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"I Know I Can't Be the Only Lesbian Out There:" an Inductive Thematic Analysis of a Virtual Community of Lesbian Breast Cancer Survivors

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“I KNOW I CAN’T BE THE ONLY LESBIAN OUT THERE:”
AN INDUCTIVE THEMATIC ANALYSIS OF A VIRTUAL COMMUNITY OF LESBIAN
BREAST CANCER SURVIVORS

by

Rachael Lynn Wandrey

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ABSTRACT
“I KNOW I CAN’T BE THE ONLY LESBIAN OUT THERE:”
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by

Rachael Lynn Wandrey

The University of Wisconsin-Milwaukee, 2015
Under the Supervision of Professor Katie E. Mosack

Sexual minority women are at a significantly greater risk for developing breast cancer (BC) than heterosexual women. Little is known about the unique BC experiences of lesbian women. The present thesis describes the findings of an inductive thematic analysis of messages posted to a large lesbian-specific discussion forum found on breastcancer.org. Fifteen themes were identified, including privileging sensation over appearance, experiencing heterosexism in medical contexts, believing others perceive a lack of distress over breast loss because of patient’s lesbian sexual orientation, feeling pressure from surgeons to get reconstructive surgery, and viewing the BC journey as a sexual-identity disclosure crisis. In addition, gender expression appeared to moderate the lesbian patients’ experience of BC. For instance, a theme identified among butch-or gender variant patients was enjoying or accepting that others were confused about their gender post-surgery. Femme-lesbian patients, in contrast, reported being frustrated about gender misidentification resulting from breast and hair loss.

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“I know I can’t be the only lesbian out there:”

A qualitative analysis of themes in a virtual community of lesbian breast cancer patients

Sexual minority women (SMW) are at significantly greater risk for developing breast cancer (BC) than their heterosexual counterparts. Emerging evidence has led researchers to suggest that lesbians and bisexual women are at an increased risk for BC not because of their sexual orientation, *per se*, but because some risk factors and barriers to screening are more prevalent in this population. For instance, differences in reproductive factors (lack of birth control use, nulliparity), alcohol use, tobacco use, and greater prevalence of obesity put SMW at greater risk for breast and other cancers (Brandenburg, Matthews, Johnson & Hughes, 2007; Cochran, et al., 2001; Rankow & Tessaro, 1998). These differences are likely due in part to the increased stress levels associated with holding a minority status (e.g., SMW may drink more alcohol as a way to cope with feelings of stigmatization). Indeed, researchers using the Rosner-Colditz risk prediction model (i.e., a mathematical model that quantifies reproductive risk factors on the incidence of BC; Rosner & Colditz, 1996) have found that SMW are at greater risk for BC compared with heterosexual women (HW) throughout the premenopausal period (Austin, et al., 2012).

SMW are also more likely than HW to have poor health behaviors in general and worse access to health care (Diamant, Wold, Spritzer, & Gelberg, 2000). Therefore, it stands to reason that they are also less likely to adhere to the American Cancer Society’s recommendations for BC screening (Grindel, McGehee, Patsdaughter, & Roberts, 2006; Roberts, Patsdaughter, Grindel, & Gatson, 2004; Powers, Bowen & White, 2001). Multiple factors are thought to contribute to lesbian and bisexual women’s lower rates of screening behaviors (i.e. mammographies, clinical breast exams, breast self-examinations), including an inability to afford services, lack of insurance, and psychological factors, such as internalized homophobia and

lowered perceived risk (Rankow & Tessaro, 1998). Indeed, same-sex couples are more likely than different-sex couples to be dissatisfied with the level of respect shown by and time spent with health care providers (Clift & Kirby, 2012).

BC is the second leading cause of death from cancer among white, black, Asian/Pacific Islander, and American Indian/Alaska Native women and first among Hispanic women, despite the fact that some SMW do not believe they are at risk (CDC, 2013). Because early detection is a key factor in survival (Goldhirsch, Colleoni, Domenighetti, & Gelber, 2003; Tabar, Vitak, Chen, Yen, Duffy, & Smith, 2001), it is reasonable to believe that SMW could be at greater risk of dying from the disease than HW because of their lower rates of screening. Indeed, researchers have found support for higher rates of BC mortality among women who cohabit with same-sex partners (Boehmer, Ozonoff, & Miao, 2013; Cochran & Mays, 2012).

There is small but growing body of literature that has led some researchers to suggest that lesbians experience BC differently than HW. For example, lesbians have reported higher stress related to diagnosis and treatment, lower satisfaction with care delivered by physicians, and more problems with chemotherapy-induced side effects than their heterosexual counterparts (Dibble & Roberts, 2002; Matthews, Peterman, Delaney, Menard & Brandenburg, 2002). However, not all of the differences are deficits. In comparison to HW, lesbians have reported less distress associated with changes in body image and less conflict with and more support from their partners (Fobair et al., 2001). However, a few researchers have found that lesbian BC patients feel isolated and disconnected from their partners because of the sameness of their bodies and subsequent inability to avoid awareness of the cancer (Sinding, Grassau, & Barnoff, 2007).

In the context of breast reconstruction, some SMW have reported that physicians encouraged reconstruction and failed to acknowledge other non-surgical intervention options

(Rubin & Tanenbaum, 2011). In this same study, SMW also discussed their conflicting thoughts on breast reconstruction in light of lesbian political ideologies, such that reconstruction is thought to be in collusion with women's objectification. There is some evidence that SMW who chose reconstruction experienced regret and difficulties, whereas those SMW who had opted out of reconstruction adjusted well over time (Boehmer, Linda, & Freund, 2007). Boehmer and colleagues suggested that in general, SMW focus more on the functional aspects of body image (i.e. body strength and survival vs. outward appearance and normative beauty standards) than HW and this may account for why some SMW experienced regret following reconstructive surgery (i.e., reconstruction did not improve bodily function).

The issue of breast reconstruction is common among all BC survivors, but homophobia is a unique concern for lesbian BC patients. A minority of lesbian BC patients have reported direct encounters with homophobia in the medical context, but a majority expressed that they felt there was a lack of attention to lesbian lives (Sinding, Barnoff, & Grassau, 2004). Specifically, some participants felt dismissed by their health care providers, especially when a provider forgot about their lesbian sexual orientation and made comments that are only relevant to heterosexual couples (i.e. "when you discuss this with your husband..."; Sinding, Barnoff, & Grassua, 2004). Heterosexist statements like these are considered microaggressions and likely contribute to patients' levels of internalized homophobia (Flatt, & Lenzen, 2013; Nadal et al., 2011). This is problematic for many reasons, one of which is the relationship between internalization of homophobia and greater distress among lesbians treated for early-stage BC (McGregor, et al., 2001). Internalization of stigma also likely leads to difficulty in sexual identity disclosure; however, disclosure is crucial to adjustment as openness about sexual orientation in daily life is

associated with less anxiety among lesbian and bisexual BC patients (Boehmer, Glickman, Winter, Clark, 2013).

Another unique factor for SMW patients is the context of heterosexism. Multiple researchers have found heterosexism in mainstream (i.e. non lesbian, gay, bisexual, and transgender (LGBT) – specific) support groups (Katz, 2009; Sinding, Barnoff, & Grassau, 2004), and in one study a group facilitator was quoted as saying lesbian inclusion is “not our mandate” (Sinding, Barnoff, & Grassau, 2004). Nevertheless, gay and lesbian cancer patients have indicated a need for gay and lesbian-specific support groups because of these negative experiences (Katz, 2009). Indeed, peer support programs for patients with BC are associated with alleviating many of the physical and psychological consequences of BC (Rankin, Williams, Davis, & Girgis, 2004; Zeigler, Smith, & Fawcett, 2004).

Minority Stress Theory

Minority stress (i.e., stress that results from being a minority in society) is one explanation for why SMW are at significantly greater risk for developing BC than their heterosexual counterparts. Minority stress theory was developed as an elaboration of social stress theory (i.e., the notion that the social environment is a source of stress and may lead to negative physical and mental health outcomes; Dohrenwend, 2000) in order to draw specific attention to the excess stress that stigmatized individuals typically experience and its role in the higher prevalence of mental health disorders among minorities (Meyer, 2003). As such, Meyer (2003) asserted that minority stress theory offers a framework for understanding mental health disparities in lesbian, gay, and bisexual populations. In this model, Meyer (2003) described stress and coping and their proposed impact on mental health outcomes. We all experience stress; however, those with a minority status, such as those who have a minority sexual

orientation, experience additional stressors such as being victims of acts of discrimination or violence. Furthermore, those who define themselves by one's sexual orientation, experience even more stress related to their perception of self as a stigmatized and devalued minority. The proposed minority stress processes associated with identifying as gay, lesbian, or bisexual include expectations of rejection, concealment, and internalized homophobia (Wandrey, Mosack, & Moore, in press). General stressors (e.g., poverty, chronic illness, etc.), in addition to stressors related to minority status and minority identity (e.g., victimization), contribute to sexual minority individuals' mental health outcomes. That is, the more stressors one experiences, the greater likelihood one's coping resources will be overwhelmed and therefore, result in negative mental health outcomes.

