

Long-Term Breast Cancer Survivors' Perceptions of Support From Female Partners: An Exploratory Study

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Social support represents a powerful resource for coping and recovering women diagnosed with breast cancer. Perceived social support, particularly as it applies to intimate, interpersonal relationships, decreases women's psychological distress related to cancer (Cohen & Wills, 1985; Koopman, Hermanson, Diamond, Angell, & Spiegel, 1998; Rodin et al., 2007; Talley, Molix, Schlegel, & Bettencourt, 2010) and critically contributes to their psychological well-being and emotional adjustment after diagnosis (Bloom, 1982; Carver, Smith, Petronis, & Antoni, 2006; Ganz et al., 2002; Harrison, Maguire, & Pitceathly, 1995; Koopman et al., 1998; Manne, Ostroff, Winkel, Grana, & Fox, 2005; Pistrang & Barker, 1995). Most studies have focused on survivorship among married, heterosexual women. As a result, ample data exist demonstrating that heterosexually partnered women most consistently identify their male spouses and partners as their most important source of social support (Neuling & Winefield, 1988; Rose, 1990), acting as a powerful buffer against their depression and anxiety (Harrison et al., 1995; Manne et al., 2005; Pistrang & Barker, 1995; Talley et al., 2010). In comparison, little research has been conducted on sexual minority women (SMW) (i.e., lesbians, bisexuals, and women who partner with women) and their partners in the context of breast cancer survivorship (Arena et al., 2006; Boehmer, Bowen, & Bauer, 2007; Boehmer, Freund, & Linde, 2005; Fobair et al., 2001, 2002; Katz, 2009; Matthews, Peterman, Delaney, Menard, & Brandenburg, 2002). Research largely has failed to examine the social support experiences and needs that affect quality of life among SMW with a breast cancer diagnosis (Arena et al., 2006; Fobair et al., 2001).

Studies of heterosexual women demonstrate that perceived emotional support, such as partners' emotional involvement after breast surgery, their willingness to communicate about difficult emotions and experiences, and their expression of empathy, markedly facilitates heterosexual women's coping and adapting to breast cancer (Fergus & Gray, 2009; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Manne et al., 2006;

Purpose/Objectives: To describe the social support experiences of long-term breast cancer survivors who have female partners, from the perspective of survivors.

Research Approach: Descriptive study using qualitative methods.

Setting: United States.

Participants: A purposive convenience sample of 15 partnered sexual minority women (SMW) (e.g., women with female partners) diagnosed with nonmetastatic breast cancer from 2000–2005.

Methodologic Approach: One-on-one interviews were conducted by telephone. Interviews were semistructured through the use of an interview guide. Transcribed data were coded and analyzed to identify emergent themes.

Main Research Variables: Perceptions of support and broad aspects of the intimate partner relationship that may critically impact the psychological well-being of SMW following breast cancer.

Findings: Six salient themes describe SMW survivors' perceptions of support: (a) female partners are the singular source of survivors' most valuable support; partners support survivors by (b) discussing survivors' health and distress, which survivors associate with (c) perceived partner distress, and (d) managing the home and caretaking, which survivors associate with (e) perceived partner burden; and partners support survivors by (f) sharing in a life beyond cancer.

Conclusions: Female partners play a central and comprehensive support role as well as experience ongoing stress and burden related to survivors' cancer.

Interpretation: Future research and direct investigation may inform healthcare providers about caring for SMW and their families following breast cancer.

Pistrang & Barker, 1995; Sormanti & Kayser, 2000) and is associated particularly with decreases in women's emotional distress (Talley et al., 2010; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005). Conversely, heterosexual women report dissatisfaction and distress when they feel their partners avoid and withdraw from discussions about women's breast cancer experiences (Lichtman, Taylor, & Wood, 1988; Manne et al., 2006; Neuling & Winefield, 1988; Peters-Golden, 1982; Pistrang & Barker, 1995; Spiegel, Bloom, & Gottheil,

1983; Vess, Moreland, Schwebel, & Kraut, 1989). Survivors desire greater empathy and communication with male partners (Lichtman et al., 1988; Manne et al., 2006) and report that their partners are better at providing instrumental supportive (e.g., material goods, assistance) than emotional support (Fergus & Gray, 2009; Sormanti & Kayser, 2000).

