

The Power of Peer-to-Peer Connections: Breast Cancer Straight Talk Support Facebook Community

By Elena Fagotto

Project on Transparency and Technology for Better Health

March 7, 2019



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ABOUT THE PROJECT ON TRANSPARENCY AND TECHNOLOGY FOR BETTER HEALTH

The Project on Transparency and Technology for Better Health studies how sharing data and information may engage patients and improve health outcomes. New platforms, fueled by advances in digital technologies, promise to empower patients by allowing them not only to access information, but also to produce and share their own health data and connect with patients, physicians and doctors. Yet the connections between data sharing and patient action remain poorly understood and underdeveloped in the literature. By conducting comparative case studies on platforms that engage patients through information we provide an inventory and typology of health information initiatives. Our research explores which characteristics are more likely to support patient engagement, at a general level and for under-served populations, and offers lessons to improve the design of future data sharing platforms. This project is part of the Transparency Policy Project at the Ash Center for Democratic Governance and Innovation at Harvard Kennedy School. Archon Fung, Winthrop Laflin McCormack Professor of Citizenship and Self-Government at Harvard Kennedy School, is the Principal Investigator. Elena Fagotto is the Project's Co-Investigator and the Transparency Policy Project's Director of Research. Victoria Alsina Burgues is the Project's Research Assistant. The Project on Transparency and Technology for Better Health was funded by the Commonwealth Fund, Grant No. 20170973.

Learn more at transparencyforhealth.ash.harvard.edu.

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INTRODUCTION

Facebook health groups are a useful tool for patients who want to connect with peers with the same condition, and the third most accessed source of health information (Laranjo et al. 2015). Many of these communities are devoted to breast cancer, the most common cancer among women worldwide (Bender, Jimenez-Marroquin, and Jadad 2011). Breast Cancer Straight Talk Support is a closed Facebook community for women dealing with breast cancer and survivors. With hundreds of posts every day, the group is a safe space where women can vent about feeling scared, depressed, or lonely and receive support from women who “get them.” For many members, the group is a window into other women’s cancer journeys, which gives them perspective and a more proactive attitude to fight the disease. The community is also an important resource to ask questions on treatments, side effects, surgery and more. Women often post pictures of their scars, rashes and medical reports to understand if what they experience is normal and get feedback from their peers. Although members are reminded that they should not provide medical advice, they are free to discuss their experiences and share what worked, or not, for them. Women exchange tips on life hacks to navigate breast cancer treatment, from the best clothes to wear after a mastectomy to ways to fight nausea or pain associated with chemotherapy, information they usually do not get from their oncologists. With 14,000 members, the group is extremely active and questions are answered in a matter of seconds. The community also has limitations. When a post gets dozens of replies it is hard to fully follow the discussion trail, responses may not be pertinent and conversations may turn unproductive. Sometimes women report information on miracle treatments that are not scientifically backed. Members are often reminded to verify information with their clinicians. Overall, however, the group offers members access to knowledge and support they would not be able to receive otherwise. Members are grateful they live in a time when they can use the Internet to connect with their peers and cannot imagine how hard it must have been to fight breast cancer before online communities existed.

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ORIGINS AND EVOLUTION

Breast Cancer Straight Talk Support (BC Straight Talk) is a closed Facebook group for breast cancer (BC) patients and survivors. The group was founded in February 2017 by Seline Arnfield, a thirty-one year old single mother of three. Arnfield, who lives in northern England and goes by the nom de guerre “Seline Arnie Van Damme,” to signal her combative attitude toward BC, was diagnosed at the end of 2016. After her diagnosis, she joined a Facebook group for BC patients to connect with women in her situation. When the group administrator announced that she would start charging a membership fee, Arnfield felt betrayed and outraged and decided she could not lose her support group in the middle of chemotherapy treatment. She created a new support group and went on to contact members of the old group to invite them. Many members migrated from the original group together with Arnfield and many more joined through word of mouth. BC Straight Talk Support was born, with a pledge to always be a free resource for its members.

The group’s banner shows a heart-shaped word cloud of members’ names and the mottos “Supporting women from all over the world dealing with breast cancer” and “Run by women who have been there and know exactly how you’re feeling we are there for one another.” Since the group is closed, as most health-related communities (Bender, Jimenez-Marroquin, and Jadad 2011), prospective members have to apply for admission and answer three questions: whether they have or have had BC, what type of cancer they have, and what is their treatment plan. Family members who want to support someone with BC are redirected to a closed support group called “Breast Cancer Straight Talk Family Support.”