Not everyone who is in the sexual minority will experience negative mental health outcomes as a result of one's minority status. Indeed, the degree to which one experiences negative mental health outcomes is moderated by prominence, valence, and integration of their sexual minority identity (Meyer, 2003). That is to say, individuals who view their sexual identity as salient and also evaluate this identity as a negative feature of self (i.e., self-invalidation) is hypothesized to be more likely to experience mental health problems than those who accept their sexual identities and view them as secondary to other less-stigmatized personal and social identities. In addition, the degree to which an individual has integrated their sexual identity into their sense of self (i.e., sexual identity is viewed as one part of their total identity) is related to increased mental health. Researchers have argued that choosing to identify as gay, lesbian, or bisexual could lead LGB individuals to find additional coping resources and social support (e.g. those who are "out" are more likely to utilize LGB supports services found in the community, such as LGBT community centers; Miller & Major, 2000). Acquisition of additional coping

resources and social support is likely to positively influence mental health outcomes (Meyer, 2003). Therefore, Meyer proposed that in some cases, a LGB identity might be a source of strength.

There is a wealth of empirical support for the applicability of minority stress theory in conceptualizing poor mental health outcomes among LGB individuals. Although progress has been made in recent years, there is much less known about minority stress as it relates to LGB health. Lick, Durso, and Johnson. (2013) argued that minority stress theory is also relevant for LGB physical health disparities, especially given the inextricable relationship between mental and physical health. Research in this area so far has supported a relationship between LGB physical health problems and experiences of minority stress. For example, there is evidence linking minority stress to physical health complaints including headaches, chronic diseases, poor general health, disability, and symptom severity among LGB-identified individuals (Denton, 2012; Fredriksen-Goldsen, Kim & Barkan, 2012; Frost, Lehavot, & Meyer, 2011; Woodford, Howell, Kulick, & Silverschanz, 2012).

In the following pages I will make an argument for the study of themes generated from an online lesbian BC support forum. First I will review the literature on mainstream BC experiences. Next I will discuss BC patients' use of the Internet, including a general discussion about the role of the internet for LGBT individuals in particular. Finally, I will conclude the introduction by enumerating the research question and significance of the proposed study.

Mainstream BC Experiences

Diagnosis

The BC journey begins at diagnosis, which has been described as a moment rife with shock that leaves many women to feel they can no longer trust their bodies (Holmberg, 2014).

Along with mistrust of one's body, many women also experience dramatic increases in anxiety and fear post-diagnosis and no longer feel comfortable relying on their interpretation of bodily sensations and instead look to medical testing for answers (Holmberg). Fear and anxiety continue to be prominent forces throughout BC treatment and as such, coping strategies are crucial to maintain psychological health during this time of uncertainty.

Researchers have identified several prominent coping strategies used by women between BC diagnosis and surgery (Drageset, Lindstrom, & Underlid, 2009). Many of these strategies are considered by Drageset and colleagues to be types of emotion-focused coping, rather than coping styles associated with cognitive defense and problem-solving. The coping strategies proposed by Drageset and colleagues are not inherently interpersonal in nature; however, a potential advantage of interpersonal support, specifically peer support (i.e., support provided by other women with BC), is that patients are less likely to need to manage the recipient's emotional response to a disclosure of a BC diagnosis. Indeed, patients have reported that they often need to provide support to the recipients of this information (Drageset et. al.). Therefore, intrapersonal or peer support might be the best options for coping with a BC diagnosis.

Treatment Decision-Making Styles & Outcomes

Shortly following a BC diagnosis, patients need to make many decisions regarding treatment. Orientations toward decision-making may vary based on patient characteristics, such as ethnicity. For instance, African-American BC patients expressed a preference for relying on family and friends for surgical decision-making support instead of seeking professional support provided by the health-care system (Schubart, Farnan, & Kass, 2014). Importantly, decision-making need not be limited to medical encounters, as women with early-stage BC perceived themselves as being involved in treatment decision-making both inside and outside of medical

encounters (O'Brien, et al., 2013). From the perspectives of these women, treatment decision-making also included gathering information and discussing this information within their informal social networks. Notably, not all women prefer the same level of engagement in treatment-decision making (Seror, et al., 2013).

Treatment decision-making outcomes also vary widely depending upon patient age (Sio, et al., 2014), psychological distress (Budden, Hayes, & Buettner, 2014), and whether or not the woman lived alone (Livaudais, Franco, Fei, & Bickell, 2013). That is, younger age has been associated with electing for a more aggressive treatment plan (e.g., bilateral mastectomy) and psychological distress and living alone were associated with being less satisfied with one's treatment decisions. Additionally, those who reported being more active in their treatment planning were more likely to be satisfied with their decision (Budden, Hayes, & Buettner, 2014; Livaudais, et al., 2012). The effects of treatment factors on treatment decision-making should also be considered as some treatments (e.g., Tamoxifen) are associated with poorer cognitive functioning, which may impair decision-making abilities (Chen, et al., 2014).

Some medical professionals have raised the question of whether or not they are expecting too much out of their BC patients with respect to involving them in the treatment decision-making process. One study revealed that 72% of BC patients believed they were given a reasonable amount of responsibility for treatment decision-making, although 21% felt that they had too much responsibility in determining their treatment plan (Livaudais, et al., 2012). Among those who felt they were given too much responsibility, many had health literacy problems and reported 6-month decisional regret. Regardless of whether or not the patient perceived having too much or too little responsibility, the majority (68%) of these women had difficulty comprehending the complexities of health information.

Surgical Decision-Making

Soon after diagnosis, the newly diagnosed individual is confronted with the task of deciding one's course of treatment. Depending upon the stage of cancer, patients need to consider the relative benefits and risks of surgeries (e.g., lumpectomy vs. uni/bilateral mastectomy) and of adjuvant therapies (e.g., chemotherapy, radiation). This decision-making process typically involves considering the perspectives of multiple individuals, including physicians, partners, family and friends.

Mastectomies. In recent years there has been a strong trend for BC patients to choose more aggressive surgeries, such as choosing to undergo a contralateral prophylactic mastectomy (CPM; Pesce, Liederbach, Czechura, Winchester, & Yao, 2014; Tuttle, Habermann, Grund, Morris, & Virnig, 2007). This procedure involves removing the malignant breast along with the unaffected one. Indeed, the primary motivations for BC patients in choosing an elective CPM is a desire to reduce risk of developing cancer in the unaffected breast, to minimize fear of recurrence, and to improve survival (Covelli, Baxter, Fitch, McCready, & Wright, 2014; Rosenberg, et al., 2013). One participant in Covelli and colleagues study (2014) viewed her decision to undergo a CPM as her way of "taking control of cancer" (Covelli, et. al., 2014).

Although there has been a significant increase in the number of CPMs performed in recent years (Pesce, et al., 2014; Tuttle, et al., 2007), according to a recent Cochrane review of the effectiveness of prophylactic mastectomies, the evidence for the procedure's effectiveness in improving survival rates is insufficient (Lostumbo, Carbine, & Wallace, 2010). Indeed, breast conservation therapy (e.g. lumpectomy) is considered an adequate course of treatment for smaller BCs which are on the rise given improved BC screening technology (Wood, 2009). Despite the drastic increase in the number of CPMs performed, Wood (2009) asserted that no

health provider would recommend a CPM if a less invasive treatment were likely to be sufficient. Predictors associated with electing a CPM include patient characteristics, such as young age, large tumor size, positive family history of BC, lobular histology (versus ductal neoplasias), and multicentric disease (i.e. two or more distinct malignant breast tumors; Arrington, Jarosek, Virnig, Habermann, & Tuttle, 2009). Only one surgeon characteristic was related to the patients' decision to undergo a CPM. Having a female surgeon was associated with a greater likelihood of choosing a CPM; this finding might suggest that patients were more comfortable initiating conversations about CPM with women (Arrington, et. al., 2009).

Genomic testing. Advances in genomic testing for BRCA1 or 2 mutations have allowed women to determine whether they are at higher risk for developing BC; however, women with BRCA1 or 2 mutations do not account for the dramatic increase in CPMs (Wood, 2009). This suggests that women electing to undergo a CPM may not be doing so for the sole purpose of decreasing risk of new or recurrent BC. Indeed, some have posited that breast symmetry is another reason why some physicians may suggest a CPM and why patients may choose to receive the procedure (Wood, 2009). Other researchers have reported that gene expression profiling provides BC patients with “certainty amidst confusion” (Bombard, et al., 2014) and that the majority of cancer patients were willing to pay for the testing, despite not being equipped to make informed decisions following receipt of the results (Cuffe, et. al., 2014). Undue confidence in the validity and clinical utility of such results on the behalf of the patients is concerning as BRCA mutation testing has been reported to strongly influence surgical decision making, such that approximately 72% of patients who get tested discover they are carriers of a BRCA mutation and subsequently chose a different surgery than what was initially planned by their surgeon (Lokich, et al., 2014). However, other researchers have argued that this decision-

making process is more nuanced than a patient using one test result to determine their course of treatment. Instead, BRCA+ women reinterpreted their risk by filtering the odds they were given through deliberation about familial history, firsthand experience of a loved one's cancer, and social support and information drawn from informal social networks (Biber, 2014).