Research regarding the long-term support experiences of heterosexual women is limited but indicates that emotional support needs exist several years after a breast cancer diagnosis (Gray et al., 1998; Luker, Beaver, Leinster, & Owens, 1996; Wilson, Andersen, & Meischke, 2000). In addition, greater social support is associated with lower distress (Helgeson, Snyder, & Seltman, 2004) and improved quality of life (Lee, 1997) among long-term survivors. A longitudinal study that reassessed heterosexual women 5–13 years after diagnosis noted that being partnered at the time of treatment predicted many self-reported psychosocial benefits at follow-up (Carver et al., 2006).

The few studies focused on the experiences of SMW diagnosed with breast cancer noted that various sources of social support function differently for lesbian women than they do for heterosexual survivors, such that lesbian women may obtain social support more frequently from friends than relatives (Arena et al., 2006; Boehmer et al., 2005; Fobair et al., 2001). However, partner support appears to be of central importance to these survivors as well. A study by Boehmer et al. (2005) indicated that 79% of SMW participants who had been diagnosed with breast cancer identified their partner as their most important source of support. A comparative study by Fobair et al. (2001) found that partnered lesbian women were more likely than partnered heterosexual women to receive social support from their partner, as well as more likely to report that their partner made them feel loved and cared for, were willing to listen, and could be relied on to help with daily tasks during the cancer experience. Because of the suggested significance of partners' support and the extreme paucity of related research, the purpose of this study was to describe and generate understanding of the social support experiences of long-term breast cancer survivors who are partnered SMW.

Methods

The current study was conceptualized in response to the opportunity to conduct additional research with SMW who had participated in a previous quantitative study of breast cancer survivors of different sexual orientations (Boehmer, Clark, Timm, Sullivan, & Glickman, 2011; Boehmer et al., 2010). In contrast to the parent study, the current study is exploratory and aimed to understand the lived experiences of SMW from the

perspective of the women themselves. Qualitative research methods were therefore employed. All aspects of the study were reviewed and approved by the Boston University institutional review board.

Participants

Study participants represent a sample of women recruited from the 181 SMW who participated in the parent study and had agreed to be contacted about follow-up studies (Boehmer et al., 2010, 2011). The women had been classified as SMW based on their self-identification as being lesbian, bisexual, or their self-reported preference for a woman partner (Boehmer et al., 2010). They were contacted by mail and telephone and invited to participate in this qualitative study of SMW. All participants provided informed consent. Although qualitative interviews were conducted with SMW of varying partnership status, eligibility for this analysis was restricted to participants who, at the time of their interview, described themselves as having a wife or female partner.

The final sample for the analysis was comprised of 15 partnered SMW who fit the inclusion criteria of the parent study, which specified a diagnosis of non-metastatic breast cancer from January 1, 2000 to December 31, 2005. Participants consisted of survivors only, not their woman partners and, at the time of the parent study, were a mean of six years past diagnosis and had a mean age of 52 years. Thirteen women were Caucasian and two identified as Latinas.

Procedures

Data collection consisted of in-depth, one-on-one telephone interviews with participants ranging from about 30–150 minutes in length. They were facilitated via telephone by one of two interviewers, including the first author, from March 2010 to November 2010. Interviews were semistructured through the use of an interview guide consisting of open-ended questions designed to elicit participants' subjective experiences regarding topics such as the current impact of breast cancer on their lives; coping with cancer-related issues; and the sources, nature, and value of social support. Interviews were digitally recorded, assigned identification codes to protect participant anonymity, and transcribed verbatim.

