



## Are mainstream support services meeting the needs of sexual minority women with breast cancer? An exploration of the perspectives and experiences of users of an online support forum

Rachael L. Wandrey, Whitney D. Qualls & Katie E. Mosack

To cite this article: Rachael L. Wandrey, Whitney D. Qualls & Katie E. Mosack (2016) Are mainstream support services meeting the needs of sexual minority women with breast cancer? An exploration of the perspectives and experiences of users of an online support forum, *Journal of Gay & Lesbian Social Services*, 28:4, 336-348, DOI: [10.1080/10538720.2016.1221783](https://doi.org/10.1080/10538720.2016.1221783)

To link to this article: <https://doi.org/10.1080/10538720.2016.1221783>



Published online: 18 Oct 2016.



Submit your article to this journal [↗](#)



Article views: 168



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 3 View citing articles [↗](#)

## Are mainstream support services meeting the needs of sexual minority women with breast cancer? An exploration of the perspectives and experiences of users of an online support forum

Rachael L. Wandrey, Whitney D. Qualls, and Katie E. Mosack

University of Wisconsin-Milwaukee, Milwaukee, Wisconsin, USA

### ABSTRACT

We conducted an inductive content analysis of messages posted to the lesbian-specific discussion board forum found on [breastcancer.org](http://breastcancer.org) for the purpose of examining sexual minority women's experiences of and perspectives on mainstream cancer support services. Our analysis indicated that currently available support services might not be adequately addressing sexual minority women's unique needs. Individuals posting to the lesbian-specific forum reported the presence of homophobia, heterosexual bias, and feelings of exclusion in mainstream breast cancer support services. In contrast, forum users generally perceived nonspecific cancer support groups to be beneficial, yet the majority preferred lesbian-specific support.

### KEYWORDS

lesbian; breast cancer; cancer support services; online support groups; heterosexual bias; homophobia; qualitative methods; sexual minority women

### Introduction

Psychological distress, such as mood disturbances and anxiety, are common among breast cancer (BC) survivors (Knobf, 2011). Unfortunately, sexual minority women (SMW) with BC have reported greater stress (Jabson & Bowen, 2014), depressive symptoms, and relationship difficulties (Kamen, Mustian, Dozier, Bowen, & Li, 2015) in comparison to heterosexual patients. Indeed, Matthews, Peterman, Delaney, Menard, and Brandenburg (2002) found that a significantly higher proportion of lesbians reported engaging in individual psychotherapy because of the emotional burden related to their cancer diagnoses. Informal social support can help mitigate psychological distress (Cohen & Wills, 1985), but may be more difficult for sexual minority cancer patients to acquire because of their greater likelihood of having experienced trauma and familial rejection (Ryan, Huebner, Diaz, & Sanchez, 2009). Indeed, researchers have found that lesbian BC patients report less social connection to family (Arena et al., 2006) and rely heavily on their romantic partners to provide support (White & Boehmer, 2012).

---

**CONTACT** Rachael L. Wandrey, MS  [wandrey@uwm.edu](mailto:wandrey@uwm.edu)  Department of Psychology, UW-Milwaukee, P.O. Box 413, Milwaukee, WI 53201.

© 2016 Taylor & Francis Group, LLC

Not all SMW with BC are able to receive support from partners and in many cases support from partners may not be sufficient, especially in the context of clinical levels of anxiety and depression. Therefore, many SMW need to seek support beyond their social circles and may do so by participating in cancer support groups. Indeed, higher levels of distress and engagement in cognitive avoidance coping are related to increased rates of participation in cancer support groups among SMW (Boehmer, Linde, & Freund, 2005). Breast cancer support programs are intended to lessen psychological distress associated with BC diagnosis and treatment and these programs are typically successful at achieving this goal (Rankin, Williams, Davis, & Girgis, 2004; Setoyama, Yamazaki, & Nakayama, 2011; Taggart, Ozolins, Hardie, & Nyhof-Yound, 2009; Zeigler, Smith, & Fawcett, 2004). However, it is unclear whether the unique experiences and concerns of SMW are being addressed in mainstream BC support programs. Indeed, support group facilitators might not think that meeting the needs of SMW is crucial, or even a “mandate” (Sinding, Barnoff, & Grassau, 2004). Dismissing the importance of creating a safe and supportive space among BC survivors who do not identify as heterosexual might explain why although SMW with BC are as likely to have participated in a cancer support group as their heterosexual counterparts, they are much less likely to remain involved (Matthews et al., 2002).