The group has a few simple rules. Members are reminded that the information exchanged on the group should not replace medical advice and that they cannot sell or advertise products or solicit donations. Not even fundraisers that are cancer-related are allowed, to ensure that no monetary exchange is linked to the community. Members are often reminded that the information they acquire through the community should be verified with their physician. These rules are intended to protect members and their modes of communication (Greene et al. 2011). Most health-related Facebook groups have mixed purposes, and may serve simultaneously as promotional spaces,

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fundraising tools, and support communities (Greene et al. 2011). Some communities are created to engage patients in research studies (Farmer et al. 2009; Bull et al. 2011). Groups focusing exclusively on meeting the informational and emotional needs of patients are relatively rare, and make up about 7% of all Facebook breast cancer groups (Bender, Jimenez-Marroquin, and Jadad 2011). With its exclusive focus on supporting its members, BC Straight Talk offers a unique protected environment where breast cancer patients can safely open up and share their stories. Women post questions about treatment and surgery options or share posts describing the depression and anxiety associated with coping with cancer. They are allowed to post images of scars, rashes, breast reconstruction or burns from radiation to inform others and get feedback. Women in the group can express themselves freely, vent and swear, without the need to sugar coat what they write, hence the reference to “Straight Talk” in the community’s name.¹

Prospective members need to apply to be admitted to the community and the founder personally reviews all applications. When in doubt, the founder uses private messages to ask additional questions. This careful vetting process is necessary to make the community a safe space where members can share their stories without anyone profiting from their vulnerable state. The founder is constantly notified of new posts. While she reads most posts, she weighs in only if there are unanswered questions, or discussions that need moderation.

Much of the success of the group depends on the hard work of Seline Arnfield, the community’s founder and primary administrator. She added administrators from Australia and the United States so there would be always someone available to moderate the discussion, across different time zones. Having multiple administrators is also a good way to distribute the heavy workload and allow administrators to “unplug” when needed.²

Administrators enforce the group’s rules and remind members to be respectful when discussions get heated. With “women of all faiths and no faith,” the group is large and very diverse.³ Whereas many offer prayers to support one another, some

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1 Platform leader A interview with author, January 24, 2018.
2 Platform leader A interview with author, January 24, 2018.
3 Platform leader A interview with author, January 24, 2018.

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make it clear that prayers are not what they seek. Overall, despite members' different beliefs, ages and circumstances, women are able to resolve their conflicts and treat each other respectfully.⁴ Administrators intervene when the tone of online conversations becomes negative and remind members to be kind and uplifting, as many women with cancer also suffer from depression.⁵ On rare occasions, administrators have to remove posts and block members. Sometimes, members report inappropriate posts or threads that may have become unproductive, for example long conversations where the original problem was already resolved but women continue to offer advice because they have not read all previous posts.⁶ Intervening quickly to resolve conflicts and expel intruders is essential for the safety and integrity of the community.

Administering the community is very labor-intensive but it is necessary to maintain respectful interactions, make sure that members feel protected, and weed out content that is inaccurate or inappropriate. "If it wasn't for the admins it wouldn't work," explained a platform leader, adding that the difference between a good Facebook group and an unreliable one "is down to administrators' leg work."⁷

Two years after its launch, BC Straight Talk has over 14,000 members and is extremely active, with about a hundred new posts and thousands of comments and reactions every day and about 800 new members every month.⁸ High group activity is appealing to women who want quick feedback on their questions. A member picked this community because other groups she considered were not as active and seemed rather outdated.⁹ Even though the administrators do not promote the community, BC Straight Talk has grown significantly through word of mouth and appears among the top Facebook search results when women look for breast cancer resources.¹⁰ With thousands of members, mostly from the United States, but also from the United Kingdom, Canada, South Africa, Australia and the Philippines, there is always someone online.¹¹

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4 Platform leader A interview with author, January 24, 2018.

5 Patient A interview with author, January 25, 2018.

6 Patient A interview with author, January 25, 2018.

7 Platform leader A interview with author, January 24, 2018.

8 <https://www.facebook.com/groups/Straighttalkbreastcancersupport/>. On February 15, 2018, the group had 721 daily posts. Accessed February 15, 2018.

9 Patient B interview with author, February 2, 2018.

10 Platform leader B interview with author, December 19, 2017.

11 Platform leader A interview with author, January 24, 2018.

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Having someone always available “also in the middle of the night if you are worried and have insomnia” is an invaluable resource for women battling breast cancer.¹²