Data Analysis

Analysis was initiated during the course of data collection, after which both occurred concurrently. Analytic procedures reflected the principles and processes of qualitative data analysis outlined by Ulin, Robinson, and Tolley (2005) and incorporated the Atlas.ti computer application to facilitate easier data management. First, each author reviewed a subset of transcripts and labeled the data, line by line, for categories of content or codes

(e.g., coping, partner reaction). Next, individual coding was compared and discussed until the authors agreed on a comprehensive book of roughly 70 inductive and deductive codes with definitions and applied them to all transcripts. Quotations relating to support, partners' behaviors, relationship history, and the perceived impact of diagnosis on partners were queried and reviewed extensively to identify emergent themes within the data. Data collection concluded when analysis indicated that new or divergent themes were unlikely to emerge.

Results

The 15 survivors in the sample described relationships with their partners ranging from 7–33 years in length. Six major themes were evident in the survivorship and support experiences shared by survivors, including (a) the fundamental perception that their partners are the singular source of the most valuable support that they currently receive. Survivors reported that their partners support them by (b) discussing survivors' health and distress, an activity with which survivors associate (c) perceived partner distress, and by (d) managing the home and caretaking, an activity with which survivors associate (e) perceived partner burden. In addition, survivors reported that their partners support them by (f) sharing in a life beyond cancer. Direct quotes from the participants are presented to illustrate the themes.

Female Partners Are the Singular Source of Survivors' Most Valuable Support

The overwhelming majority of participants explicitly and enthusiastically identified their partner as the unique source of the most beneficial support that they currently receive. They praised their partners for their long history of providing support and ongoing availability to address immediate needs, attributing a greater intensity and depth to their support than from other family and friends.

Yeah, my support system is my partner. [She] has been there from the day when I heard—had the phone call. . . . She's my number one support person, fan, the whole nine yards. . . . She supports just everything. I can't even begin to tell you everything she supports.

43-year-old, diagnosed five years earlier

Some women associated the primacy of their partner's support with deceased family, employment status, or geographic circumstances that affect their availability of support.

After we got the kids, I wondered if I would maybe not work, but I decided I kind of needed that for my professional health. And that helps, too, because I

have people at work. They're more superficial support, but I'm not one that needs a lot of in-depth support. I get most of that from [my partner]. Out where I live, I live way out in the country, I find it's been hard in this last year because I've wanted to make more friends with some of the other moms, and that's been difficult. Everybody's so busy.

46-year-old, diagnosed seven years earlier

But now, because I'm not working, [my partner]'s kind of my primary support and contact person that I have. She's just been great, wonderful in all ways. [My sisters] always are thinking about me . . . all they can do, because they're so far away, is to pray.

56-year-old, diagnosed four years earlier

Discussing Survivors' Health and Distress

Many participants related that their partners were actively involved in their care after diagnosis. Partners often accompanied participants to medical appointments, helped them research treatment options, and reassured them that they were not concerned about any surgical impact on the participants' breasts and physical appearance. Regarding the present, participants described their partners as continuing to engage in supportive conversations about health (e.g., asking about medical appointment outcomes, reminding them to take medications), and otherwise expressing what participants perceive to be an intimate concern for their physical well-being.

[My partner] prods me to make sure that I stay up on the appointments, the yearly appointments, that I don't get glib about things.

52-year-old, diagnosed eight years earlier

Participants also reported that when they experience increased fears of recurrence or other health problems related to their cancer treatment—fears that are triggered, for some participants, by perceived changes in their bodies, an upcoming mammogram, or news of another person's illness—they rely on talking to their partners as a means of coping.

[My partner] is totally right there. She wants to know everything [about my health]. Like, this summer, I've been having a weird body thing. I don't think it is related to cancer [at] all. And I'm sort of in-between doctors. [My partner] wants to know every single symptom, every single weird thing. . . . I need to have somebody to tell things to. And it is like, especially sort of being in-between doctors right now, I really need to be able to tell somebody that there is something weird going on with my body.