Exploring the support needs and experiences of SMW with BC is a relatively nascent area of research. However, evidence thus far suggests that mainstream support services may not be meeting the needs of SMW. Indeed, SMW have reported feeling excluded and dissatisfied with the topics of discussion (e.g., concerns about breasts and their importance to men) in mainstream support groups (Fish, 2010). In addition, many SMW have indicated a high degree of discomfort with disclosing their sexual orientation in these settings (Fish, 2010). The discomfort that many SMW feel appears to be grounded in expectations of heterosexism and homophobia, both of which have been reported in mainstream cancer services (Barnoff, Sinding, & Grassau, 2005). As a result of feelings of exclusion and discomfort, SMW have indicated a strong preference for SMW-specific cancer support programs (Barnoff et al., 2005). Participants in SMW-specific groups have reported feeling safe in these groups and find that this setting allays concerns about coming out and provides an opportunity to meaningfully connect with other SMW with BC by discussing issues that are specific to SMW (e.g., coming out to health care providers; Boehmer et al., 2005; Matthews et al., 2002).

The majority of research on BC support services has focused on face-to-face support groups; however, cancer patients are increasingly seeking support on the internet (Kowalski, Kahana, Kuhr, Ansmann, & Pfaff, 2014). Indeed, virtual communities for those with chronic and/or life-threatening illnesses (e.g., HIV, Huntington’s Disease) have been found to provide several types of social support, with informational and emotional support being proffered most often (Coulson, Buchanan, & Aubeeluck, 2007; Mo & Coulson, 2008). Patients seek support online for a number of reasons, including deficient offline social support (Chung, 2013; Yli-Uotila,

Rantanen, & Suominen, 2013). Fortunately, researchers have indicated that Internet-based support is effective in alleviating psychological distress and some physical symptoms, such as fatigue (Bouma et al., 2015). Other positive outcomes of participation in online support services include stronger relationships with physicians, greater acceptance of the disease, and an increased sense of optimism and control (Van Uden-Kraan et al., 2008).

Examining online support forums that focus on the needs of people who identify as SMW would be useful to develop an understanding of the support needs they have. For instance, the pronounced anonymity of the Internet might allow for more frank discussions, likely increasing the credibility of the findings. Moreover, an Internet sample may better represent those SMW who are dissatisfied with available face-to-face support services, a population whose perspectives would be valuable to practitioners who are seeking to improve the inclusiveness of current cancer-related support programs. Examining conversations about cancer support programs within an online forum may also provide insight into the usefulness and acceptability of Internet-mediated peer support. In addition, an online sample is not limited to one geographic region, as is the case in previous studies on the support needs of SMW with cancer (e.g., Barnoff et al., 2005; Paul, Pitagora, Brown, Tworecke, & Rubin, 2014) and may include a greater proportion of SMW who live in rural areas and do not have easy access to face-to-face support services.

With this study, we sought to extend the literature on the support needs of SMW with BC by examining messages posted to a large, lesbian-specific online support forum found on breastcancer.org. Specifically, we analyzed messages within this forum to better understand SMW's experiences of and perspectives on cancer support services, including the online forum from which we derived our data. Knowledge acquired from our analysis will contribute to our understanding about whether and how mainstream cancer support programs are meeting or failing to meet the needs of SMW with BC. Furthermore, the findings of this study could contribute to the development of SMW-specific BC support programs.

