



## CONNECTING WITH PEERS ONLINE

More and more women are going online for breast cancer support

1 out of every 8 women will be diagnosed with breast cancer at some point in their lives. Many of us know someone who has been affected by breast cancer, yet few of us know how to provide the support that cancer patients and survivors need. Supportive care is considered to be an essential service for cancer patients, but these needs are consistently unmet.

On top of medical needs, women with breast cancer need informational, practical, psychosocial, and spiritual support at all stages of the disease. For a woman that has just been diagnosed, there is no substitute for the kind of guidance that they can receive from someone who has been through it before. For patients, peer support is a source of hope, motivation, and empowerment, inspiring them to take charge of their own recovery. For survivors, the community helps them celebrate, cope with the threat of recurrence, and strive to regain normalcy.

Face-to-face and telephone-based peer support programs are already reaching many women in need. In recent years, however, more and more women are seeking and finding support through online communities. A recent study found that 31.5% of breast cancer survivors had used an online breast cancer community ([Bender et al. 2013](#)). These communities help members learn more about breast cancer and treatment options, as well as exchange emotional support. For women with breast cancer, emotional support has proven to be especially valuable. Cancer patients identify emotional support as the most helpful form of support, which has been shown to improve mental well-being, health-related quality of life, self-efficacy, coping with breast cancer, and survival rates of breast cancer ([Yoo et al. 2014](#)).

Breast cancer patients experience the greatest and most varied need for support during the treatment period, during which they use online forums the most frequently. Among online forum users, 91% visited daily or weekly during the treatment period ([Bender et al. 2013](#)). In this study, the most common reasons for using online peer communities were desires for informational and symptom management support from peers.

### Strengths of Online Peer Support

- **Richer informational support in greater quantities.** Informational support from peers can provide greater detail about practical matters and experience than that provided by health care providers. Larger and more diverse group composition provides access to wider variety of information and support.
- **Expression through writing.** Members have time to construct supportive messages with carefully chosen words and content. Text-based messages clearly convey supportive intention. Writing personal stories and expressing feelings can be therapeutic.
- **Finding similar people.** Online communities make it easier to find other people with similar conditions, especially others with rare conditions.
- **Availability.** Members benefit from accessing online peer support whenever they need it, instead of having to wait for a scheduled face-to-face support group or a visit with a provider. People with limited mobility do not have to worry about transportation barriers.
- **Anonymity.** For some, it is easier to discuss sensitive topics with peers online than with providers or in face-to-face support groups because of the anonymity and confidentiality afforded by the online platform. Fewer visible social status cues, such as age, gender, and ethnicity, allow for more equitable interactions.
- **Low commitment.** This is a less demanding tool that allows people to provide or receive support as much or as little as they want, depending on their immediate needs. There is a lower expectation to provide support because many users exchange support.

Most individuals turned to online peer communities in times of increased stress, after the diagnosis of an uncommon condition, when they felt they had insufficient local support, or when the information given by health care providers was insufficient. In most cases, online communities served as supplements to face-to-face support and not as a primary source of support.

Research into online support communities for cancer survivors has focused primarily on breast cancer; one review identified that two thirds of studies recruited breast cancer survivors ([Hong et al. 2011](#)). The contributions of the thriving breast cancer community are driving our understanding of online peer support.

## Keys to improving online breast cancer peer support

Given that many breast cancer patients and survivors are already taking part in online communities, greater efforts are needed to ensure consistent, high-quality, supportive interactions. Raising awareness of what online support can and cannot do will help programs reach people where they are at. Furthermore, greater understanding about how people integrate online and offline support will lead to more effective peer support programs.

Online communities help patients find informational and emotional support quickly and conveniently. The information and support provided online tends to be richer, more explicit, and provided in greater quantities. A persistent concern of online forums is the risk of spreading incorrect and misleading information, but research has found that such information is quickly corrected by the communal mind ([Chung 2013](#)).

Anonymity can be a double-edged sword. Anonymous disclosure allows patients to share sensitive concerns and questions more easily, but being able to put a name and a face to a person is important for building trust and rapport. Anonymity and low commitment are important factors behind frequent community turnover, which may be mitigated by providing the option to link community profiles to personal accounts.

For those working in offline peer support programs, questions remain about the quality of peer support delivered through online platforms. Online communities have often been created and managed by community members, which can leave providers and health professionals out of the loop. Some healthcare providers have taken the initiative to offer online peer support to their patients through integrated systems that have the potential to improve care coordination and service quality.

Online peer support can be most beneficial for women with breast cancer who are socially isolated or have unmet social needs.

## Limitations of Online Peer Support

- **Incorrect or misleading information.** Members do not undergo any education or training, and many lack the qualifications to provide health information. Many online communities have strict rules that limit interactions to sharing stories and providing support. Good community moderators are needed to manage the information provided through online forums, but they cannot control personal correspondences.
- **Not all communication is supportive.** Not all information or support is positive for the recipient. Negative comments by some participants can discourage the participation of others. Reading personal “horror stories” can be particularly damaging. This appears especially to be a problem for people with advanced disease in unmoderated groups. Such groups should have moderators who are able to step in to keep exchanges supportive and not threatening.
- **Takes time to find the right fit.** People need to try out several online communities before they find the right fit, with peers who can offer the right type of informational and emotional support. This can be a time-consuming process that postpones the receipt of needed support.
- **Frequent turnover.** Members participate when they need support and many are not closely attached to their online communities. Relationships formed online may be short-lived.
- **Disengagement with offline social connections.** Increasing reliance on online peer support may weaken existing support networks.
- **Not reaching vulnerable populations.** Online forums and other web-based programs appeal the most to highly educated, better-adjusted, healthier, non-minority populations who may already have access to more peer support resources.

Despite the amount of research conducted on online breast cancer support and the prominent health disparities in this field, few studies have reported on the impact of online support for minority populations, which could really benefit from this form of support delivery.