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The Role of Social Media in Breast Cancer Care and Survivorship: A Narrative Review

Subject Area: [Oncology](#), [Women's and Children's Health](#)[Iliana Aristokleous](#) ; [Andreas Karakatsanis](#) ; [Yazan A Masannat](#) ; [Stavroula Lila Kastora](#)*Breast Care* (2023) 18 (3): 193–199.<https://doi.org/10.1159/000531136> [Article history](#) **Content Tools** ▾

Abstract

Background: Female breast cancer (BC) is the most diagnosed cancer and the leading cause of malignancy-related death worldwide. With the widespread utilisation of the Internet, social media has presented an invaluable yet underemployed tool in the context of BC medical information dissemination, support hub formation, and patient empowerment.

Summary: In this narrative review, we explore the untapped potential of social media in this context, caveats, and future directions that may aid in formulating a new era of patient care in addition to patient-centred care. **Key Messages:** Social media represents a powerful tool with significant potential to enable the seeking and sharing of BC-related information, and enhance patient education, communication, engagement, and empowerment. However, its use is associated with a number of limitations, including confidentiality and addiction issues, excessive and inaccurate information, and a possibility of jeopardising the patient-doctor relationship. Further research is needed to shed more light on this topic.

Keywords: [Breast cancer](#), [Survivorship](#), [Social media](#)

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Introduction

Female breast cancer (BC) is according to the 2020 global cancer data (GLOBOCAN), the most commonly diagnosed cancer (11.7% of total cases) and the leading cause of cancer-related deaths worldwide, accounting for one in four cancer cases and for one in six cancer deaths [1]. Despite the ongoing reduction of BC mortality rates, disease incidence remains on the increase and by 2030, the number of BC diagnoses is expected to reach nearly 3.2 million per year [2,4]. This trend signifies improved survival owing to regular BC screening and early detection, effective cancer treatments, and better access to healthcare services [2,5].

Both BC patients and survivors often deal with numerous challenges during and after treatment. BC and the subsequent treatments can have far-reaching consequences on an individual's physical, psychosocial, emotional, sexual, and financial well-being, which in turn significantly impact upon overall quality of life (QoL) [6,8]. Pain, restricted mobility, fatigue, anxiety, insomnia, depression, fear of disease recurrence, or death, may persist for years after the disease diagnosis and despite successful treatment [6,9,11]. These challenges are further compounded by insufficient information and support services, absence of clinical guidance and care continuity, regressions in social relationships or professional performance as well as by the overall decline of moral support reserve available from family members and caregivers [12,13].

In recent years, the utilisation of the Internet and social media in the healthcare industry has seen significant growth, and it has the potential to be an invaluable resource in the context of BC care and survivorship [14,17]. The Internet provides a means of addressing some of the difficulties faced by individuals living with and after BC, by facilitating access to health information and by connecting them to support resources and interventions [14,17]. At the same time, this enables them to become part of an ever-growing community beyond geographical borders and access restrictions. The widespread use of social media platforms such as Twitter, Facebook, Instagram, YouTube, TikTok, WhatsApp, and QUORA among billions of global users has transformed them into formidable communication tools [14,21]. Through these platforms, BC patients and survivors, healthcare professionals, stakeholders, and policymakers can establish meaningful connections through sincere, non-hierarchical communication hubs, cultivating the exchange of contemporary clinical current information, experiential sharing, and ultimately the formation of strong support networks [15,21]. This can lead to improved outcomes for BC patients and survivors by ensuring that the needs and perspectives of all relevant parties are respected and incorporated into

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clinical decision- and policymaking related to BC care. However, despite the potential benefits of social media in healthcare and particularly in the field of BC, it is important to acknowledge that several limitations are associated with its usage. These limitations include concerns regarding the accuracy and credibility of the information conveyed through social media platforms. The excessive and commonly irrelevant amount of information available may lead to an information overload, in turn, harbouring a false sense of all-knowing compromising not only user privacy and confidentiality but also dissuading patients from seeking face-to-face professional medical advice [17, 21].

The current narrative review aims to explore the role of social media in the lives of BC patients and survivors. It intends to highlight the advantages and disadvantages of using social media and to provide recommendations for best practices in the future.