## **Methods**

### ***Procedure***

Data were collected from the lesbian-specific discussion forum found on breastcancer.org, the largest online support venue for BC survivors. The study was exempted from institutional review board (IRB) review, as we did not intervene or interact with human subjects and the data are considered public. Forum users are required to create a free account with breastcancer.org before they are permitted to post to the message boards, but an account is not needed to view the messages. The site is intended for those residing in the United States; however, there were a few users from other countries who participated. The average number of posts per user is six; however, there is a notable group of users that chose to meaningfully engage with others by providing support and sharing their own experiences of BC

over a period of months to years. Several users emerged as “leaders” of the forum and consistently welcomed new users, in addition to responding to requests for support and contributing to the majority of conversations. The “regular” users also provided one another with frequent, personal medical updates (e.g., disease progression, treatment decisions, and outcomes). Discussions about non-BC-related issues were common and included topics related to identifying in the sexual minority (e.g., LGBT political concerns, encounters with heterosexism and homophobia outside of the medical context, coming-out stories). Generic conversation about their lives and current events were also present. Additional details about the forum structure were reported elsewhere (Wandrey, Mosack, & Qualls, 2016). All messages posted between May 2007 and August 2013 were culled. Only data related to discussions about cancer support services, which included a total of 61 users and 139 posts, were included in the present analysis.

### ***Analytic plan***

We conducted an inductive content analysis of messages posted to the lesbian-specific BC forum found on breastcancer.org in order to gain insight into SMW’s experiences of and perspectives on mainstream support programs. This approach allowed us to identify patterns in experiences and perceptions of currently available support services for cancer patients. The first author trained an undergraduate research assistant (the second author) in the basics of qualitative coding. Next, we identified the relevant data (i.e., posts about mainstream support programs) and began open coding. Following open coding, we grouped the codes into broader codes (headings). Then, we used these headings to create categories and, finally, proceeded to the final phase of abstraction (i.e., developing an understanding of the data as a whole by contemplating the categories we developed). Finally, we discussed the data throughout all phases of coding and abstraction and discussed discrepancies until a consensus was achieved. Independent coding and categorization and the subsequent discussions about disagreements ensured dependability of our findings. In addition, we enhanced confirmability of the codes by procuring alternative perspectives from our research team.

Reflecting on the biases that researchers carry into qualitative analysis is important to ensuring the most valid interpretation of the data. The first author identifies as queer, the second author identifies as pansexual, and the third author identifies as heterosexual. Prior to beginning analysis, our shared perspective was that mainstream support services were likely falling short in meeting the needs of SMW because of the powerful influence of heteronormative social contexts. Although it is impossible to remain completely impartial, we attempted to minimize the impact of our biases by being intentional in our efforts to not overlook any data that reflect positive experiences of mainstream support programs. Negative case analyses also helped protect us from neglecting evidence that opposed our primary findings, which were mostly in line with our preexisting assumptions.

## Findings

We have identified a number of patterns in experiences of and perspectives on cancer support services among forum users posting to a lesbian-specific BC discussion board forum. In general, the forum users' experiences were rife with homophobia, heterosexual bias, and feelings of isolation. Mixed-diagnosis cancer support groups were perceived as more helpful than groups that were specific to BC. Overall, however, there was a strong preference for lesbian-specific support groups. Next, we enumerate the primary findings that emerged from the analysis.

### *Homophobia in non-lesbian-specific discussion forums*

Conversations about mainstream discussion forums were often negative in nature. Some users reported specific examples of homophobia in these forums. One user in the forum cited a post she had seen in a non-lesbian-specific discussion board: "I saw one [user], who should remain anonymous, put that it just grossed her out to think about us [lesbians]—in response to a comment about this [lesbian-specific] thread being started." Homophobic comments by other BC patients occurred in the context of their posttreatment appearance:

Wow .... It seems like that sometimes when straight women are feeling bad about their appearance (fat, short hair), they are comparing their appearances to lesbians with the disclaimer of "of course there's nothing wrong with that; why my fifth cousin once removed was a lesbian" type of comment. They apparently don't get the fact that they are making generalizations about the appearance of lesbians and disrespecting an entire group all at the same time.

One user was surprised by the homophobic behavior she found in the mainstream forums:

*Homophobic people still exist?* And in breast cancer support forums, no less?! If you do a search for the word "lesbian" on this site and discount the threads here in the lesbian forum, it's depressing. You'll find posts by women freaking out because their short hair makes them "look like a fat lesbian" and they're scared dykes will hit on them in Walmart. Another woman uses "you gays" as an insult when she's mad at a thread-full of women, and no one calls her out on it.