FROM SIDE EFFECTS TO LIFE HACKS: EXCHANGING ESSENTIAL INFORMATION TO NAVIGATE BREAST CANCER

Facebook health groups let members discuss their experiences and how they are managing their condition, and are especially useful to accumulate coping resources while protecting members’ privacy (Bender, Jimenez-Marroquin, and Jadad 2011; Greene et al. 2011; Zhang, He, and Sang 2013). By connecting with others, members can achieve greater levels of bridging social capital and access information that would otherwise be unavailable (Bender, Jimenez-Marroquin, and Jadad 2011). Participants usually like to post messages on the wall—the most frequently used communication feature—add news, join discussions, upload multimedia such as photos and videos, or simply lurk. All the women interviewed for this research reported that one of the main reasons for joining the group was the need for information and feedback to help them navigate their “breast cancer journey.” Some tried to use Google to find out more about their type of cancer, but struggled with the reliability of their search results and found some of the content upsetting.¹³ Another member joined the group because she had sufficient medical information on her condition, but needed basic or “down to earth” information produced by actual people.¹⁴ A member, who is a medical professional, wanted a place to go when she had questions that were not urgent or important enough to warrant a call to her oncologist.¹⁵ She realized she could rely on the group to find answers and learn how others were dealing with breast cancer. One member described that, after her diagnosis, she felt the need to be prepared to best fight her disease. The uncertainty scared her but, through the group, she was able to learn from other women “what was going to happen next” and felt more in control of her health.¹⁶

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12 Patient C interview with author, January 8, 2018.

13 Patient A interview with author, January 25, 2018.

14 Patient B interview with author, February 2, 2018.

15 Patient D interview with author, January 22, 2018.

16 Patient A interview with author, January 25, 2018.

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Her doctor was more into writing detailed notes than sharing information with her, so the community was an invaluable resource to access the knowledge she needed from women who had been there already.¹⁷

At the time of diagnosis, women feel extremely disoriented.¹⁸ They tend to leave the doctor's office with unanswered questions, fear and anxiety. As a member explained, "everything looks so scattered, but knowledge is power" and women can rely on each other to find the information they need.¹⁹

Typical questions that women post in the group include:

- "what is radiation therapy going to look like?"²⁰
- "which questions shall I ask my doctor?"²¹
- "what shall I bring with me when I go for chemo?"²²
- "when will I lose my hair, and when will it grow back?"²³
- "what shall I buy before surgery?"²⁴
- "will I be able to work?"²⁵

The group is not only a valuable source of information for newly diagnosed members. It can also help members understand risk, weigh options and make complex medical choices. For example, when doctors discuss surgery options such as lumpectomy versus mastectomy, single mastectomy versus double mastectomy, most patients find it hard to evaluate risks and benefits and choose the best option for them. Some struggle with the fact that there is no definitive answer and that it is up to them to decide. Members find it helpful to learn what other women did in similar circumstances, for example what type of surgery they chose based on the size of their lump and type of cancer.²⁶ Learning about other women's thought process when weighing options

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17 Patient A interview with author, January 25, 2018.

18 Patient A interview with author, January 25, 2018; Patient C interview with author, January 8, 2018.

19 Patient E interview with author, January 20, 2018.

20 Patient C interview with author, January 8, 2018.

21 Patient A interview with author, January 25, 2018; Patient C interview with author, January 8, 2018.

22 Patient A interview with author, January 20, 2018.

23 Patient F interview with author, February 1, 2018.

24 Patient C interview with author, January 8, 2018.

25 Patient F interview with author, February 1, 2018.

26 Patient A interview with author, January 25, 2018.

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and their outcomes can be helpful for women struggling with their choices. A member commented that she finds it “invaluable to speak with someone who is going through the same treatment.”²⁷ Additionally, the velocity with which women receive feedback is unparalleled, sometimes literally within seconds from posting a question, reflected a member who is a medical professional.²⁸ The group helps her find the information she is looking for and is “much more helpful than Google,” which sometimes yielded scary results.²⁹

Side effects

Side effects are a popular discussion topic, especially since doctors tend to present only the most common ones.³⁰ Members often describe side effects from their medication and ask if others experienced the same. For example, a member developed hives as a result of her treatment, and found it helpful to learn that others had suffered from the same reaction.³¹ Through the community, a member learned that surgery could result in lymphedema, swelling related to the lymphatic system, a potential side effect that her surgeon had not discussed and that she ended up having.³² Popular recommendations to mitigate side effects include taking an antihistamine used for allergy relief to alleviate bone pain from chemotherapy.³³ One member noted that taking an antihistamine was very helpful and was surprised that her doctor had not mentioned this remedy.³⁴ Another common tip is drinking plenty of lemon or cucumber water to keep well hydrated during treatment.³⁵ Discussing side effects, and how they vary across patients, is helpful and even reassuring because it gives women a more nuanced understanding of their response to treatment.

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27 Patient E interview with author, January 20, 2018.

28 Patient D interview with author, January 22, 2018.

29 Patient D interview with author, January 22, 2018.

30 Platform leader B interview with author, December 19, 2017.

31 Patient F interview with author, February 1, 2018.

32 Patient F interview with author, February 1, 2018.

33 Platform leader A interview with author, January 24, 2018.

34 Patient A interview with author, January 25, 2018.

35 Platform leader A interview with author, January 24, 2018.

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Symptoms

Women rely on the group to discuss their symptoms, learn whether their experience is normal, and decide whether they should consult their oncologist. Someone may report having a fever, or post a picture of her scar to get feedback.³⁶ Hearing from other women who had similar symptoms, or whose scars look similar to the one posted, can be very reassuring.³⁷ After reading other women’s stories, a member became more aware of infections that could result from surgery, and pictures gave her a sense of what botched surgery looked like.³⁸ Sometimes members encourage women to seek medical attention. Many members start their post with the premise “this is probably a stupid question” but other women in the group may suggest consulting a physician based on their experience with similar symptoms.³⁹ Even though women are reminded that posts should never replace medical advice, learning what symptoms other members experienced can give patients the context they need to inform their decisions.

