

How Social Media Has Changed the Landscape for Women Battling Breast Cancer

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Evan Anderson Clark

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

Advisor

S. Travis Elliott, Department of Engineering and Society

Introduction

Breast cancer is one of the most prominent and deadly conditions affecting women today. Approximately one in every eight women will be diagnosed with breast cancer over their lifetime, with nearly 287,000 new cases diagnosed annually in the United States alone (*Breast Cancer Facts and Statistics*, 2022). Throughout the progression from initial diagnosis, through treatment, and hopefully remission, women undergo immense physical and psychological hardships. These patients constantly deal with strenuous treatments, fear of death, and the burdens they feel they impose on family and friends. The difficulties of this disease do not end with remission. The return to normal life and the constant fear of cancer recurrence can be difficult. Although cancer is a personal battle, in order to effectively combat both the physical and mental challenges, help is required. These women need aid in the form of emotional support from their loved ones, sound treatment options from their primary physician, and empathy and advice from others who have experienced these same difficulties (Gustafson et al., 2008). The emergence of the internet as a social platform, primarily through social media, has drastically affected those diagnosed with breast cancer. The internet provides a source of information and an avenue for connecting with others. Social media also provides an effective platform for awareness campaigns and fundraising opportunities. Through these avenues, social media has provided new ways to improve the lives of these patients. This Science, Technology, and Society (STS) research paper will investigate how the emergence and prevalence of social media has both positively and negatively shaped the landscape for women diagnosed with breast cancer.

STS Framework

Social media and the internet at large are constantly evolving based on the needs of the various groups that utilize it, fitting well into the Social Construction of Technology (SCOT)

Framework. SCOT outlines how the development of technology is directly influenced and dictated by the various stakeholders who use it. Each group has diverse needs and experiences with the various technologies, known as interpretive flexibility. The technologies that emerge into prevalence are not the most efficient or effective option, but instead, the solution that satisfies the needs of the various users. A technology thrives when it compromises in order to satisfy everyone. This view is in direct opposition to technological determinism, which asserts that the best technology in terms of effectiveness and efficiency becomes the primary technology used by society. The development of the technology is believed to be largely outside of societal pressures. Technological determinism says that society is molded by these technological advancements, as opposed to society influencing the technology. SCOT has three primary components that make up the framework; the various stakeholders, interpretive flexibility, and stabilization (*Social Construction of Technology*, 2022).

First, Identifying the stakeholders is critical to understand how they inevitably shape it. The primary groups involved in social media are the end users and the developers. Social media is widely used throughout the United States. Approximately 82% of the US population, nearly 223 million people, reported using some form of social media between 2020 and 2021(*Social Media Usage in U.S.*, 2021). An example of how society has shaped social media can be seen with the user interfaces. Today, most social media developers have opted for a simplified, easy to use interface. A user interface with more features and complexity could be implemented to improve efficiency and potential uses. However, this would inevitably leave many users alienated and unable to use the product. Even though the increased features are more efficient or affected the interpretive flexibility of the users had led this style to reduce in prevalence. (Banner, n.d.). This compromise in the technology illustrates how social media can be affected

by the users, following SCOT principles. This example also illustrates the SCOT concept of stabilization, where after several iterations, a common system emerges among the various technologies. User interfaces have stabilized around simplistic designs. Not only does society as a whole affect technologies, but small groups can as well. The following analysis will investigate how breast cancer patients have shaped certain aspects of social media and how in turn it has changed how they deal with this disease.

The Internet Provides A Valuable Source of Information

One of the most valuable aspects of the internet is the wealth of knowledge that can be readily accessed. Receiving a diagnosis of breast cancer can leave patients confused and with many questions. The internet is a valuable tool to provide much needed information for these women (Muhamad et al., 2011). Prior to the prevalence of the internet, knowledge about the disease and treatments were primarily obtained from their doctors. Many patients expressed that their information needs were not met during these interactions, primarily due to insufficient discussion time. Additionally, patients were less able to acquire information following these appointments (*How Social Media Has Altered the Cancer Patient Experience*, 2020). Dr. Deanna J. Attai, a breast surgeon practicing in Southern California, has seen first-hand changes in patient interaction due to this readily available information. She describes patients as now being more informed and having more directed questions relating to their care (*How Social Media Has Altered the Cancer Patient Experience*, 2020). Patients are now able to effectively utilize their limited time with their physician.

The information from social media and the internet allow breast cancer patients to more effectively manage their disease. Patients can now be more active in their health care decisions

and seek more personalized care. They are able to research specific aspects of their disease, treatment, and prognosis (Pereira et al., 2000). Patients primarily use the internet to gain information in two ways. The first is through various websites such as Web M.D. and scientific journals such as through the Journal of Clinical Oncology. These sources provide accurate and up-to-date information on the disease, management strategies, and promising new treatments. The next source of information is through groups or individuals on social media platforms (Muhamad et al., 2011). Women who have already undergone treatment can help those currently battling cancer with valuable information. Not only can they provide information on the disease and treatment, but more importantly, they can help deal with the subtle nuances relating to the day-to-day struggles that only someone who has lived with breast cancer would know. These insights can make the treatment and recovery more bearable. (Gustafson et al., 2008).