This same forum user proceeded to express her disappointment over the presence of homophobia in comparison to support:

I'm feeling so sad right now that there is such homophobia in this breast cancer world, where you'd think people would understand the need to be supportive. Yes, I know there ARE supportive straight people around—thanks, [a heterosexual woman who was participating in the thread], for your kind words—but just from reading all of our stories on this thread, it's seeming to me that the homophobia outweighs the support, and it's really freakin sad.

Overall, lesbian users reported "a lot of hate and misunderstanding" of lesbian lives within the mainstream support forums. However, despite awareness of the

presence of homophobia within mainstream forums, some lesbian users found mainstream, topic-specific threads to be helpful:

When my partner Chris was dx last April I came to this site. She was stage 4. I went to the stage 4 board. I have never really been too open [about her sexuality]. I know, my loss, so stupid. I didn't give a rats azz anymore what people thought. I found all the women there to be very nice and helpful. I did not feel like they ever judged me. I learned so much from them.

It is unclear from her post, however, whether this user identified as lesbian when posting to the non-lesbian-specific thread.

### ***Heterosexual bias in topics of discussion in mainstream support services***

Discussions of homophobia were mostly limited to the non-lesbian-specific discussion boards. Heterosexual bias, on the other hand, was discussed primarily in the context of mainstream, face-to-face support programs. Users discussed how mainstream programs are “geared towards straights.” A focus on heterosexual sex was identified as particularly irrelevant to their lesbian lives. One user did not want to “have to sit through conversations about how awkward heterosexual sex is after cancer.” Another user expressed her disdain regarding “wading through multiple [mainstream discussion board] threads about sex and husbands.”

A number of forum users felt they could not relate to heterosexual BC patients because of their focus on restoring their pre-cancer appearance in order to remain attractive to heterosexual men:

I can't really relate to a lot of the women out here, due to the fact, that many of them are hoping that their boobs come out right for their dear husband (this makes me more woosy than the chemo) or else the women are talking about how they need their boobs to be perfect so that potential men find them attractive.

I went to one [mainstream support group] where all the ladies talked about how their husbands are adjusting to the new foobs [fake breasts] and so on.

The heterosexual bias in topics of conversation in mainstream support groups led some users to feel awkward:

I went to my first breast cancer support group tonight. I am 38 years old so I tried a Young survival Coalition group. It's a group of women diagnosed when they are young. It was a great group discussion but I felt awkward with everyone talking about their husband's [sic] and all of the issues straight couples have. (I have been with my wife for 6 years)

In addition to feeling uncomfortable, many users described a generic sense of feeling “out of place,” which often led them to discontinue participation in mainstream support services: “I went to one meeting and never went back, I felt so out of place.”

### ***Rejection of the Look Good Feel Better support program***

The Look Good Feel Better (LGFB) program is available in every state in the United States and its aim is to teach BC survivors how to “enhance” their appearances

through skin care, makeup, wigs, and suggestions for how to dress for one's shape and skin tone (Taggart et al., 2009). The LGFB program was roundly rejected by the forum users, although most involved in this discussion had not attended the program. One woman felt she would be "forced to come out again" and that the program should be named "Look Straight Feel Straight." Users who identified as having an androgynous or more masculine gender expression did not understand the benefit of attending LGFB:

I've always been kind of androgynous, and I just couldn't relate to a lot of the things other people thought would be helpful. A social worker, whom I was sent to see when I was mentally losing it during radiation, suggested the makeup program "Look Good Feel Better" and I could only reply, "Um, I'm a kind-of-butch lesbian, I just don't understand that stuff."

In addition, some users viewed the program's focus on appearance as inconsequential in comparison to concerns of survival:

It just seemed so wrong—here I am with a locally advanced cancer, afraid I'm going to die young and leave my kids, afraid of the bad stuff that was happening to my axilla—and a SW and so much patient ed materials focus on my appearance and how I can fool people into thinking I still have my natural two "lumps of flesh."

Although many users rejected the program, a few users acknowledged that LGFB has provided useful support for some women, despite recognizing that the program reflects a society that is focused on appearance for the sake of others' pleasure:

I do have to defend [LGFB], something that one of my best friends volunteers for. She is a hairdresser and has made countless women feel better about themselves. Remember, we are not too far away from a generation of women whose self-worth was reflected by others. How they look, right or wrong, is important to them, even if it is to please someone else.