Type of cancer and treatment

Women often seek information about their specific type of cancer, or look for women undergoing the same type of treatment. The group is large and diverse, but women are able to find members with similar diagnoses to have more targeted conversations.⁴⁰ Members learn so much about one another that they “become to be like a family doctor,” and can recommend which specialists one should see or suggest resources to read.⁴¹ A patient used the community to learn more about her treatment course. After her diagnosis, she thought she would have surgery and that would cure her cancer. It was through the group that she learned that cancer could come back after surgery and that some women needed to have surgery, followed by chemotherapy and radiation, which ended up being her treatment plan.⁴²

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³⁶ Patient C interview with author, January 8, 2018.

³⁷ Platform leader A interview with author, January 24, 2018.

³⁸ Patient F interview with author, February 1, 2018.

³⁹ Platform leader A interview with author, January 24, 2018.

⁴⁰ Patient B interview with author, February 2, 2018.

⁴¹ Patient C interview with author, January 8, 2018.

⁴² Patient F interview with author, February 1, 2018.

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The fact that the group is international helps women learn about differences in treatment and expands their horizons. For example, hearing that in Australia women wait six months to a year to have reconstructive surgery after a mastectomy might give new perspective to women in the United States, where reconstruction tends to be performed sooner.⁴³

Often women learn that there are closed groups for their specific type of cancer, or for women taking a certain medication, and may join those groups as well.⁴⁴ For example, a member who is taking estrogen blockers learned through BC Straight Talk that there is a closed group of women undergoing the same treatment, and joined that community for more targeted conversations.⁴⁵ Another member learned about a group called “Sisters in Scars” and seeing pictures of other women’s scars made her feel more prepared for her surgery.⁴⁶ There are also groups for women with triple negative breast cancer, for patients who are under 30 and for women who choose not to have breast reconstruction.⁴⁷

Translating complex medical information in easier terms

Sometimes, women rely on the group to find information in terms that they can easily understand. For example, a woman with triple negative BC recalled that during her visit she was too overwhelmed to grasp her oncologist’s explanation, but the community helped her understand the characteristics of her type of cancer at her own pace.⁴⁸ Sometimes, members who are doctors or nurses weigh in to explain and simplify information. A nurse often explains the steps of breast cancer treatment to new members.⁴⁹ Members in the medical field also try to control the spread of misinformation by singling out information that is not supported by empirical evidence.⁵⁰ But also

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43 Platform leader B interview with author, December 19, 2017.
44 Platform leader A interview with author, January 24, 2018.
45 Patient C interview with author, January 8, 2018.
46 Patient F interview with author, February 1, 2018.
47 Patient E interview with author, January 20, 2018.
48 Platform leader A interview with author, January 24, 2018.
49 Patient E interview with author, January 20, 2018.
50 Patient E interview with author, January 20, 2018.

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members who have no medical training can become very knowledgeable and help others interpret medical information.⁵¹ For example, a woman was confused by her post-mastectomy report and decided to post it on the group's wall. Several members offered reassurance and helped her understand the content.⁵²

Life hacks

Women share a wealth of practical tips to navigate life with breast cancer. These simple tips prepare women for the changes that will occur when they undergo treatment, making them feel more aware and in control of their health. They also help make treatment and surgery more bearable, and some found it surprising that doctors often neglect to discuss these topics.⁵³

Some of these tips include:

- Bring a recorder or a friend or family member to a medical appointment in order not to miss important details.⁵⁴
- Spend time with friends and family because, once treatment starts, your immune system will be weak and you will not be able to be around people who could make you sick.⁵⁵
- Eat and drink what you like before starting treatment because chemotherapy will affect your sense of taste and food you normally enjoy may taste bad.⁵⁶
- Bring a blanket when you go for your chemo because you will be at the hospital for hours and you will get cold.⁵⁷
- Eat small meals and drink plenty of water to avoid nausea.⁵⁸
- Buy a specific type of bra to be comfortable after a lumpectomy.⁵⁹

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51 Platform leader A interview with author, January 24, 2018.