50-year-old, diagnosed four years earlier

There are times when I might be feeling something in my body that, you know, I get worried about. [My partner] sort of puts it in perspective more . . . she might say, "Don't worry about that yet. Just have it looked at." Or stuff like reassuring types of things, like, "You've had that pain before. It turned out to be nothing."

55-year-old, diagnosed seven years earlier

Similarly, some participants stated that they talk to their partners to deal with feelings of isolation and anger resulting from other issues related to their breast cancer, such as perception that other individuals have minimized or attempted to invalidate the extent to which breast cancer has impacted the participants' lives. They repeatedly praised their partners' ability to actively listen, empathize with their feelings, and respond in ways that calm distress.

I'll mention it to [my partner], and she's always supportive. . . . We can talk about those things. I can tell her what happened and she'll just support me and say, "Oh boy, that must not have felt good." She lets me have that experience. She's not uncomfortable with it.

46-year-old, diagnosed seven years earlier

I get angry about it. Put it this way, somebody tells me that they twisted their ankle and are in pain, I want to punch them in the face. When [my partner] gets home from work, I would tell her how I felt at the moment and she understands. She calms me down. Like I said, she does have a lot of empathy.

53-year-old, diagnosed seven years earlier

Perceived Partner Distress

Many participants described a perception that their partners continue to experience worry and anxiety about participants' health, particularly regarding cancer recurrence and death.

I mean [my partner] gets pretty scared, too. When I go to the mammogram, she always says, "Call me right away. Let me know right away what they say." You know, my mammogram affects us all.

50-year-old, diagnosed four years earlier

Participants related that those fears can cause their partners to respond to concerns in a way that is perceived to be unhelpful. However, those participants also described themselves as able to communicate with their partners about responding more helpfully to their concerns.

[My wife] listens and she gets it. . . . She is very rational. So if I'm freaking out about something, she will stay calm. Sometimes she is almost too much like a man and she will be like, you know, "You're

fine. There is nothing wrong." Then I have to remind her that that is not helpful. But usually, she is just empathic and she is willing to be there with me and deal with it and stick there. I mean sometimes it is hard. Because if I get really freaked out, she can also get freaked out because she doesn't want me to be sick. But usually she can really be there and is very supportive.

45-year-old, diagnosed seven years earlier

I've told [my partner], "I'm trying to get rid of this verbally, to let go of it. I don't need you to reinforce the negative. . . . I just want you to listen." And so she is getting really good now at just keeping her mouth shut and just listening. . . . And so, we have learned to discuss our fears with each other, just to help us let go of them, and pray.

61-year-old, diagnosed seven years earlier

Managing the Home and Caretaking

Participants stated that their partners currently support them by regularly managing household and domestic needs. One survivor, whose physical capabilities remain limited by several chronic health problems, some attributed to cancer treatment, referenced her partner's assistance even with tasks such as showering and grocery shopping. Participants cited cooking and child care—including, for one participant, the coordination of autism-related services for the couple's adolescent child—as the most significant ways their partners support them at the present time.

[My partner] does everything. She's so helpful. She is really a participant in maintaining our home. . . . It's great.

56-year-old, diagnosed nine years earlier

[My partner] gives me TLC. She gets me a cup of coffee. She will say, "Is there anything I can get you right now?" She fixes me food. She will go out of her way sometimes to try to find something that I can eat that I would enjoy eating. . . . It is her way of showing me that she loves me. She tells me she loves me all the time. But I'm one that wants to see the evidence. I don't need to, but it is always nice to see it. Then, like, sometimes she will go fill up the car with gas so I don't have to do it. You know, just those little things.