### ***Nonspecific cancer groups are a better fit than BC-specific support groups***

One way in which the lesbian BC patients coped with biased mainstream BC support groups was to join nonspecific cancer groups. After attending a BC-specific support group, one user decided a nonspecific cancer group was more beneficial:

Then [after attending a BC-specific support group], I went to a plain old any kind of cancer support group and it was such a better fit. There's something about everybody being different that made the sameness more obvious to me. Helped that there were a couple other lesbians in the group, but it really was very mixed. I got to a place where I didn't feel like I needed to go anymore, so I don't, but it was a good thing for me.

For some users, nonspecific cancer groups were appealing because there was less of a focus on appearance and more of a focus on psychosocial issues. One woman reflected on why she attends a general cancer group: "What really drew me to [a nonspecific cancer group] was being able to talk about things like fear and loss, not [tissue expanders] and whether skin will look normal after radiation."

Despite the need some women had to look for alternatives to BC-specific support groups, not all forum participants evaluated BC-specific support groups negatively:



I went to a support group at a local community based cancer organization. The bc group is women only and they invited my partner to join too. I was blessed with a tremendous amount of support.

### ***Preference for lesbian-specific support groups***

Although some users reported benefiting from nonspecific cancer support groups, there was a strong consensus among forum users that lesbian-exclusive support groups are desired over mainstream groups. Users described how these groups would include others with whom they can better relate:

People I meet [in mainstream groups] are lovely but, and it is a big but, I cannot relate to them and vice versa. So thank you for this [lesbian-specific] group as it gives me a group of women that I can relate to.

Another user noted, “I do feel a comraderie (sure that isn’t spelled right) with you womyn that I don’t feel with [non-lesbian survivors], I don’t feel like I have to explain anything to you guys.” Users also expressed that they have unique issues they would prefer to discuss with other lesbians: “Certainly BC is BC, but I have some weird issues with it just because I’m a lesbian. I need to talk to other lesbians sometimes!” Another woman agreed: “We need to talk to each other!!!!!!!!!!!! Our experiences are different ... If we don’t support each other who will?!”

A few patients felt strongly enough about a need for a lesbian-specific space that they expressed intentions on starting a lesbian BC support group: “I want to start a lesbian breast cancer support group and have been waiting because I dont [sic] know if I will have the energy but think I am going to go ahead with it.” Another woman wanted to create a separate website for lesbians as a response to the sense of marginalization on breastcancer.org: “If I knew more about Web design, I WOULD create a new website JUST for lesbians with breast cancer to talk with each other, so we wouldn’t have to be relegated to our little corner in an otherwise hostile environment.”

A desire for lesbian-exclusive support groups was evident. Some patients discovered in-person lesbian groups that once existed but have since vanished: “It seems like there were more than one lesbian BC group in this county a decade or so ago. Now I can’t find anything, but just the regular (all inclusive) BC support groups for women.” A lack of participation appeared to be the reason for stopping in-person lesbian groups, but a lack of activity on the lesbian forum was also reported. One user expressed her disappointment with the frequency of posts: “[I] have come to the site often and it continues to provide wonderful support and information, so was a bit disappointed to see the last post to this group was in December.”

## **Discussion**

Forum users posting to the lesbian-specific BC forum found on breastcancer.org expressed their dissatisfaction with mainstream BC support services. Users

discussed difficulty finding their space on [breastcancer.org](http://breastcancer.org) and recounted homophobic posts on some discussion boards within the forums (e.g., some heterosexual users reported having fears about looking like a lesbian posttreatment). Notably, there was a lack of discussion of homophobic behavior in face-to-face support programs; however, heterosexual bias in topics of discussion was profound in both settings (i.e., discussions that were perceived as only relevant to heterosexual women). For example, users found discussions focused on appearance and heterosexual sex to be unhelpful. An exemplar of heterosexually biased BC support services was the LGFB program, whose aim is to help BC patients enhance their appearance posttreatment (Taggart et al., 2009). This program was rejected by those with androgynous- and more masculine-presenting gender expressions, in addition to those who place diminutive importance on appearance in comparison to issues of survival. To cope with biased BC support groups, users reported attending and finding support in mixed-diagnosis cancer groups, which provided topics of discussion that were deemed more relevant to their lives (e.g., fear and loss). Despite increased acceptability of mixed-diagnosis groups over BC-specific groups, users expressed a strong desire for lesbian-exclusive support groups. Users held the perception that lesbian-exclusive groups would increase their comfort and ability to relate to other BC patients.