The mass prevalence of social media has also led to widespread misinformation. There are a wide variety of trusted websites with valuable information on breast cancer, much of which comes from peer-reviewed publications. Social media, however, allows anyone to post information and make claims that have no scientific basis or validity. This leads to the propagation of information that can be damaging to patients. “It’s clear that cancer misinformation is a pervasive problem across social networks,” says Dr. Stacy Loeb of the NYU School of Medicine. She continues, saying that videos and posts with this misinformation get more views and likes due to the exciting nature of these false breakthroughs, further perpetuating the misinformation (*The Challenges of Cancer Misinformation on Social Media*, 2021). Misinformation on experimental and more natural treatment options have led to tangible harm for patients. In a study conducted in 2017, researchers found a 5.68 times increase in patient harm as a result of using alternative treatments over conventional breast cancer treatment

methods (Johnson et al., 2018). Social media has fueled many people to follow these alternative treatment methods. A study performed in 2021 investigated the rates of misinformation on social media platforms including Facebook, Twitter, Reddit, and Pinterest. Researchers found that 30.5% of all articles on cancer contained harmful misinformation (Johnson et al., 2021).

Delineating between accurate and inaccurate information can be difficult, especially for less skilled internet users. The internet provides valuable information that can save patients' life, but also has the potential to misinform the public, leading to serious problems for patients.

Social Media Allows for Increased Support Networks

Breast cancer is a difficult diagnosis to receive and is followed by the immense stress of treatment and the fear of death. These patients can feel a wide range of emotions, uncertainties, and social anxiety. New life challenges manifest in the form of novel decisions, impairments to everyday functions, and difficulty maintaining relationships (Gustafson et al., 2008). During the long battle with the disease, many patients undergo a switch in their self-perception. People often socialize and empathize with others based on how they define themselves. For example, an owner of a company may see themselves as a "successful business person" and relate with other successful business people. However, after a diagnosis of breast cancer, the self-perception as a successful business person, mother, etc. often switches to "breast cancer patient." This switch in self-perception can lead to a sense of isolation from others they once easily connected to (Gustafson et al., 2008). The sense of isolation permeates throughout their family life, their professional life, and their relationships with friends. Most people rely on their family as their primary support group. The inability of family members to fully relate can make continued

support difficult. This increased sense of isolation makes the need to find others who can empathize more important (Smith, 2019).

Social media provides the ability to connect with patients through survivor blogs, chatrooms, and online support groups. These forms of support are vital to effectively dealing with the disease. Research into the effectiveness of social support on breast cancer patient's quality of life was performed by the American Cancer Society. They showed a significant improvement in mood swings, depression, anxiety, anger, and confusion when compared to those who were not part of a support group. The research group also showed that there was "strong evidence for a psychological benefit for group support of various types," showing that a variety of connection avenues, such as through social media, have similar positive benefits. (Goodwin, 2005). Social media posts and blogs from other breast cancer patients also helps reduce the sense of isolation. Reading the stories, daily struggles, and eventual remission from cancer can help these people know they are not alone. These posts also often contain motivation to keep their spirits high, improving their mindset and letting them more effectively deal with their emotional turmoil. Social media also provides the ability to connect one-on-one with other breast cancer patients. These direct and more personal connections to other survivors help these women gain friends who can truly empathize and provide support. These various forms of support also provide a safe space to vent frustrations and fears without the potential to burden family members. Patricia Moreno, PhD, of the Comprehensive Cancer Center of Northwestern University says "You may hold back from expressing all of your feelings with your family members, out of a desire to shield them from worry. In a support group, there is no need to pretend" (Califano, 2018). One major difficulty prior to the internet, was a lack of accessibility to support groups. The internet improves the ability to connect many patients together. As stated by

Dr. Adam Awolu, “The availability and/or accessibility of social support or otherwise significantly determines the prognosis and quality of life of breast cancer patients” (Adam & Koranteng, 2020).

Connections through social media have provided specific benefits over in person support groups. The various treatments including chemotherapy, radiation, mastectomy, and breast reconstruction can leave patients physically ravaged (*Breast Cancer Treatment Causes Severe Side Effects in Many Women*, 2017). This can make leaving their home increasingly difficult, limiting their ability to attend in person support groups. Social media provided a much-needed avenue to connect with other patients in a way that is advantageous for breast cancer patients. As social media has continued to develop, new and more specific avenues of connection have emerged. Patients originally were limited in who they could connect with. As described by Jody Schoger, a member of Breast Cancer Social Media, breast cancer is thought of as one disease and falls under one umbrella. However, after receiving a diagnosis of cancer it becomes clearer that there are a wide variety of stages, hormone statuses, or individual characteristics. Subsequently, one patient's experience can be vastly different from that of another. This varied experience means support from certain patients may be less effective or applicable than others (*How Social Media Has Altered the Cancer Patient Experience*, 2020). In person support groups are geographically limited with who can attend the meetings. There may be few people in the immediate area that share their exact condition. Social media's vast outreach allows breast cancer patients to narrow their social network to people in more similar situations. This can lead to deeper connections and more relevant information exchanges.