Benefits

Currently, the use of social media is a worldwide phenomenon with an ever-growing reach. According to a definition provided by Kaplan and Haenlein (2010), “social media is a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content” [22, 23]. Data obtained in January 2023 indicated that approximately 4.76 billion individuals, representing 54.9% of the total global population, are utilising social media platforms [24]. These platforms encompass blogs, microblogs, content and virtual communities, online professional and social networking sites, content posting sites, collaborative projects, and research forums [22, 23, 25]. The world’s most widely used social media platform is Facebook [24]. However, when it comes to cancer patients, Twitter is emerging as the most popular and frequently used networking platform [26]. BC patients and survivors stand to benefit from this social media expansion. Notably, prior research has shown that online information-seeking and engagement are greater among BC patients compared to other cancer patients [27].

To begin with, social media has significant potential for delivering health promotion messages and for advocating behaviour change [28]. It has been demonstrated that their general use has a positive impact on increasing awareness about modifiable BC risk factors [29] and cancer screening [30, 32], and when combined with mobile interventions, it has a promising role in promoting cancer screening participation [33]. Furthermore, women who use social media platforms to share their experiences, thoughts, and reactions about screening procedures might encourage others to follow the recommended screening

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guidelines [17, 34]. Celebrities and particularly social media influencers have proven to be valuable allies in communicating information about BC prevention strategies, signs of potential malignancy, and available treatment options [35].

Several studies have highlighted the value of social media platforms as a tool for exchanging medical information and advice, enhancing knowledge, facilitating communication, and providing psychosocial support among BC patients [36, 38]. Medical information can be delivered in multiple different formats such as videos, animations, and images, which allows patients with restricted literacy skills to also utilise this information [39]. Of note, social media offers academic and evidence-based information by citing to peer-reviewed journals in 5% and up to 20% of cases [39, 40]. The acquisition of medical information online enables cancer patients to gain up-to-date, reliable knowledge, empowering informed consent, and active participation in clinical decision-making, while enabling them to provide experiential support to others, creating powerful hubs of patient interconnectivity and advocacy [18]. According to Attai et al.'s study [37] (2015), active participation in social media support groups, such as the Breast Cancer Social Media Twitter support community (#BCSM) can enhance the apprehension and knowledge basis of BC patients regarding their disease-specific condition and management, and in turn, reduce the anxiety relating to disease prognosis and anticipated outcomes. Specifically, the study participants reported an increase in various knowledge domains, spanning from fundamental cancer biology and targeted treatment options to survivorship, screening, and genetic testing. Engagement in such cancer-related forums may also strengthen patient-physician interactions embodying the principles of patient-led care [37]. Simultaneously, when physicians disseminate reliable and accurate cancer-related information on social media platforms, they might positively influence patients' perceptions towards the medical community and cultivate the trust necessary to formulate a dynamic patient-physician collaboration [41].

It has been also found that information exchange through online patient communities on Twitter extends beyond medical information and cancer-related news [36]. Instead, these patients' networks primarily revolve around psychosocial support and daily life news, such as treatment updates and greeting and combating feelings of isolation by networking [36]. Another benefit of social media is the ability for cancer patients to engage in open discussions and share their experiences, personal stories, feelings, and opinions anonymously with others. Anonymity promotes open and unbiased communication, minimizes the fear of stigmatisation and encourages self-disclosure, leading to wider social support and empowerment [42]. This is of particular importance in the context of disease-related stigma, which in turn can engender adverse health behaviours [43]. Research has

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indicated that a larger formal social network size and high satisfaction with this support network may have a positive impact on the general health of cancer patients [44]. Specifically, studies have suggested that increased social contact and support may be associated with a greater likelihood of survival following a BC diagnosis [45, 46]. In their study, Farpour et al. [47] (2022) identified a robust association between social media networks and BC patients' general health. The study also suggested that utilising such social media networks and engaging in outdoor work exhibited a direct and affirmative influence on patient behaviour [47]. All these findings highlight the essential role of social media, much beyond information dissemination and towards psychosocial sustenance across BC patients and survivors.