Overall, our findings seem to indicate that mainstream cancer support services are falling short in meeting the needs of SMW with BC. In our evaluation of the shortcomings of mainstream support, it became evident that SMW have unique needs particularly with respect to issues of sexuality and body image. Users reported frequent discussions about heterosexual sex and appearance in mainstream support groups, which are topics that were deemed unhelpful and contributed to feelings of exclusion. It may be the case that SMW experience difficulties with sexuality that remained unaddressed because mainstream groups are predominantly comprised of heterosexual women. In fact, users speculated about being the only lesbian in the room and as a result, felt out of place and uncomfortable with raising issues that are pertinent to their sexuality. Although users expressed a desire to connect with other lesbians with BC because of a greater ability to relate, there was a notable absence of specific sexuality-related issues that the SMW felt were better discussed with one another. Based on the report of users who had attended mainstream support services, there appeared to be an overwhelming emphasis on addressing issues related to appearance, which excludes SMW who express a need to talk about their bodies in the context of survival.

A potential solution to the problems of homophobia and heterosexual bias in face-to-face mainstream support services is to adapt current interventions to be culturally competent. Indeed, some users were concerned that support service staff and participants lacked knowledge of the lives of SMW. Adaptations to face-to-face support groups might include “safe space” training for group facilitators. Safe space training, which primarily involves educating allies about lesbian, gay, bisexual, and transgender (LGBT) communities and identities, is a step toward increasing the comfort of SMW; however, support groups that are predominantly comprised of

heterosexual individuals likely foster an environment conducive to heterosexual bias in topics of discussion. That is, as our findings suggest, heterosexual women tend to prefer to discuss different issues (e.g., appearance) from SMW. Because there are more heterosexual than sexual minority women in support groups, it is likely that the topics of conversation are mostly issues that heterosexual women raise. Perhaps the structure of cancer support groups encourages heterosexual bias in discussion. Although diagnosis-specific groups are probably quite helpful for many people, it might be beneficial to create groups based on topics of discussion (e.g., appearance posttreatment) rather than specific cancer diagnosis. This way, all participants can feel included in the discussion, instead of being at the mercy of the needs of the majority (often heterosexual women). Indeed, this approach to cancer support groups could also benefit other patient populations (e.g., men with BC).

Although the present study did not allow us to determine whether the online lesbian-specific forum was meeting the needs of SMW with BC, the findings clearly indicate that currently available services may be underserving SMW. Consistent with previous research (Barnoff et al., 2005; Paul et al., 2014), the users expressed a strong desire to participate in lesbian-specific support services. However, the availability of lesbian-specific support groups is limited. Barnoff and colleagues (2005) noted that several lesbian BC support groups have existed, but many of them did not subsist, likely due to lack of funding and participation. Indeed, the number of SMW with BC is miniscule in comparison to heterosexual women. Therefore, for practical reasons, face-to-face lesbian-specific support programs might not be feasible.

Increasing the availability of lesbian-specific online support services might provide the most satisfactory support. The lesbian-specific discussion forum on breastcancer.org was deemed useful by what appeared to be the majority of users. However, users experienced distress related to reading the posts on the mainstream support forums on breastcancer.org, which in some cases reflected homophobic beliefs. As users suggested, the safest option may be to create a website that is designated for lesbian BC patients and protected by a secure login (i.e., one must be a member of the site to participate) and moderator. The role of the moderator, possibly a licensed mental health professional, could be to monitor posts for their appropriateness and provide support. Researchers should examine the feasibility of such a site and determine whether this avenue of support better meets the needs of lesbian BC patients. Furthermore, it would be helpful to investigate the efficacy of an online lesbian-specific support group in reducing levels of distress (e.g., depression, anxiety) and improving perceived social support.