61-year-old, diagnosed seven years earlier

If I'm feeling tired, [my partner will] do extra around the house. She's really supportive around the kids. She'll come home from a long day at work and she'll take over with the kids. She works full-time, and yet she's fortunately not traditional in that the person who works all the time just comes home and stops. She'll come home and help around the house. We've

got a really good partnership that way. We kind of take care of each other. If one is sick, the other takes on more. It feels really equitable. I'm such a lucky person that way. She's just supportive.

46-year-old, diagnosed seven years earlier

Perceived Partner Burden

Participants shared a perception that their partners' increased responsibilities in the home, and as caretakers in general, placed great demands on them and contributed to their feelings of isolation, anger, and frustration during the participants' diagnoses and treatment. Some participants also stated that their partners received assistance from friends, family, and individuals who were familiar with cancer experiences.

I think that . . . it's just very hard to be in that position because sometimes, when you're the one under the knife, you just sort of surrender to it. But when you're always feeling responsible or like you need to take care of the person, it's really hard. And I know that people who have been there were very supportive to her. Because they know what she was going through.

51-year-old, diagnosed seven years earlier

Participants expressed that even now, several years after diagnosis, their partners remained burdened by home and caretaking demands. One participant explained that her partner still is struggling from the loss of income she incurred during the initial year of treatment, when she attended medical appointments, cared for their child, and "pretty much had to run the house." Participants also expressed a high regard for mutually supportive relationship dynamics and a balance in caretaking roles. Some referenced this reciprocity not as an achieved reality, but rather as an ideal to which they aspire. Others described their relationship dynamics as having greater balance following breast cancer.

So, I think, poor thing, [my partner] had struggled—she kind of went through it with me and cancer, and then I hurt my ankle. That really stressed her out because we were out of the country when it happened. So she's been really strong. And I think with her father passing. . . . I'm able now to support her and do for her in ways that she would just bite her tongue and was independent and doing it all . . . and now that I'm more mobile, things are starting to get a little bit more balanced with me being able to provide more for her.

57-year-old, diagnosed four years earlier

[My partner and I have] been together now almost 27 years. And [breast cancer] changed our relationship insofar as she became . . . I saw her strength. She

had to take care of me. And, in the past, it has always been reversed. Physically, emotionally, spiritually, she had to take care of me. So, [it was] the first time I allowed her to really step forward, even though that was uncomfortable for her. It made a difference in our relationship because she found things in herself.

61-year-old, diagnosed seven years earlier

Sharing in a Life Beyond Cancer

Participants explained that their partners currently support them by participating in activities and relationship dynamics—"sharing lives," in the words of a few survivors—that are pleasurable, forward-looking, and otherwise not centered on breast cancer.

Breast cancer isn't the main focal point in our lives. I mean, it just happened. [My partner and I] went through it, we dealt with it. We know that if it happens again, we can deal with it. We didn't let it consume us.

60-year-old, diagnosed five years earlier

Participants emphasized the elements of fun, laughter, and excitement with their partners, and a few survivors referenced recent vacations with partners as extremely positive experiences during which they mutually delighted in exploring stimulating environments and, in one case, celebrated the couple's 20th anniversary. Survivors who feel supported by their partners' involvement in preparation for the future characterized their partners as dedicated counterparts in financial planning and overall efforts to establish long-term personal and family stability.

And I would say [my partner] prods me to keep on getting through life. Not to sit and wait to see if it comes back, not to sit and wait to die. . . . "Where [are] we going next? What are we doing? What do we want to do?" Financial planning for the long-term and respecting if I say I'm tired. You know, it's not always about running, it's about just building a life.

52-year-old, diagnosed eight years earlier

Discussion

The authors' findings promote an enhanced understanding of female partners as critical and valued sources of social support for SMW who are long-term breast cancer survivors. Participants' belief that their partners provide the most beneficial support they currently receive is consistent with data reported in other studies of SMW with breast cancer (Boehmer et al., 2005; Fobair et al., 2001).