Given that QoL concerns constitute central points of discussion among BC patients, social media can present valuable sources of information on up-trending QoL research and advice for oncology patients [48]. In a study carried out by Tapi Nzali et al. [48] (2017), the authors identified that treatment duration and the diagnosis itself, hair loss, employment status during the disease, the effects of the diagnosis upon, and the support from patients' immediate social network, were topics frequently discussed across social networks and health forums. Interestingly, two additional themes relevant to patient QoL, *"complementary and alternative medicine,"* as well as the relationships between the patients and their relatives, were also identified, and the authors recommended incorporating these emerging subjects into existing QoL questionnaires [48]. Postoperative aesthetic outcome and body image perception, physical, social, sexual, and cognitive functioning also present crucial QoL aspects for BC patients [10, 49, 50]. These parameters could be further explored by analysing social media content, which would allow for country of origin and cultural background to be taken into account and in turn allow for relevant content to be offered to the appropriate patient groups [51]. To that end, advancements in artificial intelligence software, such as ChatGPT, may aid in recognizing such groups and enable the tailoring of informative content to their demographic and disease-specific characteristics.

Women living with and surviving BC reported that they have incorporated the use of diverse social media platforms, such as YouTube, Facebook, WhatsApp, and Twitter, into their everyday routine as a way of effectively self-managing both ongoing BC care and psychosocial needs [52]. Ure et al. [52] (2020) presented three themes exploring how women use social media to aid self-management, which includes *"finding timely, relevant, and appropriate support (support); navigating disrupted identities (identity); and (re)gaining a sense of control (control)."* Better self-management and control, along with improved subjective and psychosocial well-being, lead to patient empowerment. Regaining this lost sense of control results in increased patient confidence and eagerness to actively engage in

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clinical interactions, which, subsequently promotes equality in the patient-healthcare provider therapeutic relationship [15, 41].

Limitations

Despite the potential advantages of social media in BC care and survivorship, its usage is also linked with certain limitations. Patients using social media for healthcare purposes may experience loss of privacy, promotion spanning, addiction to social media, and reduction in subjective well-being [15]. In their review, Moorhead et al. [21] (2013) identified several pitfalls related to concerns regarding the quality, validity, and reliability of information provided across social media, as well as possible breaches in user confidentiality. A large volume of inadequately filtered information may lead to information overload, misinterpretation, and segmentation of the given topic. Adverse health consequences and negative health behaviours may be developed, while patients may opt out of seeking advice from their physicians [21]. Young women diagnosed with BC have voiced concerns about the veracity and quality of the available online information, the absence of specificity to their particular diagnosis, and the difficulties in sorting through vast amounts of information [53]. These women reported encountering more negative information than initially intended, a fact that contributed to increased anxiety and a failure to locate correct and accurate information [53]. What is more, although social media platforms can be a source of support for BC patients and survivors, it appears that such support may be insufficient. As per the findings of Mikal et al. [54] (2020) study, the social support deputed through Facebook may be sporadic, and inconsistent, it lacks collective effort and sufficient funding. In addition, BC patients with low digital literacy may be unable to engage and participate in online peer support groups. Lepore et al. [55] (2019) showed that individuals with low digital literacy experienced higher levels of computer anxiety, distress, and symptoms of depression. Likewise, research has demonstrated that individuals with lower socioeconomic status, as well as elderly patients, are less likely to participate in diverse online activities [56]. Therefore, the caveat in solely focusing on efforts of patient engagement and education online lies within invertedly excluding potentially the most vulnerable across an already at-risk population.

The acquisition of online health information can pose a challenge to the patient-doctor relationship, principally due to a lack of consensus between the two parties about its utilisation [57, 58]. It has been documented in the literature that most healthcare professionals believe that information gathered online may have adverse effects on patients [59]. Physicians' negative reactions to the content obtained through online health