Lesbian-specific online support services are likely more sustainable than lesbian-specific face-to-face support services because of practical concerns (e.g., lack of participation, fear of being “outed”). However, some patients will inevitably prefer face-to-face support. As such, practitioners should not overlook the finding that lesbian users reported that nonspecific cancer support groups provided more relevant support than BC-specific groups. Service providers could refer lesbian BC patients who prefer face-to-face support to nonspecific cancer support groups. This protocol could be implemented immediately by medical social workers and would not

require the development of additional face-to-face support groups. Furthermore, nonspecific cancer support groups could provide a satisfactory alternative for lesbian patients who await the availability of safe, online lesbian-specific BC support services.

The present study contributes to a nascent area of research on the support needs of SMW with BC. However, our study is not without limitations. Although we found that individuals posting to a lesbian-specific BC forum are dissatisfied with mainstream services, our sample may be biased. That is, our sample consisted of SMW who are actively seeking support through an online venue. It may be the case that there are SMW who find mainstream face-to-face support services beneficial and as a result, do not rely on Internet-mediated support. As such, this group of patients (those who find mainstream face-to-face support services advantageous) may not be represented in our sample. Furthermore, our sample likely includes a greater proportion of BC patients who are younger than the average BC patient because age and Internet use are negatively correlated (Pew Research Center, n.d.). A significant strength of our study is the lack of observation bias; however, given the method of data collection, we were unable to ask clarifying questions and may have missed important nuances in experiences and perspectives. For instance, we were unable to probe the position that the issues lesbian BC survivors experience are unique to those experienced by heterosexual women. Additional strengths and limitations of our methodology are discussed elsewhere (Wandrey et al., 2016).

Researchers should further study the unique support needs of lesbian BC patients in order to provide the most appropriate and effective care. Our study demonstrates the utility of examining data from online support forums for insight into patients' experiences of and perspectives on cancer support services. Other types of analyses are also warranted. For instance, researchers could examine the interactions between users to determine whether support needs are being met in this type of venue. Investigators could also examine discussion board posts by user to gain a better understanding of individual differences that influence the experiences and support needs of SMW with BC. Another fruitful endeavor would be to conduct additional studies examining the support needs of SMW using varying methodology (e.g., focus groups, surveys). These studies could then be compared with the findings of the present study in order to gain insight into whether the current sample's perspectives align with other samples that may be demographically different from our Internet sample.

We close with a call to arms with respect to intervention development. There is clearly a need for online support services for SMW with survivors. Although forum users discussed creating their own lesbian-specific website, they were hamstrung by a lack of energy and technical expertise. Although it will be critical to have patient input and buy-in into such a website, the burden of creating it should not be left to those who are simultaneously navigating the health care and insurance systems, coping with treatment considerations, and facing the physical, emotional, and social stress that living with BC entails. Instead, interventionists should make it a priority

to develop and test lesbian-specific online cancer support services in hopes of better meeting their needs.

## Acknowledgments

We would like to thank Maral Safavi for her assistance with data collection and management.

## Funding

This research was conducted while Rachael L. Wandrey was funded by the University of Wisconsin system's Advanced Opportunity Program Fellowship.