Breast Reconstruction. Once a course of treatment has been established (usually including some type of surgical removal of breast tissue), the BC patient is typically invited to consider the option of breast reconstruction in order to rehabilitate the appearance of her breast. Breast reconstruction can occur immediately following breast removal (i.e., in the same surgery) or it can be delayed and performed at some point following the surgical treatment of the BC. Some women chose to undergo immediate rather than delayed reconstruction because it required one fewer surgery and others chose to delay reconstruction because they became dissatisfied with wearing prostheses or immediate reconstruction was not offered as an option (Begum, Grunfeld, Ho-Asjoe, & Farhadi, 2011). Interestingly, many BC patients feared living with a mastectomy and initially intended to undergo reconstruction but after the surgery no longer viewed reconstruction as necessary (Lardi, et al, 2013).

General predictors of electing breast reconstruction included having early stage BC, receiving no adjuvant therapy, being young, being white, and having private insurance and higher education (Brennan & Spillane, 2013). The primary motivator for breast reconstruction appears to be related to body image. In one study, more than 75% of patients reported agreeing to breast reconstruction because it helped them to maintain a "balanced appearance" (Duggal, Metcalfe, Sackeyfio, Carlson, & Losken, 2013). Indeed, Duggal and colleagues also reported that body image appeared to be more motivating than sexuality or femininity for many women who decided to undergo reconstruction. However, regaining a sense of normalcy may also be an

important motivator for BC patients who have undergone or who will undergo breast reconstruction and who have defined normalcy as including “looking normal” (Denford, Rubin, & Pusic, 2011). Other researchers have constructed a grounded theory model of the role of breast reconstruction in women’s self-image following BC (McKean, Newman, & Adair, 2013), supporting the notion that breast reconstruction might largely be about reconstructing one’s sense of normal. The model depicts how some BC patients view breast reconstruction as symbolic of survival and that it allows them to feel whole again by regaining femininity and confidence in daily activities which, in turn, enables them to transcend the image of a sick person (McKean, et al., 2013).

Although some women reap psychological benefits from reconstructing their breast(s), many patients have reported that they felt underprepared for the emotional and physical difficulties that go along with undergoing breast reconstruction and some have reported that had they known of these difficulties, they would not have chosen to move forward with the procedure (Fallbjork, Frejeus, & Rasmusen, 2012). Indeed, decisional regret with respect to breast reconstruction has been linked to patient dissatisfaction with the preoperative information received from plastic surgeons, retrospectively (Zhong et al., 2013). Furthermore, some BC patients have reported that information about breast reconstruction was neither easily accessible nor routinely available and that they desired to know this information earlier in the treatment decision-making process (Lam et al., 2012).

Patient satisfaction with breast reconstruction has been associated with non-paternalistic decision-making (Ashraf, et al., 2013) and not being treated with radiation therapy (Albornoz et al., 2014). Although breast reconstruction is thought to be common among those who undergo mastectomy or lumpectomy, a recent systematic review estimated that about 17% of BC patients

chose to receive breast reconstruction (Brennan & Spillane, 2013). Furthermore, the authors found that breast reconstruction was only offered to a minority of women and only half of those offered agreed to the procedure. These conclusions, however, need to be interpreted with caution as Brennan and Spillane (2013) noted that published studies of breast reconstruction have been methodologically heterogeneous.

Psychological Responses and Social Support

Psychological responses to BC are wide-ranging, but common outcomes can include mood disturbances, anxiety, and newfound existential concerns (Knobf, 2011). Knobf (2011) concluded in her review of the literature that approximately 20-30% of BC patients experience depression and anxiety and that post-traumatic stress disorder (PTSD) has an incidence rate of 3-19% among this population. Unfortunately, some patients' psychosocial responses include a dramatic increase in health anxiety, especially if they have experienced unsupportive social interactions regarding their BC diagnosis (Jones, Hadjistvropoulos, & Sherry, 2012). Furthermore, Knobf (2011) describes four patterns of psychosocial functioning among BC survivors that have been proposed in the literature: persistent, progressive, recovery, and resilience. Persistent individuals remain highly distressed from diagnosis through the end of treatment and into survivorship; in contrast, progressive individuals become more distressed over time experiencing small hikes in an upward trend shortly after diagnosis and at the end of treatment. On the other hand, recovery individuals experience increased distress after diagnosis and nearing the end of treatment but recover to normal levels of functioning following the end of treatment. Resilient individuals are the least distressed and experience only marginal increases in distress following diagnosis and nearing and through the end of treatment. Certainly, personal factors such as self-efficacy and adjustment styles (e.g. active vs. passive coping) contribute to

BC patients' sense of emotional well-being, including over a twelve-month period (Rottman, Dalton, Chistenson, Frederiksen, & Johansen, 2010). The relationship between coping styles and emotional well-being also extends to husbands of BC patients (Bigatti, Wagner, Lydon-La, Steiner, & Miller, 2011). That is, the husbands' coping styles (e.g., escape-avoidance coping) were found to mediate the relationship between perceived social support and depression.

Social support is a robust buffer against psychological distress and has been related to lower levels of anxiety and depressive symptoms among patients who underwent BC surgery (El Sayed & Badr, 2014). Indeed, greater perceived emotional and instrumental support has been prospectively associated with lower levels of depression among BC survivors (Talley, Molix, Schlegel, & Bettencourt, 2010). Based on her review of the research on social support and psychosocial responses to BC, Knobf (2011) agreed that social support is an invaluable resource that protects against anxiety, depression, and PTSD and that women without social support prior to receiving their BC diagnosis and who do not have close family members or children to support them during treatment are reported to be at an increased mortality risk. She further noted that family members are typically viewed as a major source of support for BC patients, but that family members of the patient are also experiencing high levels of distress. Indeed, one study found that approximately 20% of family caregivers were clinically depressed when caring for their loved ones with BC (Nik Jaafar et al., 2014).

Although negative psychological responses are expected to occur following a BC diagnosis and during the treatment and survivorship phases, some have estimated that only 25% of female cancer patients (all types of cancer) reported wanting psychological support (Merckaert et al., 2010). However, there was no relationship between desire for psychological support and levels of psychological distress (therefore, one could be highly distressed but not

express a desire for support). Fortunately, overall quality of life (QoL) among BC patients improved over a two-year period, although some areas did not change (i.e., cognitive functioning, body image, insomnia, constipation, and diarrhea; Hartl, et al., 2010). Hartl et al. (2010) also found that initial distress at diagnosis was the strongest predictor of poor QoL over two years.

Virtual Social Support Among LGBT Individuals and BC Survivors

Should a sexual minority woman be diagnosed with BC, social support may be a crucial factor contributing to long-term survival (Glanz & Lerman, 1992; Holland & Holahan, 2003). Although a few researchers have suggested that some lesbians may have an advantage in social support, it is more commonly thought that social support is more difficult for SMW to acquire than for HW because of lower levels of parental support (Needham & Austin, 2010), sexual orientation nondisclosure, and family rejection. Indeed, sexual minority participants have consistently reported higher rates of victimization in early-life family and romantic relationships, including physical and sexual abuse (McLaughlin, Hatzenbuehler, Xuan, & Conron, 2012; Balsam, Rothblum, Beauchaine, 2005; Corliss, Cochran, & Mays, 2002). This reality likely forces many SMW to create “families of choice” in order to garner the support that they need, especially during stressful life events such as being diagnosed with a life-threatening illness. Indeed, social support from friends rather than family predicted higher mental quality of life and lower depression, anxiety, and internalized homophobia among older (over 50-years-old) LGB adults (Masini & Barrett, 2008).

Fortunately, the internet has made it easier for sexual minority individuals to find social support and has been deemed a “safety net” by researchers who found that LGB youth used it differently than non-LGB peers in order to access accepting and supportive friendships and to

find potential romantic partners and other people like them (Hillier, Mitchell, & Ybarra, 2012). Indeed, virtual communities have been found to provide varying types of social support for those with BC (Blank, Schmidt, Vangness, Monteiro, & Santagat, 2010; Setoyama, Yamazaki, Nakayama, 2011; Sillence, 2013; Vilhauer, 2009). In one study, participants in an online BC community were determined to have exchanged valuable information and social support and there was little separation between the two (i.e., messages designed to share information also included expressions of emotional support at the same time; Rubenstein, 2014). In another case, an internet based psychosocial intervention for women with BC, which involved creating a personal website in which patients could express emotions related to cancer, provide medical status updates, and communicate to others what would be helpful, was found to decrease depressive symptoms and loneliness and increase positive mood, life appreciation, coping self-confidence, and perceived social support from friends (Cleary & Stanton, 2015). Thus, even though social support is traditionally understood in the context of face-to-face personal relationships, there is evidence that virtual social support can be exchanged.

Researchers have even suggested that there may be benefits of virtual over face-to-face social support, such as anonymity (the ability to say personal things without knowing one another face-to-face), optimization of expressiveness (the affordance of asynchronous communication in being able to carefully craft supportive and support-seeking messages), and the ability to seek or provide support at any time (24/7 access; Walther & Boyd, 2002). Yet another advantage of virtual communities is that participants are better able to locate others who share their illness and other personal characteristics, such as minority sexual orientation. This advantage is important because one-on-one peer support has been linked to benefits to the QoL of patients with BC (Ashbury, Cameron, Mercer, Fitch, & Nielsen, 1998). In addition, other

researchers have found that the feared disadvantages of online support groups that have been identified in the literature (i.e. potential for socially inappropriate comments and exchange of incorrect information) were mostly non-existent in practice (van Uden-Kraan, et al., 2008). Instead, researchers suggest that participation in online support groups may bolster patients' empowerment (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008).