52 Platform leader B interview with author, December 19, 2017.

53 Patient A interview with author, January 25, 2018.

54 Platform leader A interview with author, January 24, 2018.

55 Patient C interview with author, January 8, 2018.

56 Patient C interview with author, January 8, 2018.

57 Patient A interview with author, January 25, 2018.

58 Patient A interview with author, January 25, 2018.

59 Patient A interview with author, January 25, 2018.

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- Lifting your arms after surgery will be painful. Place objects at a lower level so you can reach them easily, choose shirts with buttons so you can wear them without lifting your arms, and get plenty of pillows to be more comfortable.⁶⁰
- Get a notepad and write things down because chemotherapy can impact your memory (a phenomenon referred to by members as “chemo brain”).⁶¹
- Buy an inexpensive cart where you can hang your post operative drains.⁶²

A member explained that “doctors take care of the treatment, but the community provides this valuable information,” which can significantly improve the day-to-day lives of breast cancer patients.⁶³ A patient credited her oncologist for providing her with the necessary medical literature on BC, but it was the group that gave her “the whole picture.”⁶⁴ Women also exchange information on useful books as well as financial resources available to support BC patients and tips on negotiating with their insurance companies.⁶⁵

Alternative treatments

The group supports cures that are evidence-based and the majority of members undergo treatments involving chemotherapy, radiation and surgery.⁶⁶ Occasionally, women discuss alternative treatments, or post articles purporting the cancer benefits of certain foods, such as lemons, or essential oils. In general, however, women post about natural remedies they are using without trying to convince other members.⁶⁷ Women interested in alternative treatment are reminded that posts should be backed by scientific evidence and that there are specific groups for alternative treatments. As a platform leader explained “everybody is entitled to an opinion” but it is important to

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60 Patient C interview with author, January 8, 2018.
61 Patient C interview with author, January 8, 2018.
62 Patient E interview with author, January 20, 2018.
63 Patient C interview with author, January 8, 2018.
64 Patient F interview with author, February 1, 2018.
65 Patient E interview with author, January 20, 2018.
66 Patient B interview with author, February 2, 2018.
67 Patient D interview with author, January 22, 2018.

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differentiate between treatments that have scientific backing from opinions.⁶⁸ Nevertheless, women who discuss alternative treatments are not excluded from the group and their views are respected.⁶⁹ Such treatments may be part of a woman’s “healing journey” and they may offer hope for women who have exhausted all other options.⁷⁰

CONNECTING WITH OTHERS WHO “GET IT”

One of the main impacts of Facebook health communities is that they expand patients’ access to emotional support, which promotes coping and reduces negative thoughts and anxiety (Bender, Jimenez-Marroquin, and Jadad 2011). Participation in online health communities favors patient-centered goals, promotes a sense of self-efficacy, and helps patients articulate positive, realistic self-images (Greene et al. 2011; Newman et al. 2011; Zhang, He, and Sang 2013).

All the women interviewed for this case study described the sense of isolation that came with their diagnosis. Women reported that, even though spouses, family members and friends try to be helpful, they do not understand all the implications of having BC. The community is a safe space where women can get the emotional support they need from women who understand what they are going through. Even though certain hospitals organize face-to-face groups where patients can meet and discuss their struggles, these encounters may not be for everybody. A member described that she is in denial of her condition and would not be able to open up with other women in person. For her, the community “is a place where you can ask any question, even embarrassing ones,” including questions one would not ask her doctor “and you know you’ll find someone who’s going through the same.”⁷¹

Women rely on the community to get support for a number of challenges associated with their disease.

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68 Platform leader B interview with author, December 19, 2017.

69 Platform leader A interview with author, January 24, 2018.

70 Platform leader B interview with author, December 19, 2017.

71 Patient B interview with author, February 2, 2018.

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First, after diagnosis, women are shocked, in denial and in a “panic mode,” as they wonder whether they will die, and what will happen to their children and families. Comments like “this is normal,” “you have a right to be upset” and “things will get better” are common and give members a sense of validation and support.⁷² A member felt calmer after she realized she was not alone: the support of members made her feel stronger in the face of cancer.⁷³ Breast cancer requires a re-adjustment of one’s identity and the group helps women get used to their “new normal.”⁷⁴

Second, many members encounter problems with their partners due to changes in their body, side effects of medications, depression and body image problems. Patients go to their community to share intimate details on how breast cancer is affecting their relationships and sexuality.⁷⁵ Some patients may feel embarrassed to discuss these issues with their doctors or with their family (Bender, Jimenez-Marroquin, and Jadad 2011). The privacy of a closed group allows members to open up, without worrying that anyone they know will read their posts.⁷⁶

Third, many patients struggle with uncertainty and wait times, for example waiting for test results, or waiting for their surgery. For a patient, the anxiety associated with waiting for test results was particularly hard to bear, so she decided to join the group to get the support of other women and fill those wait times.⁷⁷ A platform leader explained that the time when women end their therapy and need to wait to see if they are clear of cancer, a period she calls “wait, watch, and worry,” can be particularly stressful.⁷⁸ Connecting with other women and going through this worrisome wait together can be helpful.

