trained bilingual facilitators; included discussions of topics of interest	Feasibility; depression, coping with pain, QOL, personal growth
Chen—Dissecting an Online Intervention for Cancer Survivors: Four Exploratory Analyses of Internet Engagement and Its Effects on Health Status and Health Behaviors [36]	Six-week program measures at baseline and 6 month follow-up	Structured self-directed behavior change: Discussion Center, My Tools, Post Office, Help Center	Engagement
Grau—Forumclinic: the shaping of virtual communities to assist patients with chronic diseases. [37]	Seven web and DVD based chronic disease portals (including BC) with accompanying resources	Collaborative self-management; interaction with other users and providers	Feasibility; absence, or presence of a virtual community
Han—Lurking as an Active Participation Process: A Longitudinal Investigation of Engagement with an Online Cancer Support Group [52]	Comprehensive Health Enhancement Support System (CHESS) Living with Breast Cancer program; 6-week and 3-month follow-up included	Asynchronous bulletin board, monitored by trained facilitators	Engagement and psychosocial outcomes associated with engagement (functional well-being, depression, and perceived social support)
Han—Social and psychological determinants of levels of engagement with an online breast cancer support group: posters, lurkers, and non-users [29]	Computer-mediated social support groups in CHESS (ongoing)—baseline only studied	Demographic/psychosocial factors that influence engagement; removing technology access as a constraint	Engagement (based on demographic, disease-related, and psychosocial predictors)
Han—Empathic Exchanges in Online Cancer Support Groups: Distinguishing Message Expression and Reception Effects [59]	Computer-mediated social support groups in CHESS (ongoing) baseline and 4-month follow-up included	Empathy expression and reception	Breast cancer-related concerns
Han—Expressing positive emotions within online support groups by women with breast cancer [53]	Computer-mediated social support groups in CHESS (ongoing) baseline and 4-month follow-up data used	Emotional expression	Breast cancer-related concerns
Harris—Project connect online: User and visitor experiences of an Internet-based intervention for women with breast cancer [44]	One- and 6-month assessments	Positive/negative word use in blogging	User experiences, expression, psychological health
Kim—Process and effect of supportive message expression and reception in online breast cancer support groups [30]	Computer-mediated social support groups in CHESS (ongoing); baseline and 4-month follow-up data used	Supportive message expression and reception	Psychosocial health outcomes (positive reframing, breast cancer-related concerns, emotional well-being)
Kim—Predictors of Supportive Message Expression and Reception in an Interactive Cancer Communication System [54]	Computer-mediated social support groups in CHESS baseline and 4-month follow-up included	Predictors of supportive message expression	Providing/receiving support
Klemm—Effects of Online Support Group Format on Depressive Symptoms and Extent of Participation in women with BC [31]	RCT—online support group (peer led or moderated); baseline, 6-, 12-, 16-week follow-up	Type of group format (moderated vs. peer led)	Depressive symptoms; participation
Lepore—Comparing Standard Versus Prosocial Internet Support Groups for Patients with BC: RCT [32]	RCT—Internet support group; baseline and 1-month follow-up	Type of support group (standard vs. prosocial, professionally facilitated)	Anxiety and depression