communities and other social media can often leave patients feeling disempowered [60]. In the context of BC, while physicians may engage in discussions pertaining to online-sourced information with their patients, they tend to downplay its potential benefits and overemphasise its risks. Healthcare providers have expressed concerns that such information could lead to misinformation, confusion, and uncertainty, ultimately resulting in increased worries and emotional distress [58]. Meanwhile, BC patients are often hesitant to share or discuss online information with their doctors, fearing that it might negatively affect their therapeutic alliance [58]. In addition to their concerns related to patient misinformation online, physicians have highlighted additional challenges that prevent them from engaging with patients through social media platforms and sharing their expertise [61]. These barriers consist of the need to maintain patient privacy, limited time availability, insufficient involvement of their colleagues, lack of support from their workplace, and difficulty in determining the trustworthiness of other social media users [61]. Albeit major healthcare regulatory bodies, including the General Medical Council and the American College of Physicians, have produced recommendations regarding the use of social media in healthcare, these mainly focus on associated risks, hindering patient-physician communication online rather than providing practical advice and promoting such an interaction [62]. Therefore, as anticipated, no specific guidelines currently exist regarding the appropriate use of social media in the context of BC care. To that end, given the lack of a clear framework enabling and securing online patient-physician communication, BC patients and survivors should always be cautious of individuals or organisations seeking financial gain by making unverified, controversial, and potentially harmful claims regarding cancer remedies online [41]. These claims may include unproven and unlicensed medications, high-dose vitamin and mineral supplements, magic diets, oxygen therapies, and electronic devices [41, 63, 64]. Consequently, patients may fall victims to financial exploitation, as certain organisations may specifically target vulnerable populations [65].

Medical misinformation on social media is a growing public concern [65]. To address this issue, a multifaceted approach with various countermeasures is required [66]. Firstly, healthcare professionals can help by identifying and correcting inaccurate information and by sharing evidence-based content on social media platforms [66, 67]. Moreover, the careful dissemination of accurate medical research findings and expert fact-checking of social media posts may be effective strategies [66]. Medical journals can contribute to this effort through their review process and by adopting easily accessible lay language summaries to communicate scientific context in a simple and comprehensible way for non-expert readers [68, 70]. Peer-review plays a crucial role in this process, as it identifies and filters out potential flaws and biases to ensure that published articles have undergone

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rigorous evaluation, thus maintaining the validity and integrity of the research disseminated [71]. Making peer-reviewed lay abstracts available on social media reinforces the sharing of credible knowledge and trustworthy information, promoting correct patient education and awareness [69, 70]. By using targeted interventions, such as algorithmic adjustments, social media platforms can make misleading online content less visible to users and thus, improve the overall quality of the provided information [72]. Social media campaigns involving influencers and/or key leaders as well as public health campaigns led by expert health organisations can also mitigate this issue [66]. In this context, the World Health Organization (WHO) has suggested a 3-way partnership among member state authorities, industry/platform owners, and civil society organisations to cooperate and ensure the provision of accurate and reliable medical information while holding each other accountable [65].

Conclusion

While numerous research articles exist regarding the use of the Internet and social media in healthcare, the literature remains limited concerning their implementation in the setting of BC care and survivorship. Undoubtedly, social media represents a powerful tool with significant potential to facilitate BC-related information seeking and dissemination and enhance patient education, communication, safety, engagement, and empowerment. Increased patient empowerment and active involvement in the decision-making process could contribute to more patient-centred BC care and higher levels of patient satisfaction.

It is important to recognize, however, that the use and incorporation of social media are not without its limitations and potential drawbacks, and any integration into routine clinical practice should be subject to careful consideration and evaluation. Healthcare providers including breast surgeons, oncologists, and policymakers involved in the care of BC patients, bear the responsibility of being knowledgeable about the possibilities and impact of social media on patients' psychosocial, emotional, cultural, and financial well-being. As such, they should act as guides and guardians, ensuring the appropriate and ethical use of social media and protecting against the potential for misinformation, disproportionate delivery of information, and other risks related to patient well-being.

Without a doubt, there is a need for further research and development of interventions that guarantee the effectiveness, accuracy, reliability, and evidence-based nature of the information and support provided to BC patients and survivors via social media. These interventions should also safeguard the patient-physician relationship from being

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undermined or compromised. In light of these considerations, it is evident that social media presents both opportunities and challenges for the delivery of BC care and survivorship support. Therefore, ongoing exploration and assessment of social media's application in this context are vital to realise its full potential while minimising risks and maximising benefits.

Conflict of Interest Statement

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Author Contributions

ICMJE authorship contribution statement:

Iliana Aristokleous: study design, data acquisition, quality control of data, formal analysis, interpretation, manuscript preparation, manuscript editing, manuscript review, and final approval of the version to be published. Andreas Karakatsanis: conceptualisation, study design, quality control of data, formal analysis, interpretation, manuscript editing, manuscript review, and final approval of the version to be published. Yazan A. Masarwa and Stavroula L. Kastora: conceptualisation, study design, manuscript editing, manuscript review, and final approval of the version to be published.

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