Significance and Study Goal

There is a dearth of data related to the lesbian BC disparity and the studies that do exist tend to focus on screening and prevention (Brown & Tracey, 2008). As such, there is an urgent need for researchers to better understand SMW's BC experiences. A fuller understanding of the unique experiences of lesbian BC patients is crucial for the development of targeted interventions. One way in which we might learn about lesbian BC experiences is through the examination of online social support venues designed for BC patients. Data collected from a lesbian-specific BC forum may be particularly fruitful for gaining an understanding their unique experiences.

For this study, I conducted an inductive thematic analysis (Boyatzis, 1998) of messages posted to the lesbian-specific discussion forum found on breastcancer.org. Breastcancer.org is a non-profit organization that serves to provide the latest reliable information about BC, such as information about symptoms, diagnosis, treatment and treatment side effects. The site also includes a community aspect in which users can interact with one another on discussion boards, blogs, and chat rooms. An analysis of the salient themes found in the messages of a virtual community of lesbian BC patients might allow researchers and clinicians to better understand the unique experiences of lesbian BC patients.

Methods

Procedure

Identifying lesbians with BC is a challenging task and recruiting via cancer registries is labor intensive and historically has not resulted in sufficiently large samples (Boehmer, et al, 2010). Furthermore, researchers have found that convenience samples of lesbians with BC are not significantly different from samples derived from cancer registries (Boehmer, Clark, Timm, Glickman, & Sullivan, 2011). Thus, a convenience sample may be both efficient and provide an adequate representation of the broader lesbian BC patient population. For this study, I collected data from the lesbian-specific discussion board forum found on breastcancer.org. I chose this forum because it was the largest online support venue for BC survivors and their partners. At the time of data collection there were over 141,000 members. Within the lesbian-specific forum there were 173 topics and each topic had its own discussion board. A typical discussion board included posts from users seeking support. Often, multiple users responded to these requests and a back and forth dialogue ensued. I collected data from all 173 discussion boards found in the “Lesbians with BC” forum. Data from these discussion boards were collected and transferred into NVivo 10 qualitative software for analysis.

The UWM IRB determined that the present study did not qualify as human subjects research, and therefore, did not require IRB approval. This study did not meet criteria for IRB review because the study did not involve intervention or interaction with human subjects nor did the online data involve identifiable private information. Although the study did not involve identifiable *and* private information it did involve potentially identifiable information, such as usernames (which sometimes resemble real names) and other specific information about the individual such as geographic location and BC diagnosis, stage, and treatment. The latter information was often in the signature of each discussion board post made by a user and is

therefore connected to the individual's username. The online data collected for this study was not considered private because neither a log-in nor an invitation from a site administrator was required to access the information. The posts in the discussion boards are fully public for anyone to view; however, it is possible that the discussion boards could be blocked or taken down in the future.

Analytic Plan

An inductive thematic analysis (Boyatzis, 1998) was conducted in order to gain a better understanding of the unique experiences of lesbian BC patients who posted on the lesbian BC forum on breastcancer.org. This analysis included data from all 173 discussion boards, each board ranging from 1-748 posts each. I recruited and trained one undergraduate research assistant (RA) to aid in this analysis. First, I trained the RA on the basics of qualitative coding and thematic analysis. Next, we read the discussion board posts and made notes of potential themes. Then we conducted open coding until saturation of emergent codes occurred, at which point I developed a preliminary coding structure that combined codes into over-arching themes that best depicted the data. The RA and I met to discuss the validity of this initial structure and then began coding posts in accordance with this structure. We had at least weekly (sometimes bi-weekly) meetings to discuss the data we coded. If there were discrepancies in codes we discussed them until a consensus was met. During this time adjustments to the coding structure were made as we saw fit, particularly as it pertained to refining definitions of codes and themes. Data were also brought to lab meetings in order to acquire alternative perspectives.

A secondary analysis was conducted about halfway through data analysis because we noticed that BC experiences appeared to be differential based on self-identification as more femme or butch. Some women would label themselves as femme or butch, while others simply

described themselves in ways that were consistent with more feminine (e.g., “looking and feeling feminine”) or masculine (e.g., having short hair and wearing baggy clothes) gender presentations. In cases where an individual did not self-identity as femme or butch or describe their gender expression, we excluded their posts from the secondary data analysis. The RA and myself coded for more femme or butch gender expressions within the existing coded data in order to examine the experiences of femme and butch patients separately.

Findings

My thematic analysis resulted in the identification of several unique aspects of the BC journey among lesbian women. For the sake of readability, I will present themes within two broad categories: Being a Lesbian Matters and the Intersection of Gender Expression and Lesbian Sexual Orientation. Within each of these categories are topic areas that further organize the themes, but are not themes themselves.

Under the “Being a Lesbian Matters” category, I will report themes that are specified under three topics areas A) general BC experiences, B) mastectomy, and C) breast reconstruction. Themes that influence general BC experiences among lesbians included 1) experiencing heterosexism in medical contexts, 2) viewing the BC journey as a sexual-identity disclosure crisis, and 3) having worries about her partner not being considered family. Themes specific to mastectomy included 1) focusing on survival over appearance, 2) being concerned that surgeons’ recommendations for mastectomy were grounded in biased gender identity beliefs, and 3) believing others perceive a lack of distress over breast loss because of patient’s lesbian sexual orientation. With respect to breast reconstruction, five themes emerged: 1) rejecting being identified by their bodies, 2) perceiving their social context as supportive of no

reconstruction, 3) believing that being breastless is protective, 4) privileging sensation over appearance and 5) feeling pressure from surgeons to get reconstructive surgery.

Under the “Intersection of Gender Expression and Lesbian Sexual Orientation” category, I will report themes that represent two topics areas: themes among femme-lesbian patients and themes among butch- and gender variant patients. I identified two themes among femme-lesbian patients, including 1) having a preference for breast reconstruction because breasts are an important part of femme-lesbian identity, and 2) being frustrated about gender misidentification resulting from breast and hair loss. There were also two themes that emerged among butch- and gender variant lesbians: 1) deciding against breast reconstruction because it contradicts preferred gender expression, and 2) enjoying or accepting that others were confused about their gender.

Being a Lesbian Matters

Discussion board users had numerous conversations about their BC journeys, some of which were directly related to their status as lesbian women. It is clear that sexuality played a significant role in their general experiences of BC, but especially so in discussions focused on mastectomy and breast reconstruction. Themes that appeared to be directly related to lesbian sexual orientation will be presented under three topic areas: 1) general BC experiences, 2) mastectomy discussions, and 3) breast reconstruction discussions.

General BC Experiences.

Experiencing heterosexism in medical contexts. Forum users discussed instances in which they experienced heterosexism (i.e., a system that privileges or is biased in favor of heterosexual individuals; Herek, 1990) in medical contexts. This theme was consistent across time and appeared within conversations that had taken place over multiple years (i.e., 2009, 2010, 2012, and 2013). These discussions often involved the assumption by medical

professionals that the BC patient is heterosexual: “My academic [oncologist] basically told me [to have] lots of intercourse [to improve sexual functioning]. I didn't even bother to correct her about the intercourse thing, I was so dejected.” Other instances of heterosexism included assuming the patient’s partner was male and assuming that there was a possibility that the patient was pregnant:

When I asked if my partner could come in to discuss treatment options, he [“the clueless oncologist”] asked what "his" name was; I replied Steph, he said, Steve? This went on for a couple of exchanges until the nurse finally said, "I'll go get her..."

I signed up for a clinical trial that will cover the cost of my Oncotype [diagnostic] test, but my tumor got sent off a week later than I had anticipated because the oncologist's office called me and told me I'd have to have a pregnancy test first!!! It was super annoying to have to drive 60 mins [round trip] to pee in a cup to prove that I'm not pregnant - because being a lesbian who was currently menstruating at the time wasn't proof enough!!

One patient encountered a medical professional who challenged her sexual identity on the grounds of religion, although the patient denied that this encounter resulted in substandard care:

I'm in Texas, which isn't exactly the center of tolerance, so I had some interesting experiences while I was in the hospital. The woman who did my pre-op check-in told me "don't tell me GOD made you that way - I can be tolerant but I won't hear that!" It made me uncomfortable. We did discuss the folk in her family that are gay. Weird. And one nurse I had a good relationship with saw that my pastor visited and asked me how I rationalize my lesbianism with my religion. I just said "My god loves me!" My religion isn't her business, but I think she was just curious, not [censorious]. I did feel my homosexuality was a problem personally for some people - fortunately, my care absolutely did not suffer.

Viewing the BC journey as a sexual-identity disclosure crisis. Forum users who were partners of the BC patient consistently described the BC journey as stressful. Partners of the patients were especially concerned about their need and their partner’s need to disclose their sexual orientation to employers in order to receive benefits:

Has anyone here tried to [or been able to] use [the Family and Medical Leave Act] to take care of her [girlfriend]? I'm not sure how [or if] to broach the subject at work. I am a

state employee in a right to work state, and feel that I might risk termination for 'outing' myself.