Online support groups are generally beneficial to breast cancer patients, but they are not without issues. Many users of these online support groups express concerns of alienation from

the group as a whole. If they do not feel like a true member, they are more likely to drop out of the online group, limiting their ability to receive emotional support. Many factors lead patients to not fit into a support group. Patients may feel their personal story is too positive relative to other members. They feel guilt when sharing their story, thinking their own struggle is not comparable to those who have had worse experiences. The inverse is also true. Many users feel their story is too depressing or grim. They do not want others to be disheartened by their struggles (Goodwin, 2005). Both feeling your story is too positive or too negative leads breast cancer patients to internalize their own personal experiences and feelings. This imposes significant psychological distress for these patients. Additionally, many patients do not want to listen to or read about painful details of others' struggles or instances of cancer recurrence. The pain of others' struggles can cause some users to become more disheartened, both from an empathetic stand point and due to concerns of experiencing the same problems (Brandt, 2017). Another primary concern in user anonymity. The battle with cancer is a very personal affair and most patients want to keep their battle private. Patients may be hesitant to join a support group with people they know from places outside of the group. Additionally they may be dissuaded from the group if they are required to provide their name when posting online (Goodwin, 2005). Support groups are a valuable asset in dealing with breast cancer, but the various downsides must also be considered.

Social Media's Effect on Awareness and Research

The internet's ability to connect people also provides an avenue to spread awareness of the disease. Cancer has been a well-known condition in modern society for many decades, with many people having friends or loved ones who have been affected. The wide reach of social media has provided an avenue to spread awareness and increase funding for breast cancer

research specifically. Today, many online users prefer to receive most of their news from social media platforms such as Facebook and Twitter, whether through news agencies or friends. As a result, these social media platforms have become the primary marketing avenues for many breast cancer awareness organizations. They raise awareness on cancer symptoms, risk factors, and how to screen for breast cancer. Social media provides a cheap and effective way to easily disseminate this information to many people. A study investigating the effect of these social media-based awareness campaigns showed that social media interventions increased breast cancer screening and early diagnosis (Plackett et al., 2020). Breast cancer awareness month also plays a large role in this effort. Social media allows various companies to promote breast cancer awareness during October. This has been shown to lead to a large uptick in donations and breast cancer screenings during this time. The increased screening as a result of the campaigns during October accounts for approximately 6,400 women in the U.S. each year not losing their life because of early detection (*Breast Cancer Awareness Month: Remembering the Burden of This Disease*, 2021). These campaigns have also proven incredibly successful in their ability to crowdsource funding for research. An example of this success can be seen with Cancer Research UK, which raised \$11 million dollars for cancer research through Facebook and Twitter, in just six days (Dockterman, 2014). The money raised through social media and other routes, such as government funding, have led to noticeable improvements in breast cancer detection and survival. The increased funding has led to many positive outcomes such as sophisticated digital mammography machines, discovery of genetic risk factors, new drugs, medical bill subsidies, and many more (Goldman, 2011). Additionally, many organizations use the money raised to support women financially through treatments, elevating some of the immense burden caused by medical bills and lost time at work.

Annually, approximately \$6 billion is raised in the name of breast cancer. Any industry that is able to accumulate such large sums of money will inevitably be fraught with malicious organizations trying to make a profit. The prevalence of the internet provides a platform for charity scammers to reach a large audience. These charities prey on the good nature of people who fail to properly investigate the organization, taking their donations for financial gain. These organizations can also crowd out other, more legitimate organizations. Some charity organizations also only give a small amount of their total donations to research, some keeping nearly 90% of the donations for so-called “company expenses” (Hubbard, 2021). Other issues also begin to arise during breast cancer awareness month. During October, many large commercial organizations will come out with a pink version of their product, marketing it as a way to help the fight against breast cancer. These companies often advertise these products on social media. Unfortunately, they only put a small fraction of the profits towards cancer research, typically around 1% (Goldman, 2011). Although social media has largely benefited breast cancer awareness and research, it is imperative to be wary of malicious charity scammers.

Conclusion

Breast cancer is a devastating disease that has a major impact on people’s lives, from grueling treatment, emotional distress, and financial burdens. The internet and social media have changed the way those with breast cancer battle the disease and navigate their life. The internet allows easy access to information on the disease that can help to make informed decisions about treatments and day-to-day life. Social media provides an avenue to connect with other survivors and a way for organizations to spread awareness and fund research. These online resources can have profoundly positive effects on patient outcomes. Being able to easily connect with other

people who have suffered through breast cancer allows these patients to not feel alone in their battle with cancer. As with any technology there are negative consequences that must be considered. Social media allows for the wide spread of misinformation on treatments that can cause physical harm to patients and even result in loss of life. Some women can also experience difficulty fitting into support groups. Lastly, social media provides an avenue for charity scammers to siphon money away from cancer research and instead turn it into profit. Social media has become an invaluable tool for breast cancer patients. Future efforts must focus on expanding the positive effects of social media, while working to mitigate some of the unintended negative consequences as well.

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