Members may “give you a hug, make a joke, tell you how beautiful you are” to support their peers.⁷⁹ Many women offer prayers or ask for prayers to comfort and support them. Symbols like angels and teddy bears are often posted to support members.⁸⁰ A

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72 Platform leader A interview with author, January 24, 2018.

73 Patient A interview with author, January 25, 2018.

74 Patient C interview with author, January 8, 2018.

75 Patient E interview with author, January 20, 2018.

76 Patient F interview with author, February 1, 2018.

77 Patient F interview with author, February 1, 2018.

78 Patient leader B interview with author, December 19, 2017.

79 Patient C interview with author, January 8, 2018.

80 Patient E interview with author, January 20, 2018.

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popular member tries to be uplifting to the community by shooting videos or pictures of herself with funny animations.⁸¹ Women get support also when they do something good, which motivates them to keep up positive habits. Facebook health communities influence individuals' health behaviors by shaping their perceptions of social norms and the expectations that they set for themselves. Research indicates that health communities exert social influence and can be motivational: participants influence peers in their decision-making processes and in maintaining healthy behaviors (Zhang, He, and Sang 2013; Newman et al. 2011; Morris et al. 2011; Laranjo et al. 2015). For example, a member posted that she kept exercising when she started chemotherapy and received 300 likes, which she found very inspiring.⁸² She attributes her positive mood and good response to therapy to the support she received from the community.⁸³ Members also check in on each other and reach out to members who have been less active.⁸⁴ Sometimes, the emotional support turns into concrete help. There have been cases when members who live close to each other met face to face⁸⁵ or even offered to accompany someone to the hospital.⁸⁶

Women continue to belong to the group even when they are free of cancer to help other members and to continue to get support. A patient, who has had a double mastectomy and is taking an estrogen modulator to reduce her chances of reoccurrence, explains that the group is still a valuable resource for her because with cancer “you can’t take your guard down.”⁸⁷ Breast cancer made her more fragile and anxious and her online community continues to support her.

All members value immensely the emotional support they receive from their community. Some described it as “like having a sister [...] like a safety blanket.”⁸⁸ Others expressed a profound sense of belonging “this is my group, [...] these are my friends. [...] I get more out of this group than going to a psychiatrist.”⁸⁹

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81 Patient C interview with author, January 8, 2018.

82 Patient D interview with author, January 22, 2018.

83 Patient D interview with author, January 22, 2018.

84 Patient C interview with author, January 8, 2018.

85 Patient F interview with author, February 1, 2018.

86 Patient E interview with author, January 20, 2018.

87 Patient F interview with author, February 1, 2018.

88 Patient C interview with author, January 8, 2018.

89 Patient C interview with author, January 8, 2018.

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The community gives members hope when they feel demoralized and a patient wondered “how did women do it in the old days, before Facebook?”⁹⁰

Ability to vent

Members value having a safe space where they can vent about the emotional distress associated with hair loss, bone pain, or their nails breaking. Women also vent about hurtful comments, for example that having breast reconstruction will improve their looks, or that they look good despite having cancer. A member explained, “we might look good, but we are broken,” a shared feeling among women in the group.⁹¹ As a member put it, “with breast cancer sometimes you really need to explode, women need to be mad and let it all out. It is important to have a place to vent rather than bottle things up.”⁹² Having a safe place to share their struggles, and swear if they need to, is an important safety valve for women battling cancer. For a member, the community is an outlet and sometimes just reading what others are posting is enough to ease her pain.⁹³

Hearing others’ stories gives perspective

The group is large and diverse, with women of different ages and with different types of breast cancer, including incurable ones. Intuitively, women with advanced breast cancer should not want to hear the complaints of members who caught their cancer early and have much higher chances of survival. Yet women develop camaraderie and a sense of shared journey, irrespective of their specific circumstances and differences. Women learn not to judge one another and remind themselves that “we are all suffering.”⁹⁴ They understand that the “common denominators” they face create cohesion among members.⁹⁵ Through the group, a woman learned that all patients are different, some women experience multiple side effects, while others do not. Hearing

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90 Patient E interview with author, January 20, 2018.

91 Patient C interview with author, January 8, 2018.

92 Patient C interview with author, January 8, 2018.

93 Patient B interview with author, February 2, 2018.

94 Patient C interview with author, January 8, 2018.

95 Patient B interview with author, February 2, 2018.

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other women’s stories “can scare you, but it can also give you hope,” in her case, she hoped her side effects would be milder.⁹⁶ Through the group, members are inspired by women with metastatic breast cancer who go on to live for years and have such good spirits that they cheer up women with less invasive types of cancer.⁹⁷ Members develop an understanding that individual circumstances and responses to treatment are very different, which increases mutual respect and tolerance.⁹⁸ “When you think what you are going through is the end of the world, you can compare it to other people’s experience” and gain strength to cope with cancer.⁹⁹

Answers from real people

Women go to the group with any type of questions, from side effects, to the impact of cancer on their relationships. With over 14,000 members, posts receive dozens, sometimes hundreds, of comments and reactions. A platform leader explained that the personal connection is as important as the knowledge that women exchange. For example, even though the group has some files that offer information on cancer, the strength of the community is the ability to post questions and receive advice from real people who understand what the member is going through. Whereas there are sites that give good information on breast cancer, with BC Straight Talk “you have someone there to help you and answer your questions.”¹⁰⁰ This gives members a unique sense of being not only prepared and well-informed, but also deeply connected and supported by thousands of women in their same circumstances.