Another woman, a BC patient, expressed her frustration that her partner is not out at work and is thus unable to provide the support that the patient desires:

I don't know if this will ring any chimes out there, but one of my biggest difficulties right now is that my partner is not out at her work--cannot be out. If she came out, she would lose her job--and she is only 3 years from retirement, and is trying to hang in there for the retirement pay. The thing is, that she cannot share this huge stress in her life--that I, her partner, have BC. She's been able to take a few days of leave to be with me for the major things, like the surgery and the first visit to the [oncologist] and first chemo...but the ongoing stress of not being able to explain why she's stressed, or why she would like to take more time off--let alone get much support. She does have some friends at work to whom she is out, but not her supervisors, of course.

Indeed, one patient noted how her partner's openness about her sexual orientation at work has allowed her partner to provide support at medical appointments: "Her workplace is being terrific about letting her rearrange her schedule to go to appointments with me. She commented that she couldn't imagine how someone in the closet at work could make it through having a partner with cancer!" More generally, though, forum users were acutely aware of the necessity of sexual-identity disclosure if they wish to have their partner present during treatment: "My partner has been by my side throughout my treatment, something I couldn't have done without "coming out" as how else would I explain her presence without lying about it?"

Having worries about her partner not being considered family. The challenge of acquiring support does not end with sexual-identity disclosure. Rather, a few forum users remained concerned that their partner would not be considered family and therefore, would not be treated as such in medical facilities:

My partner and I are having a tough time as we live in the South -- and in a very conservative area where they don't necessarily view my partner as "family." They of course list her as friend/other on everything, and I'm very afraid that when I start my surgeries, etc, there will be issues with the doctors/surgeons/nurses sharing information

with her. I don't need the stress of her having to fight for information along with the stress of the cancer.

Others were aware of their hospital visitation rights, but were unsure of the process of accessing these rights: "I'm wondering what I can expect by way of hospital procedure when I want to visit her and things. Does it depend on her family?"

Mastectomy discussions.

Focusing on survival over appearance. Much discussion was related to the loss of breasts from mastectomies. Forum users stated various opinions about the decision to get a mastectomy and shared a range of emotional responses to the surgery and resultant breast loss. The majority of the lesbian BC patients, however, were squarely focused on survival even in the face of physical deformity. One woman stated that she did not mourn the loss of her breasts and instead saw the removal as a cause for celebration: "I never experienced the mourning the loss of my breasts; I was just thrilled to have the cancer gone." Another woman assumed that losing her breast would be emotionally taxing, and was surprised that she was "not as devastated as [she] thought" because her body modification meant that her cancer was eradicated. Others echoed a similar sentiment about focusing on survival by choosing to get a bilateral mastectomy in order to attempt to prevent recurrence. One woman shared that she loved breasts but that this love did not outweigh the risk of her cancer spreading to the non-affected breast: "Of course I love breasts, I'm a lesbian! I just don't want to risk getting cancer in the other breast and going through this hell again."

Overall, it was evident that most of the women were focused on survival over breast preservation. One woman stated "I feel good about my choice [to get a mastectomy], this is a result of my desire to survive." Another woman found beauty in having received a mastectomy: "I never felt like I looked deformed or silly. When I see my chest all I see is an absence of cancer

and that to me is beautiful.” Despite many women’s preference for a mastectomy, physicians were not always supportive of such a course of action: “Of course my doctor was male and just couldn't believe that I would even consider losing a breast that didn't have cancer in it, what a jerk.” Another woman expressed frustration with her doctor’s response to her requesting a bilateral mastectomy: “You know, I have Stage IV and when I asked my doctor about a bilateral mastectomy he acted as if I was insane!”

Being concerned that surgeons’ recommendations for mastectomy were grounded in biased gender identity beliefs. Many women discussed electing for bilateral mastectomies because of a strong desire to beat their cancer quickly and to lessen anxiety associated with the possibility of reoccurrence or transmission to an unaffected breast. One woman, however, was concerned that her surgeons perceived their desire to get mastectomies as related to gender-identity issues:

He gave me a look and a paranoid part of me wondered if he was erroneously thinking I wanted my breasts removed for transgender reasons (he knows I'm a lesbian). Then I thought I was crazy for being paranoid about that. Now I wonder if I was being paranoid or perceptive.

Later in the discussion board, this same woman received criticism from other users for her concern about potentially being perceived as transgender, but denied that her statement was transphobic. Instead, she speculated that her surgeon gave her a “look” because the surgeon thought her rationale behind wanting a bilateral mastectomy was not sufficient; therefore, she thought the surgeon might be searching for additional unstated reasons for why she wanted the surgery:

So, I guess I don't think my paranoia about the transgender thing was internalized transphobia....it was more of a feeling like what I view as my "reasonable concerns" needed further justification....that my experiences thus far, my illness, my fears, my anxieties, are not enough to warrant having the other breast removed....that there would have to be "some other" reason.

Believing others perceive a lack of over breast loss because of patient's lesbian sexual orientation. In a similar vein, one woman described an instance when someone assumed that she was not as upset about her breast loss because of her sexual identity: "I also had a bilateral w/o reconstruction and had someone ask me if the reason I wasn't more upset about losing my breasts was because I'm lesbian. Again, WTF?"

Breast reconstruction discussions.

Rejecting being defined by their bodies. The lesbian-specific BC forum was littered with discourse about embodiment and how their bodies do not define them. This conversation was not always specific to breasts: "I believe a person is more than their physical being and you often fall in love with a person because of other things, not just their body." This sentiment was most prominent in discussions about breasts. Many women stated clearly that they are not defined by their breasts. One woman found that breasts got in the way of her activities and stated that breasts were not a part of her identity: "I've found that breasts, while nice to have, [are] kinda annoying to my activities (horses, soccer) and [are] definitely not part of my self-identity." Another woman declared that she is not her breast: "I am having [a] bilateral [mastectomy] this Friday with no reconstruction. I am not my breast. I will not live with fear." There was often a sense of empowerment that came with having made the decision to not reconstruct: "I made the decision [to not get reconstruction] and I am proud of my decision. Boobs does not define who I am."

Although breasts are often associated with sexuality, some women asserted that the body is just one part of sexuality: "Although I have never claimed to be less than vain, even I know that my body is just one part of my sexuality and sensuality." Others rejected that the body played any role in sexual attractiveness: "And exactly what do I need [breast reconstruction]

for? I don't feel it defines myself as a female or has anything to do with my sexual attractiveness to others.” Many of the women also discussed how they are not responsible for how others perceive their bodies without breasts. One woman referenced Audre Lorde’s (a lesbian-feminist writer and civil rights activist) book, *The Cancer Journals*, which documents her BC journey and decision to undergo a single mastectomy without reconstruction. The user mentioned this book in an attempt to support another user who was having difficulty deciding whether or not to pursue reconstruction: “[Lorde] wrote a lot about how a fake breast would make other people more comfortable to be around her, but how it was not comfortable for HER, and that's what really matters - what YOU want for YOUR body!”

In one of the many lengthy discussions about the value of breasts and breast reconstruction, one woman agreed with other users that breast reconstruction, by definition, is largely for others’ benefit because the reconstructed breast does not have sensation:

Especially since fake boobs do not have sensation...that, more than anything, makes me feel like they would be for others' benefit, not my benefit. If I couldn't feel them, I would feel like my reconstructed breasts would be just for looks, and I don't need that.

Another woman hypothesized that HW might not share the same opinions about the importance of body image, especially with regards to the pressure to conform to beauty standards put forth by heterosexual men: “And I personally believe that hetero women are not necessarily more body conscious than lesbians but do know that they have to visually/sexually appeal to men, who are much more body conscious.” Ultimately, many women viewed their body not as an object for others to observe, but rather as something to appreciate for its utility. This is the rationale behind many women’s decisions to decline breast reconstruction:

A few months ago, I found this 4-page journal entry I'd written for my women's studies class, all about how I love and appreciate my body for its health, strength, usefulness, and ability, not so much its appearance, and how much I don't care about all of the mainstream, patriarchy-induced beauty rituals that are either bad for women's health or at

least unnecessary, and how I would never consider cosmetic surgery. Ten yrs later, I still feel the same, and would not consider fake boobs.

Perceiving their social context as supportive of no reconstruction. Many lesbian women described existing in a social atmosphere that was supportive of variations in the appearance of breasts, including missing breasts and breasts with scars. Of particular influence was the Michigan Womyn's Music Festival (where many choose to attend topless), which was mentioned throughout the discussion boards. These women described their experiences at this festival and how they informed their own perspectives on breasts. One woman noted that the festival normalized breast loss:

I've been to women's music festivals where topless, post mastectomy women bared their scars proudly, so in some ways I feel like I've had experiences where breast removal, both by choice and necessity, has kind of normalized the experience of breast loss through my community.

Another woman felt liberated from breast beauty standards as a result of her experience at the music festival:

I also attended Michigan Womyn's Music Festival, albeit many years ago, and it gave me a totally new and better view of my body and my breasts. You do see every possible kind, including burned, missing, sunburned, pointy, hairy, huge, flat w/nipple only, wrinkled, bouncy, etc. It's very freeing.

Beyond the anomalous Michigan Womyn's Music Festival, the lesbian women's social communities, in general, espoused acceptance of women who transcended gender lines. As a result, these communities also contributed to a sense that breast variations, including missing breasts is normal:

I'd never been particularly attached to my tits, and I came out in a time and in a community where blurring gender lines was pretty well accepted and celebrated. I've also spent a lot of time in women's space where women of all shapes and sizes have been topless, and some of those women had mastectomies, single, double, and it was a normal part of the landscape.