In addition, themes regarding discussion of health and distress emphasize partners' emotional support and appear consistent with lesbian survivors' high

ratings of partners' provision of emotional support (Fobair et al., 2001). Participant descriptions of perceived emotional support resonate with explicit evaluations of their partners as empathetic communicators responsive to participants' cancer experiences and related feelings, partner qualities known to facilitate patient coping, and adaptation to breast cancer among heterosexual women (Fergus & Gray, 2009; Manne et al., 2004; Pistrang & Barker, 1995).

In contrast, problematic emotional support themes that are recurrent in studies regarding partnered, heterosexual women following breast cancer (Fergus & Gray, 2009; Manne et al., 2005, 2006; Manne, Taylor, Dougherty, & Kemeny, 1997; Sormanti & Kayser, 2000) were not evident in the current study. Participants rarely referenced perceptions of unsupportive partner responses. Notably absent were reports of perceived partner withdrawal from cancer-related discussions, an issue that has received much focus in the context of heterosexual women because of its association with normative gender roles and its negative impact on women's and couples' coping with breast cancer (Lichtman et al., 1988; Pistrang & Barker, 1995; Vess et al., 1989).

Participants' reports of perceived partner support in managing household and childcare needs is compatible with findings that lesbian survivors favorably rated their partners' assistance with daily tasks (Fobair et al., 2001). That theme also illustrates the comprehensiveness of partner support described by participants. Survivors' desire for balance in household and caretaking responsibilities, as well as their perception that their partners experience long-term, cancer-related distress, indicates that the emotional involvement of partners and perceived comprehensiveness of their support involves great demand.

The current study has several limitations. First, the sample primarily consisted of Caucasian SMW, with the exception of two Latina SMW. Given the racial and ethnic distribution, the authors were unable to explore race and ethnicity-based patterns in the data and findings may not reflect the support experiences of non-Caucasian SMW. Second, the sample was limited to survivors without metastatic disease and who did not experience a recurrence of breast cancer. SMW who undergo continued treatments for breast cancer and endure a second bout of breast cancer may have different support experiences, and their partners also may respond differently than as described by long-term healthy survivors. Third, the authors can only report the support experiences of SMW who accepted the invitation to participate in a qualitative interview that was not time-limited. During the recruitment from an existing pool of SMW, the authors were unable to establish contact with some participants whose invitation letters were returned as undeliverable and

whose phone numbers had been disconnected. In addition, SMW with otherwise prohibitive schedules were engaged by allowing them the option to interrupt their interviews and then continue them at a later time; however, some women still reported that they were too busy to accept the invitation. The support and relationship experiences of women who moved or were too busy to participate may differ from the current sample. Finally, all data were derived from interviews with survivors only. The findings are therefore limited to survivors' perceptions of their partners' experiences.

Despite these limitations, this exploratory study has considerable strengths. Qualitative analysis resulted in rich descriptions of support provided by female partners of sample participants. Findings note that these female partners are responsive to survivors' needs at the time of diagnosis as well as several years later when survivors continue to face reminders of their disease and fears of recurrence. Because the findings also note that partners experience ongoing stress and burden related to cancer, future studies should involve female partners directly and investigate their self-reported experiences and support needs. Finally, qualitative studies also must address the social support experiences of SMW who are not partnered.

Implications for Nursing Practice

The support experiences of breast cancer survivors inform nurses and clinicians about the central role of survivors' female partners, suggesting that nurses and clinicians should recognize and consider female partners to the same extent they would consider a male spouse or partner. In light of previous descriptions of partner support involving ongoing discussions about the survivors' health, nurses and clinicians may consider integrating female partners into educational sessions about survivorship care and ongoing disease management. The findings of participants' perceptions that their partners experience distress and burden should encourage nurses and clinicians to be aware of both survivors' and partners' distress levels and needs. Although nurses and clinicians may already be aware that cancer is a disease that affects the family, the findings of this study enhance the awareness that care involves patients with diverse family constructs, including survivors who have female partners.

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