Giving back to the community

Supporting other members during their cancer journey is also an important motivation for being part of the community. A member who has had a double mastectomy, for example, feels it is now her turn to support newly diagnosed women, since that is

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96 Patient F interview with author, February 1, 2018.
97 Platform leader A interview with author, January 24, 2018.
98 Patient B interview with author, February 2, 2018.
99 Patient E interview with author, January 20, 2018.
100 Platform leader A interview with author, January 24, 2018.

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an especially difficult time.¹⁰¹ A member, who is also a nurse, feels compelled to help women understand information about their cancer and treatment steps.¹⁰² She also wants to raise awareness about resources available in many care centers, for example “nurse navigators” who help women deal with different aspects of BC treatment.¹⁰³

MEMBERS GET ACTIONABLE AND PERSONALIZED INFORMATION

The information patients get is both actionable and personalized. Advice on how to fight nausea and pain, how to prepare for surgery or how to combat anxiety, for example, can be readily followed by members. Information on cancer treatment may not be as actionable because it is not something patients can implement by themselves. The group, however expands the knowledge of patients and gives them the confidence to ask questions and bring up new information at their clinical encounters. Through the group, one member learned about clinical trials and was able to discuss these with her oncologist.¹⁰⁴ Another member discussed options to calm her pain, something she did not think she could bring up with her physician.¹⁰⁵ Members who fear disturbing clinicians with irrelevant questions may learn that their concerns are legitimate. Especially younger patients are reminded “don’t take no for an answer, go back” until their doubts are resolved.¹⁰⁶ Members also encourage women to seek a second opinion or to find a new doctor when the one they have is not a good fit. They empower women to say, “This is not working, what are my other options.”¹⁰⁷ Giving women a stronger voice as patients may help turn information acquired through the group into actionable steps in their cancer treatment.¹⁰⁸

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101 Patient F interview with author, February 1, 2018.

102 Patient E interview with author, January 20, 2018.

103 Patient E interview with author, January 20, 2018.

104 Patient F interview with author, February 1, 2018.

105 Platform leader B interview with author, December 19, 2017.

106 Patient E interview with author, January 20, 2018.

107 Patient E interview with author, January 20, 2018.

108 Platform leader A interview with author, January 24, 2018.

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Some of the information patients receive is personalized because it is elicited by posting questions. When members reply, they offer personalized feedback to answer the specific needs of the poster, for example based on the type of cancer, type of treatment, age, location, or other circumstances described in the original post. Sometimes, however, women share stories about their treatment and symptoms, which, while informative, may not be as personalized.

DISTRIBUTIVE EFFECTS: FILLING INFORMATION GAPS FOR WOMEN IN UNDER-SERVED COMMUNITIES

The group is easily accessible via computer or smart phone to women who have a Facebook account and qualify for admission to this closed community. Given how widespread Facebook is, a cancer group embedded in this community is likely to reach a broad and diverse community of women. Additionally, this group is one of the top results that one gets when searching for breast cancer support groups on Facebook, making it easy to identify the community. Members praise this community because it is a free resource they can conveniently access whenever they have a question or time to catch up on group activity.¹⁰⁹ Some hospitals offer face-to-face support groups for BC patients, but women may feel intimidated by meeting in person, or may not have the time or resources to attend a meeting. One member explained that during chemotherapy her symptoms were so bad that she could not have driven to an in person meeting. For her, having the support of thousands of women while staying at home was invaluable.¹¹⁰ For women who live in remote and sparsely populated areas, this online community of patients is a real “lifeline.”¹¹¹ Additionally, the knowledge shared on the group can be particularly helpful for women who are less educated, and for younger patients, who may be dismissed by the health care system.¹¹² The group may give these women the knowledge and support they need to have a stronger voice as patients and seek adequate medical care.

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109 Patient E interview with author, January 20, 2018.