Having a desire for sensation over appearance. Forum users frequently discussed their decision-making with regards to choosing to reconstruct their breasts post-mastectomy. Some of the women elected to get breast reconstruction, especially if they were femme-identified or single, but many chose not to undergo plastic surgery. The reasons for choosing to opt out of reconstruction tended to center around a preference for sensation over appearance:

Besides I still feel like I get hard nipples in the grocery store (even tho i have none) and I still have some nerves and feeling there....those fake boobs could have messed with that! I was concerned that I may have no nipple or reduced nipple sensation after the symmetry surgery and I did not want to risk this.

Another woman echoed a similar sentiment about the importance of sensation: “There is nothing even the best surgeon could do to give me sensation in those perky new nipples, and that's what I miss.”

Believing that being breastless is protective. Interestingly, some women chose not to reconstruct for reasons not related to preserving sensation. Instead, they saw their breastless chest as protection from unwanted attention: “My D cups got constant attention....blech! No one looks twice at my flat chest!” Other women appreciated that their lack of breasts would serve as a filter, allowing them to sift through potential romantic partners who may only be attracted to them because of their breasts: “And anyone who wouldn't want to get to know me if I had no breasts isn't the kind of person I'd want to know ANYWAY! Breastless chest = instant a**hole detector!”

Feeling pressure from surgeons to get reconstructive surgery. Many women discussed the multitude of ways they felt pressured to reconstruct their breasts, despite the fact that reconstruction did not align with their wishes. Specifically, the forum users described instances where they felt pressured by their surgeons to consent to breast reconstruction. Sometimes the pressure was direct and resulted in a surgery that was later regretted:

I went with immediate reconstruction based solely on the pressure of my surgeon and the fear she put in my head that my partner, while agreeing with my decision not to reconstruct may actually just be telling me what I hear. Having been in a previous relationship where that was a huge issue, I worried that might be the case this time as well. Honestly, they have presented more problems than not doing it could ever have caused. Lesson learned; follow your own instincts and let others adjust to what you chose, or not depending on their own baggage.

Other times the pressure from surgeons took a more indirect form, such as assuming that the patient would want plastic surgery: “At first, it sounded like reconstruction was the normal course I had to take.” Another woman did not want her surgeon to discuss reconstruction with her, but he did so anyway: “He is a great surgeon and did a fantastic job on my right breast. But then he starts talking about reconstruction....which is not what I want and I advised him as such.” Other women found that their doctors were surprised by their decisions to not reconstruct: “One doctor seemed surprised by my decision not to have implants.” Sometimes surgeons would go as far as failing to acknowledge the option to decline reconstruction: “When I was faced with all these decisions (I did unilateral, with implant reconstruction), none of my doctors even raised the possibility of going unreconstructed.” The pressure to undergo reconstructive surgery did not end with their surgeons. Indeed, many women also shared instances where family and friends also pressured them to reconstruct:

I did get an implant on my right (I only had single [mastectomy], and I am having it out for physical reasons. It hurts and it is migrating under my armpit! I got it because I felt pressured into having the consult because after the [diagnosis] of [BC] I was in no position to make major decisions, (or so I thought). I just wanted my breast off and the cancer gone! I really wish I had gone with my initial reaction. I never have been vain about my breasts, I have never felt like they define me as a woman or anything. I guess I just listened too much to my family and friends, and I now regret having the plastics done at all. It is so fake looking, numb, painful...how stupid of me!

Gender Expression and Lesbian Sexual Orientation

The lesbian women who trafficked the online BC support forum represented a wide range of self-reported gender expressions. A number of women would often self-identify as “femme,”

“butch” or “androgynous” or simply would describe themselves in more feminine (e.g. “feeling and looking feminine”), or masculine (e.g, having short hair and wearing baggy clothes) ways. Gender expression appeared to be an important aspect of forum users’ identities. Specifically, gender seemed to influence the patients’ perspectives on breast reconstruction and responses to bodily changes post-treatment (e.g., short hair).

Self-identified as Femme.

Having a preference for breast reconstruction because breasts are an important part of femme-lesbian identity. Femme lesbians seemed to be more willing to go through the pain of breast reconstruction surgery because breasts were important to their lesbian femme identity:

I have had reconstruction because I identify my sexuality by feeling and looking feminine. Not that reconstruction is for everyone, I knew it was a no brainer for me. I suffered more from the reconstruction than the mastectomies but that’s the price I paid for what I wanted.

Other femme-lesbians wanted breast implants but ultimately reversed course after difficulties with breast implants and prosthetics:

I had my [bilateral mastectomy] last May. I identify as "on the femme side". I tried implants and omg they were horrendous. They came out three weeks later. Now here I am almost nine months later and I still can't wear the falsies because they are too heavy - my chest is numb and there is chronic pain where the bra would go so I go without anything.

Being frustrated about gender misidentification because of breast and hair loss. Many femme women expressed frustration with others who would question their gender because of their short hair and flat chests:

Since I'm over six feet tall, I get a lot of people looking at me and wondering if I am a man in women's clothing - the extremely short post-chemo hair and the flat chest and the height obviously confuses them. I hate it but don't know what I can do about it. Even if I got some of those micro bead inserts, I still have to wear a bra and that's just not going to happen.

One femme woman stated that she does not want reconstruction, but that she feared the social consequences of this decision, particularly the potential of being misidentified as a man:

For various reasons I don't want reconstruction, but I'm afraid of the social consequences. I don't wear make-up or dresses and even now people often mistake me for a man unless I wear clothes that are rather tight fitting and obviously feminine. My concern is that this 'mistake' is going to happen more frequently. In some cases it's not a problem, but when for example, I want to use a public toilet, it could become one.

Self-identified as Butch or Gender Variant.

Deciding against breast reconstruction because it contradicts preferred gender expression. Butch lesbians often failed to see any benefits of electing for breast reconstruction.

These women discussed how fake breasts would likely lead them to feel as if they were in drag:

My partner and I talked it over and couldn't see any benefit in doing reconstruction - and I think I would feel kind of like I feel if I wear a dress - like I'm in drag. Sticking some foobs (fake boobs) on there aren't going to make me more feminine, that's for sure.

Enjoying or accepting that others were confused about their gender. Other women enjoyed the fact that others were likely confused about their gender: "I got called "sir" a lot when I was bald. I didn't really care. My body really looks like a 13 year old boy's now. Really, I kind of like it."

Another forum user was fond of the fact that others might read her as transgender:

I have a bit of a different take. I, too, had a [bilateral mastectomy] and I didn't do [reconstruction] or prosthesis. I actually LIKE the fact that some people might read me as Trans. I enjoy the confusion and love being around trans boys, who have also had "top surgery"...it is the one place that I feel at home and accepted for my decision.

Many butch-lesbians were not bothered when others would misidentify them as male: "I think people think I am a man because I am very tall (6'2") and have short hair and no chest... and it doesn't bother me." Other gender non-conforming patient's simply did not care that others perceived her as male: "Since chemo, I really like my hair really really short. Now, I get sirred a lot now, and now...I really don't care!"

Discussion

The present study is the first qualitative study to examine the unique experiences of lesbian BC survivors. I conducted an inductive thematic analysis (Boyatzis, 1998) to examine the messages posted to a lesbian-specific online support forum found on breastcancer.org. This analysis resulted in the identification of several themes that I have organized into two broad categories: Being a Lesbian Matters and Intersection of Gender Expression and Lesbian Sexual Orientation. Within the “Being a Lesbian Matters” category, themes are further organized into three topic areas: general BC experiences, mastectomy, and breast reconstruction. Within the Intersection of Gender Expression and Lesbian Sexual Orientation category, themes are organized into two topic areas: themes about femme-lesbian patients and themes about butch- and gender variant patients. The themes will be summarized in the following paragraphs before I consider them in relation to the extant literature on topics related to breast cancer survival and stress and coping among lesbian-identified women.

Being a Lesbian Matters

Three themes emerged related to general BC experiences: 1) experiencing heterosexism in medical contexts, 2) viewing the BC journey a sexual-identity disclosure crisis, and 3) having worries about her partner not being considered family. In addition, sexuality also appeared to play a role in the context of treatment decision-making (i.e., mastectomy and breast reconstruction discussions). I identified three themes related to the topic of mastectomy: 1) focusing on survival over appearance, 2) being concerned that surgeons’ recommendations for mastectomy were grounded in biased gender identity beliefs, and 3) believing others perceive lack of distress over breast loss because of patient’s lesbian sexual orientation. I found five themes related to breast reconstruction: 1) rejecting being defined by their bodies, 2) perceiving

their social context as supportive of no reconstruction, 3) privileging sensation over appearance, 4) believing that being breastless is protective, and 5) feeling pressure from surgeons to get reconstructive surgery.

Gender Expression and Lesbian Sexual Orientation

This inductive thematic analysis revealed themes that appear to be related to gender expression, specifically at the intersection of gender expression and lesbian sexual orientation. That is to say, self-identified femme and butch lesbians seemed to provide distinct perspectives on issues related to breast reconstruction and post-mastectomy body image. I identified two themes among femme-lesbian patients, including 1) having a preference for breast reconstruction because breasts are an important part of femme-lesbian identity, and 2) being frustrated about gender misidentification. There were two themes among butch and gender variant patients: 1) deciding against breast reconstruction because it contradicts preferred gender expression, and 2) enjoying or accepting that others were confused about their gender.