**Table 3** (continued)

First author—title	Intervention (duration and follow-up, if applicable)	Key features of the intervention, including constructs of interest	Main outcomes of interest
	Six professionally facilitated live chat sessions (weekly)		
Lewallen—How language affects peer responsiveness in an online cancer support group: implications for treatment design and facilitation [60]	Health-space.net trial—cross sectional analysis of asynchronous discussion board	Language features of posts (word count, positive emotion, particular topics)	Peer responsiveness; topic content
Lieberman—The role of insightful disclosure in outcomes for women in peer-directed breast cancer groups: a replication study [35]	Bulletin boards; baseline and 6-month follow-up (recruited through existing active breast cancer-related bulletin boards)	Insightful disclosure	Breast cancer concerns, emotional distress, functional limitations
Lieberman—Effects of disease and leader type on moderators in online support groups [55]	Four types of bulletin boards studied—cross-sectional	Type of group leader (peer vs. professional)	Positive emotion, negative emotion, cognitive functioning
Lieberman—Not all negative emotions are equal: the role of emotional expression in online support groups for women with breast cancer [49]	Existing breast cancer bulletin boards—baseline and 6-month follow-up	Emotional expression	Quality of life and depression
Lieberman—The relationship between religious expression and outcomes in online support groups: a partial replication [61]	Breast cancer bulletin boards—baseline and 6-month follow-up	Religious expression	Negative emotion, self-efficacy, functional well-being
Morris—Adopting a survivor identity after cancer in a peer support context [62]	Randomized controlled trial—Internet support group; baseline and 1-month follow-up type of support group = standard vs. prosocial (six professionally facilitated live chat sessions weekly) and asynchronous discussion board	Survivor identity	Engagement with peers and cognitive processing
Namkoong—The Effects of Expression: How Providing Emotional Support Online Improves Cancer Patients' Coping Strategies [22]	Computer-mediated social support groups in CHESS, baseline and 4-month follow-up data used	Expression of emotional support	Perceived bonding, coping strategies
Owen—Engagement with a Social Networking Intervention for Cancer-related Distress [39]	Twelve week intervention—baseline and 12-week data included	Predictors of engagement	Engagement
Paxton—African-American breast cancer survivors' preferences for various types of physical activity interventions: a Sisters Network Inc. web-based survey [26]	Cross-sectional survey	Needs assessment	Physical activity intervention preferences
Portier—Understanding topics and Sentiment in an Online Cancer Survivor Community [63]	ACS Cancer Survivors Network	Topics and sentiment	Change of thread emotional sentiment
Radin—"To me, it's my life": Medical communication, trust, and activism in cyberspace [56]	Breast Cancer Action Nova Scotia	Peer to peer medical communication	Elements of peer to peer medical communication
Rimer—How New Subscribers Use Cancer-Related Online Mailing Lists [57]	Health eCommunities (longitudinal study; only baseline cross sectional data used here)	Reasons for joining online mailing lists	Use of online mailing lists, information seeking
Rubenstein—"Things My Doctor Never Told Me" Bridging Information Gaps in an Online Community [43]	Participant observation in an online community over several weeks	Information gaps	Information provision; social support, and community
Seckin—I Am Proud and Hopeful: Age-Based Comparisons in Positive Coping Affect Among Women Who Use Online Peer Support [64]	Cross-sectional survey	Age	Positive coping affect
Setomaya—Benefits of Peer Support in Online Japanese Breast Cancer		Levels of engagement (poster vs. lurker)	Social support given by online peers'—new tool created

**Table 3** (continued)

First author—title	Intervention (duration and follow-up, if applicable)	Key features of the intervention, including constructs of interest	Main outcomes of interest
Communities: Differences Between Lurkers and Posters [65]	Cross sectional survey (exploratory, descriptive)—recruited through existing online support communities		
Shaw—Effects of prayer and religious expression within computer support groups on Women with Breast Cancer [34]	Computer-mediated social support groups in CHES—baseline and 4-month follow-up data included	Prayer and religious expression	Breast cancer-related concerns, negative emotions, emotional well-being, functional well-being, health self-efficacy. Social support, positive reframing
Shaw—How women with breast cancer learn using interactive cancer communication systems [66]	Computer-mediated social support groups in CHES—baseline and 4-month follow-up data used	Different types of services used (informational, communicative, interactive)	Learning outcomes (e.g., health information competence measure)
Shaw—Communicating about Self and Others within an Online Support Group for Women with Breast Cancer and Subsequent Outcomes [67]	Computer-mediated social support groups in CHES—baseline and 4-month follow-up data used	Communicating about self (pronoun use)	Breast cancer-related concerns; negative emotions
Shaw—An Exploratory Study of Predictors of Participation in a Computer Support Group for Women With Breast Cancer [38]	Computer-mediated social support groups in CHES—baseline and 4-month follow-up data used	Predictors of participation	Level of participation
Shim—How does insightful and emotional disclosure bring potential health benefits? Study based on online support groups for women with breast cancer [58]	Computer mediated social support groups in CHES—baseline and 4-month follow-up data included	Insightful/emotional disclosure	Self-efficacy, emotional well-being, functional well-being, breast cancer-related concerns
Stanton—Project Connect Online: Randomized Trial of an Internet-Based Program to Chronicle to Cancer Experience and Facilitate Communication [68]	Project Connect Online—RCT, baseline, 6-month follow-up included)	Expression of feelings/communication	Depressive symptoms, mood, cancer-related intrusive thoughts
Stephen—Talking with text: Communication in therapist-led, live chat cancer support groups. [40]	CancerChat Canada—synchronous live chat with therapists; within 6–8 weeks of group completion	Therapist led; live cancer chat	Exploratory—identified five themes (reaching out, feeling safe, emotional release, talking with text, resonance and kinship)
Stephen—Evaluation of CancerChatCanada: a program of online support for Canadians affected by cancer [69]	CancerChat Canada—synchronous live chat with therapists; within 6–8 weeks of group completion	Therapist led; live cancer chat	Satisfaction, mood
Vilhauer—Online support groups for women with metastatic breast cancer: A feasibility pilot study [70]	Monthly for 6 months throughout program	Peer support	Feasibility and acceptability
Wakelin—An online expressive writing group for people affected by cancer: a virtual third place [71]	Online asynchronous (private shared blog), over 6 months	Online expressive writing (creative poetry and prose)	Emotion expression

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