110 Patient C interview with author, January 8, 2018.

111 Platform leader A interview with author, January 24, 2018.

112 Patient E interview with author, January 20, 2018.

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The group may also redistribute knowledge and help women who do not have access to the best care. For example, some women may be dealing with side effects but there may not be medical specialists on call in their area. For these women, being able to pose a question to the community and getting immediate feedback may be more helpful than leaving a message on an answering service.¹¹³ Finally, by exposing women to other women’s stories and by focusing on their common goal of fighting breast cancer, the group may help bridge socio economic gaps and increase mutual respect and tolerance.¹¹⁴

CONCLUSION AND CHALLENGES

The main challenges for the community are associated with the quality of the information exchanged. Given how large and diverse the group is, with women from different backgrounds and all educational levels, not all the information shared in the group is accurate. A member reported that there is a fair amount of misinformation circulating in the group, with recurrent stories on how soy may be harmful for women with breast cancer. This member replies by posting scientific evidence that soy is not risky, but eradicating the belief that soy is bad for patients remains hard.¹¹⁵ Sometimes, women share information without carefully verifying its accuracy or scientific backing, for example posting sensational headlines of what causes or cures breast cancer, which may generate confusion.¹¹⁶ Finally, illegitimate members may post links with non evidence-based information with the sole goal of getting clicks and increase Internet traffic. Even though the group administrators are watchful of the accuracy of what is being discussed and intervene quickly asking to correct or remove posts that are misleading, some misinformation is inevitable. Administrators favor information that is evidence-based, while also providing a safe space where women are free to share what they know and what works for them, including alternative remedies that lack scientific

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113 Platform leader B interview with author, December 19, 2017.

114 Platform leader B interview with author, December 19, 2017.

115 Patient B interview with author, February 2, 2018.

116 Patient E interview with author, January 20, 2018.

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backing. Administrators sometimes intervene to clarify the distinction between evidence-based information and opinions to make sure members develop the tools to be more discerning. Additionally, members are often reminded to take all information “with a grain of salt” and clarify any doubts with their doctors.¹¹⁷ For example, after learning that supplements could help with hair growth, a member decided to discuss that with her oncologist. Through her doctor, she learned that supplements did not help grow hair and could exacerbate her side effects, so she decided against their use.¹¹⁸

Furthermore, the way the discussion is organized, in threads with sometimes hundreds of replies, may make it challenging to find information. Women are often encouraged to use the search box to look for specific key words in previous conversations.¹¹⁹ However, when one gets too many comments to her original post, reading all the responses may be arduous, and important information may be lost. One member suggested using the shared knowledge to create lists and resources for new members, who need to learn more about breast cancer but can easily become overwhelmed by too much information.¹²⁰ The long trail of responses may also lead to misunderstandings, generating anxiety, almost collective hysteria, among members.¹²¹ For example, once a woman posted that her scar was not in good condition and members suggested to get medical help. She did, was hospitalized and felt better, but women continued to worry about her because the post in which she reported feeling better got lost among dozens of replies.¹²² Sometimes original posts are followed by a long trail of responses, and members chime in without reading all the previous content, which can generate confusion and needless worries. Even though administrators do a good job at intervening to control unproductive conversations, some threads get out of hand.

Whereas the group is international and diverse, a more focused and local dimension could be beneficial. A member wished that there were some integration between the group and her care center and suggested, “why don’t hospitals create their

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117 Patient F interview with author, February 1, 2018.

118 Patient F interview with author, February 1, 2018.

119 Patient E interview with author, January 20, 2018.

120 Patient A interview with author, January 25, 2018.

121 Patient E interview with author, January 20, 2018.

122 Patient E interview with author, January 20, 2018.

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groups?”¹²³ For her, an online community of women who are treated at her hospital would be even more helpful because she could share information about doctors and other resources in her area.¹²⁴

Overall, even though some information should be taken with caution, the information available through the group is quite accurate and helpful. Members with medical training reported that the quality of the information that is posted is generally good and that most information is reliable.¹²⁵ One member with a research background recognized that the group is a supportive environment where “a lot of people are well informed and provide good tips.”¹²⁶

In general, members understand that the group has limitations and that it is better to verify some information with their doctors, but they are also grateful for a chance to connect with women in their same circumstances to tap into their knowledge and receive the support they need to fight breast cancer. More than one appreciated the importance of living in a time when the Internet makes connecting with others so seamless and fast, and could not imagine how it must have been for breast cancer patients from previous generations.¹²⁷ With over 14,000 active members, the community is an invaluable resource for women with breast cancer, from those who need prayers for emotional support, to those who seek to discuss their treatment options with their peers. Much of its success depends on the time and dedication invested by its administrators.

Going forward, a platform leader promises to continue to support and protect members in her community and be there for them because “there is a need for it [...] It really feels like being a mother.”¹²⁸

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123 Patient F interview with author, February 1, 2018.

124 Patient F interview with author, February 1, 2018.

125 Patient D interview with author, January 22, 2018; Patient E interview with author, January 20, 2018.

126 Patient B interview with author, February 2, 2018.

127 Patient D interview with author, January 22, 2018; Patient E interview with author, January 20, 2018.

128 Platform leader A interview with author, January 24, 2018.

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