Overall, the findings are consistent with previous literature that suggests lesbian women experience BC differently than HW (e.g., Dibble & Roberts, 2002; Matthews, et al., 2002). I contend that the lived context of heteronormativity and homophobia, lesbian social norms, and gender expression are integral to the interpretation of the findings and will discuss each context in turn.

Living in a Heteronormative and Homophobic Context

Minority stress theory (Lick et al., 2013) is a framework for understanding poor health outcomes among LGB individuals in comparison to those who are heterosexually identified. Indeed, researchers have indicated a consistent relationship between minority stress and physical health problems (Denton, 2012; Fredriksen-Goldsen, Kim & Barkan, 2012; Frost, Lehavot, &

Meyer, 2011; Woodford, Howell, Kulick, & Silverschanz, 2012). This association also likely extends to the context of BC, as researchers have found support for higher rates of BC mortality among women who cohabit with same-sex partners (Boehmer, Ozonoff, & Miao, 2013; Cochran & Mays, 2012). Furthermore, lesbian BC patients have reported higher stress related to diagnosis and treatment, lower satisfaction with care delivered by physicians, and more problems with chemotherapy-induced side effects compared to HW (Dibble & Roberts, 2002; Matthews, et al., 2002). These findings, in addition to the findings of the present study, could be understood in terms of the stress and dissonance that result from living within a heteronormative, and in some cases, homophobic context.

Within the medical context, researchers have found that only a minority of lesbian BC patients have experienced direct encounters with explicit homophobia although heteronormativity is ubiquitous (Sinding, Barnoff, & Grassau, 2004). Indeed, the women in my study recounted numerous occasions in which they experienced heterosexism in the medical context, including in support groups. These findings are corroborated by previous research (Katz, 2009; Sinding, Barnoff, & Grassau, 2004) and might also explain why forum participants expressed concern that their partners would not be considered family by medical staff, despite legislation that mandates visitation rights for same-sex couples (Shear, 2010).

The types of heteronormative and homophobic incidents revealed by the participants (e.g., a physician assuming the patient is heterosexual) can be best described as microaggressions (i.e., subtle and commonplace forms of discrimination; Nadal, et al., 2011). Microaggressions have been associated with reports of internalized homophobia (Flatt & Lenzen, 2013). In the context of BC, internalized homophobia has been associated with greater distress among lesbians treated for early stage BC (McGregor, et al., 2001). Additionally, lesbian BC patients' fear of

discrimination by health care providers has been identified as a significant barrier to sexual-identity disclosure (Boehmer & Case, 2004), despite lesbian patients' acknowledgments of the benefits of disclosure (Bjorkman & Malterus, 2007).

Sexual-identity disclosure to health care providers is crucial if women wish to be recognized as lesbian patients. In fact, there are practical reasons for disclosing to medical staff (e.g., ensuring that her partner be present for medical consultations) and associated mental health benefits, such as decreases in anxiety (Boehmer, et al., 2013). Despite these benefits, the task of sexual-identity disclosure in the health care context is not without its challenges, especially because the majority of health care providers do not assess for sexual identity (Stein & Bonuck, 2001; van Dam, Koh, & Dibble, 2001) or initiate discussions about it in primary care (van Dam, Koh, & Dibble, 2001; Mosack, Brouwer & Petroll, 2013), leaving the burden of disclosure on the patient. Working under the assumption that most of the women in my study were beyond mid-life, coming out may be an undertaking that they have not engaged in for many years. Furthermore, these older women might be more likely than younger women to have experienced overt discrimination (versus microaggressions). That is, across their lifespans it is probable that they have suffered or have seen others suffer from serious consequences (e.g., police harassment and brutality) of sexual orientation disclosure (e.g., police harassment of "homosexuals" in New York City from 1960-1980; Rosen, 1982). These experiences may contribute to forum users' fear of disclosure and create a perception that receiving a BC diagnosis is a cause for significant concern if they wish their partner to be present at health care appointments and treatments. Therefore, it is understandable that these women expressed concern about disclosing their identities to health care providers.

Two findings are related to the perceptions that others hold about the lesbian patients. First, some patients were concerned that their surgeons believed they opted for a mastectomy because of gender identity reasons. Second, respondents described how it seemed that others presume that because they identify as lesbian, they would not be distressed about their breast loss. In both of these cases the importance of the breast is minimized because of sexual orientation. I also believe that these perceptions represent how gender expression moderates the experiences of lesbian BC patients. That is, it seems likely that those patients who express themselves in feminine ways may be more concerned about their surgeons falsely assuming they want a mastectomy because of gender-identity reasons. This fear may also be a reaction to common stereotypes about lesbian women (e.g., lesbian women are tomboys) which are particularly distressing to those lesbians who express themselves in feminine ways. The second perception regarding an assumption that others perceived their lack of distress over breast loss may be related to a perception that more masculine-presenting lesbians hold, as supported by the findings of the present study. That is, patients with a more masculine gender expression indicated experiencing less distress by their breast loss likely because this better aligns with how they wish to express their gender. A more detailed discussion of how gender expression appears to moderate experiences will follow in the “Gender Expression as a Moderator of Experience” section.

Integration of Lesbian Social Norms

Social norms endemic to many lesbian communities should be considered in the interpretation of a number of the findings of the present study. First, I will discuss lesbian body image norms in relation to the finding that forum users focused on survival and physical sensation over appearance. Next, I will utilize objectification theory to examine the findings that

many women rejected the notion that they are defined by their bodies alone and believed that being breastless is protective. Finally, I will draw on both objectification theory and the social norms found in the frequently mentioned, lesbian-feminist music festival, the Michigan Womyn's Music Festival, to support the finding that the participants perceived their social context as supportive of non-reconstruction.

Body image was a prominent topic of discussion in the lesbian BC forum discussion boards. Some women, particularly more feminine lesbians, found the changes in body image post-treatment to be bothersome. However, many more women discussed the positive aspects of bodily changes that resulted from the BC treatments (e.g., the changes allowed for political statements and more identity congruent gender expression). The findings from this study are harmonious with previous research that has indicated that lesbian BC patients report less distress associated with changes in body image (Fobair et al., 2001). Indeed, the majority of the forum users placed very little emphasis on physical appearance post- mastectomy or –lumpectomy. Instead, participants more frequently discussed concerns related to functionality. Specifically, most patients who posted on the topic relayed concerns about survival over appearance. That is, these forum users shared that they opted for the most invasive surgery option in order to be most assured that the cancer is removed. This treatment decision was made by a number of women, regardless of how the surgery affected the appearance of their breasts. Furthermore, many women wrote that they valued sensation over appearance and as such, declined reconstructive surgery, which they believed further reduced sensation in breasts. Taken together, these findings support researchers who found that SMW focus more on the functional aspects of the body (e.g., body strength; Boehmer, Linde, & Freund, 2007).

The focus on the functional aspects of the body are not consistently found in the extant literature on lesbian body image, however. Indeed, there are two competing theoretical positions offered by prominent feminist theorists. Both Dworkin (1988) and Brown (1987) have attempted to address lesbian body image in comparison to that of HW. Dworkin (1988) asserted that lesbian women do not differ from HW in their experiences of body image because heterosexual and lesbian women live in the same patriarchal culture that expects women to abide by the female beauty standards put forth by heterosexual men. In contrast, Brown (1987) argued that lesbians might be more accepting of their bodies than HW presuming they are able to effectively decrease their levels of internalized heterosexism as their sexual identities develop. If lesbians are successful reducing internalized heterosexism, Brown thought that they are better able to reject US culture's rules about what your body should and should not look like. The findings of the present study best support Dworkin's (1988) perspective; however, a recent meta-analysis revealed that feminist identity is a key moderator in the relationship between lesbian sexual orientation and positive body attitudes (Murnen & Smolak, 2009). That is to say, the association between feminist identity and positive body attitudes was the strongest for older women. The lesbian BC patients in this study are presumably beyond mid-life, as BC diagnoses are typically made post-menopause (McPherson, Steel, & Dixon, 2000). Therefore, it is likely that the sample largely represents older lesbian-feminists whose generation was marked by lesbian separatism and a stark rejection of normative beauty standards. This assumption is supported by the numerous discussions that suggested that many of the participants held a strong feminist orientation (e.g., discussions about the Michigan Womyn's Music Festival and women's rights).

Objectification theory offers a framework for understanding why many of the women chose to define themselves as more than their bodies, in addition to the finding that some women

viewed a breastless chest as protective. The former was often discussed as being consistent with their feminist ideals. Indeed, previous researchers have reported SMW's hesitation with breast reconstruction for fear that reconstruction might suggest an endorsement of women's objectification (Rubin & Tanenbaum, 2011). The finding that some women believed that being breastless is protective may also be a function of the women's consciousness of heterosexual male objectification of women. If the patients no longer have breasts that would be viewed by heterosexual men as sexual objects, they will likely avoid unwanted sexual attention. This was, in fact, the stated goal of many women who chose to go breastless. A few women, however, viewed a breastless chest as an advantage in dating. Specifically, they commented that not having breasts will allow them to sift through romantic partners in order to avoid those who are fixated on physical attractiveness as a primary criterion when looking for a partner. This implies that some women felt objectified by both heterosexual men and SMW and used the physical results of BC treatment as an opportunity to shield themselves from situations that may cause psychological harm.