## References

- Arena, P. L., Carver, C. S., Antoni, M. H., Weiss, S., Ironson, G., & Duran, R. E. (2006). Psychosocial responses to treatment for breast cancer among lesbian and heterosexual women. *Women's Health, 44*(2), 81–102.
- Barnoff, L., Sinding, C., & Grassau, P. (2005). Listening to the voices of lesbians diagnosed with cancer. *Journal of Gay and Lesbian Social Services, 18*(1), 17–35.
- Boehmer, U., Linde, R., & Freund, K. M. (2005). Sexual minority women's coping and psychological adjustment after a diagnosis of breast cancer. *Journal of Women's Health, 14*(3), 214–224.
- Bouma, G., Admiraal, J. M., de Vries, E. G. E., Schroder, C. P., Walenkamp, A. M. E., & Reyners, A. K. L. (2015). Internet-based support programs alleviate psychosocial and physical symptoms in cancer patients: A literature analysis. *Critical Reviews in Oncology/Hematology, 95*(1), 26–37.
- Chung, J. E. (2013). Social interaction in online support groups: Preference for online social interaction over offline social interaction. *Computers in Human Behavior, 29*(4), 1408–1414.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310–357.
- Coulson, N. S., Buchanan, H., & Aubeeluck, A. (2007). Social support in cyberspace: A content analysis of communication within a Huntington's Disease online support group. *Patient Education and Counseling, 68*, 173–178.
- Fish, J. (2010). *Coming out about breast cancer in lesbian and bisexual women*. Leicester, UK: Health Policy Research Unit; De Montfort University Funded by the NHS National Cancer Action Team.
- Jabson, J. M., & Bowen, D. J. (2014). Perceived stress and sexual orientation among breast cancer survivors. *Journal of Homosexuality, 61*(6), 889–898.
- Kamen, C., Mustian, K. M., Dozier, A., Bowen, D. J., & Li, Y. (2015). Disparities in psychological distress impacting lesbian, gay, bisexual and transgender cancer survivors. *Psycho-oncology, 24*(11), 1384–1391.
- Knobf, M. T. (2011). Clinical update: Psychosocial responses in breast cancer survivors. *Seminars in Oncology Nursing, 27*(3), e1–e14.
- Kowalski, C., Kahana, E., Kuhr, K., Ansmann, L., & Pfaff, H. (2014). Changes over time in the utilization of disease-related Internet information in newly diagnosed breast cancer patients 2007 to 2013. *Journal of Medical Internet Research, 16*(8), e195.
- Matthews, A. K., Peterman, A. H., Delaney, P., Menard, L., & Brandenburg, D. (2002). A qualitative exploration of the experiences of lesbian and heterosexual patients with breast cancer. *Oncology Nursing Forum, 29*(10), 1455–1462.
- Mo, P. K. H., & Coulson, N. S. (2008). Exploring the communication of social support within virtual communities: A content analysis of messages posted to an online HIV/AIDS support group. *CyberPsychology & Behavior, 11*(3), 371–374.

- Paul, L. B., Pitagora, D., Brown, B., Tworecke, A., & Rubin, L. (2014). Support needs and resources of sexual minority women with breast cancer. *Psycho-Oncology*, 23, 578–584.
- Pew Research Center. (2014). Internet users in 2014. Retrieved from <http://www.pewinternet.org/data-trend/internet-use/latest-stats/>
- Rankin, N., Williams, P., Davis, C., & Girgis, A. (2004). The use and acceptability of a one to one peer support program for Australian women with early breast cancer. *Patient Education and Counseling*, 53, 141–146.
- Ryan, C., Huebner, D., Diaz, R. M., & Sanchez, J. (2009). Family rejection as a predictor of negative health outcomes in White and Latino lesbian, gay, and bisexual young adults. *Pediatrics*, 123, 346–352.
- Setoyama, Y., Yamazaki, Y., & Nakayama, K. (2011). Comparing support to breast cancer patients from online communities and face-to-face support groups. *Patient Education and Counseling*, 85, 95–100.
- Sinding, C., Barnoff, L., & Grassau, P. (2004). Homophobia and heterosexism in cancer care: The experiences of lesbians. *Canadian Journal of Nursing Research*, 36(4), 170–188.
- Taggart, L. R., Ozolins, L., Hardie, H., & Nyhof-Young, J. (2009). Look Good Feel Better workshops: A “big lift” for women with cancer. *Journal of Cancer Education*, 24(2), 94–99.
- Van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Shaw, B. R., Seydel, E. R., & van de Laar, M. A. F. J. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative Health Research*, 18(3), 405–417.
- Wandrey, R. L., Qualls, W. D., & Mosack, K. E. (2016). Rejection of breast reconstruction among lesbian breast cancer patients. *LGBT Health*, 3(1), 74–78.
- White, J. L., & Boehmer, U. (2012). Long-term breast cancer survivors’ perceptions of support from female partners: An exploratory study. *Oncology Nursing Forum*, 39(2), 210–217.
- Yli-Uotila, T., Rantanen, A., & Suominen, T. (2013). Motives of cancer patients for using the Internet to seek social support. *European Journal of Cancer Care*, 22, 261–271.
- Zeigler, L., Smith, P. A., & Fawcett, J. (2004). Breast cancer: Evaluation of the Common Journey Breast Cancer Support Group. *Journal of Clinical Nursing*, 13, 467–478.