Finally, the Michigan Womyn's Music Festival (MWMF), also known as 'the land,' is an exemplary source of lesbian social norms because the festival is predominantly run and made up of lesbian-feminists. Specifically, the MWMF is an annual outdoor music festival that was established in 1976 to promote lesbian-feminist community and music (Goldin-Perschbacher, 2013). The festival is argued to be one of U.S. lesbian culture's most important institutions, largely representing 1970s lesbian feminism (i.e., a separatist movement that viewed lesbianism as a critical component of feminist strategy; Cvetkovich & Wahng, 2001). The participants described their experiences at this festival as liberating and often referred to the many topless "womyn" who populated this event, including womyn who wore their mastectomy scars with

pride and without shame. Another aspect of the discussions about the MWMF was that the experience was viewed as normalizing. That is, the patients described the various types of breasts (e.g., flat, lopsided, etc.) seen at the festival and used this experience to normalize their own breasts, especially post-surgery. Given the prominence of discussion board participants who referred to the MWMF as a source of empowerment, it follows that many of the women were surrounded by a social context that was supportive of the refusal of breast reconstruction. However, the feminist values that many of the participants held extended beyond the context of this one event. Feminism was clearly a part of the broader lesbian culture the forum users live in, at least for the presumably older lesbian BC patients who posted to the lesbian-specific discussion boards. Therefore, feminism appears to be an important contextual factor to consider in the interpretation of our findings.

Gender Expression as a Moderator of Experience

The importance of gender expression as a moderating factor in the experiences of lesbian BC patients is a novel finding. Gender expression among lesbians is typically dichotomized into two polar identities, femme (i.e., greater feminine gender presentation; Walker, Golub, Bimbi, & Parsons, 2012) or butch (i.e., greater masculine gender presentation; Walker, et al., 2012). There has been limited research to date that examines gender expression as a moderator of psychological or health outcomes for SMW. However, researchers have found that butch SMW reported drinking alcohol, using marijuana, and smoking cigarettes more frequently than femme women (Rosario, Schrimshaw, & Hunter, 2009). The tobacco and marijuana disparities are thought to be mediated by gay-related stressful events, internalized homophobia, and emotional distress (Rosario, et al., 2009). Indeed, butch SMW reported experiencing more discrimination in comparison to femme SMW in general (Levitt & Horne, 2002) and in the healthcare context

(Hiestand, Horne, & Levitt, 2008) and this is likely related to their poorer outcomes, as has been explained by minority stress theory (Lick et al., 2013; Meyer, 2003).

Gender expression appeared to moderate the experiences of and perspectives on breast reconstruction and post-mastectomy body image, in particular, within the context of this lesbian-specific BC discussion forum. Femme patients expressed a desire to undergo breast reconstruction in part because they did not want to be misidentified as a man. Furthermore, femme women also reported frustration with their short hair after chemotherapy because it sometimes led others to question their gender. On the other hand, self-reported butch women did not see any benefits in breast reconstruction and likened it to feeling as if they would be in “drag.” Butch women also welcomed the short hair and flat chest that resulted from the treatment of their BC. They reported that this was more consistent with their desired gender expression and some indicated that they enjoyed being misidentified as a man. Gender expression may be a useful factor/construct in terms of developing a more nuanced understanding of lesbian BC experiences; however, it may be more useful and respectful to examine gender expression among a continuum rather than purely as a butch/femme dichotomy (Rosario, Schrimshaw, Hunter, Levy-Warren, 2009).

Gender expression provides a useful lens through which to examine the nuances of experiences in the context of discussions about breast reconstruction and body image. However, one finding in particular, that the patients felt pressure from surgeons to undergo breast reconstruction, can be understood in light of gender performativity and institutionalized heterosexism. The concept of gender performativity emerged from feminist literature concerning embodiment. Butler (1990) in particular, asserted that as embodied beings, we “do” or “perform” gender, which is then observed by others. Furthermore, she argued that the “doing” of

gender is controlled by the “heterosexual matrix,” which includes a demand that women perform femininity (Butler, 1990). Indeed, the presence of breasts on women’s bodies is thought to be a key aspect of femininity (Tolman, Bowman, & Fahs, 2013). Therefore, many surgeons’ expectations that their patients undergo breast reconstruction can be understood as a regulation put forth by the “heterosexual matrix” as it operates in the medical context. That is, the assumption that all BC patients desire reconstructed breasts could be a function of institutionalized heterosexuality, wherein heterosexual men have used their power to control the norms of BC “treatment” (i.e., the reconstruction of breasts has been institutionalized as a part of treatment).

Study Limitations

To my knowledge, this is the first qualitative, inductive thematic analysis of lesbian BC experiences. Although my study has yielded important information about the experiences of lesbian BC survivors, it is not without limitations. As with all qualitative studies, these findings are not intended to be representative of the broader population of lesbian women with BC and one should be cautious when generalizing the findings of this study. In particular, this study represents a sample of lesbian BC patients who feel a need to seek social support in online discussion boards. However, researchers have found that convenience samples of lesbians with BC are not significantly different from samples derived from cancer registries (Boehmer, Clark, Timm, Glickman, & Sullivan, 2001).

The context in which the data were collected also needs to be taken into consideration. I collected data from a lesbian-specific online support forum; however, I had no way of verifying that the individuals posting to these discussions boards were in fact lesbians with BC. Despite this, I have reasonable confidence that this sample represented lesbian BC patients and their

partners. HW who posted to this forum and who self-identified as such and their posts were subsequently removed from our database. Another drawback of my study is that I have limited knowledge of the demographics of the users because I collected the data from a public forum and did not interact with the users of the forum in order to respect their privacy. However, users often posted demographic data within their posts. These data are currently being collected and will be represented in the publication that follows the defense of this thesis. In addition, because we took care to not interrupt the discussions within the forum, we were not able to ask clarifying questions about what was written in the posts. Therefore, some of the data collected were uninterpretable, but may have been relevant to the experiences of lesbian women with BC. This weakness (i.e., no interaction with the forum users), notwithstanding, is also a strength of the present study. An important benefit of having collected data from an online-forum without having made my presence known is that the data may be more candid given there are no response biases.

Finally, another consideration for the interpretation of my findings is that the discussion boards that I collected data from spanned several years (2007-2013). As such, the data from the earlier years may be less applicable to the present experiences of lesbians with BC. In addition, it could be the case that a few users dominated the conversations in the forum; however, the data that were coded within the identified themes appeared to represent a wide range of users. Therefore, I am confident that the themes that emerged in this study represented many of the users who utilized the lesbian-specific forum. The exact number of users within the data that were coded will be reported in the publication that follows this thesis.

Implications/Future Research Directions

My analysis allowed for the emergence of important themes related to lesbian BC experiences. It is evident by the sheer number of posts posted to the lesbian-specific online support forum that many patients found it important to proffer and receive support from others lesbians with BC. As such, researchers should examine whether forums (or other online venues) are viable means of exchanging quality social support. Examining the viability of online support forums is of particular importance if peer support is desired by lesbian patients. Face-to-face peer support is likely not practical given the small number of BC patients who are lesbian. Online peer support would also benefit those patients who are in more rural areas as they have even less access to other lesbians with BC. Furthermore, given the themes represented in this study, there is a clear need to develop social support programs that target this group's unique needs (e.g., coping with heterosexism, managing sexual-identity disclosure). In addition, given the finding that a breast cancer diagnosis caused significant concern regarding the management of one's sexual identity, support service individuals (e.g., social workers, patient navigators) should provide assistance to those women who wish to disclose their sexual-identity to health care providers in order to be properly recognized as lesbian patients.

The emergence of experiences with heterosexism in the medical context was not an unsurprising finding; however, it is a reminder that healthcare providers need to be aware of their heterosexist biases. In addition, healthcare providers should create a safe space by making it known that they are accepting of women regardless of sexual orientation. Because patients were concerned about sexual-identity disclosure, providers should give sufficient opportunity to disclose their sexual orientation. One rudimentary way to start is by ensuring that BC patients are provided with an opportunity to disclose their sexuality on paper, such as on intake forms.

However, the burden of disclosure should not be on the patient. Once a safe space is established, providers should routinely ask all patients if they wish to disclose their sexual identity. This would help eliminate an undue stressor during a time of crisis and likely lead to improved health outcomes. For example, a patient who is “out” with their medical team is more likely to involve her partner in medical appointments which would allow the partner to provide superior social support in comparison to a patient whose partner is not present at appointments due to fear of prejudice. Indeed, social support is a well-known contributing factor to physical health and well-being (see review by Cohen, 1988). At a broader level, health care administrators and staff should be mindful of various other microaggressions that may be present in their offices or standard procedures. One microaggression that could be eliminated with minimal effort is health history forms that assume heterosexuality (e.g., sexual history only including opposite-sex behaviors). The communication of standard treatment procedures for BC should also be reviewed for heterosexist biases, such as implying that breast reconstruction is a part of a normal course of treatment. In order to decrease pressure to undergo breast reconstruction, surgeons might also consider displaying photos of different breasts in their consultation rooms to demonstrate that there is a range of normal breasts. Finally, there was a strong perception that one’s partner would not have appropriate access and treatment decision-making rights in the health care context. Health care providers should be clear about their visitation policies to allay such concerns.

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