

“Guys Don’t Have Breasts”: The Lived Experience of Men Who Have BRCA Gene Mutations and Are at Risk for Male Breast Cancer

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Abstract

Men with BRCA1 or BRCA2 gene mutations are at increased risk of developing breast cancer and may have an indication for breast cancer screening using mammography. Since breast cancer is often viewed as a woman’s disease, visibilizing and understanding men’s experience of having a BRCA mutation and specifically, of screening for breast cancer through mammography, were the objectives of this research study.

The theoretical framework of interpretive phenomenology guided the process of data collection, coding, and analysis. Phenomenology is both a philosophy and research method which focuses on understanding the nature of experience from the perspectives of people experiencing a phenomenon, the essence of and commonalities among people’s experiences, and the ways in which people experience the world through their bodies. Data were collected via in-depth interviews with a purposive sample of 15 male participants recruited from the Male Oncology Research and Education (MORE) Program.

This article reports findings about participants’ use of gender-specific language to describe their breasts, awareness of the ways in which their bodies changed overtime, and experiences of undergoing mammograms.

This study is the first to describe men with BRCA’s perceptions of their breasts and experiences of mammography in a high-risk cancer screening clinic. This study sheds light on an under-researched area—breasts and masculinities—and could potentially lead to improved clinical understanding of men’s embodied experiences of BRCA, as well as suggestions for improving the delivery of male breast cancer screening services.

Keywords

men’s health, gender, mammography, BRCA, breast cancer risk

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Breasts and mammograms: These terms are invariably associated with women. Biologically however, everyone has breasts and if there is a clinical indication to image breasts, whether a man’s or a woman’s, then it is often done via a mammogram. A notable case study in 2012 reported a contralateral breast cancer in a man with a BRCA2 gene mutation identified while undergoing annual screening mammography (Freedman, Keto, & Rosenbaum Smith, 2012). The lifetime risk for male breast cancer in BRCA2 carriers ranges from 2.8% to 6.9% by ages 70 to 80 respectively (Tai, Domchek, Parmigiani, & Chen, 2007; Thompson & Easton, 2001). Although less established in the literature, the lifetime risk for male breast

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cancer in BRCA1 carriers appears to be higher than in the general population as it ranges from 1.2% to 5.8% by ages 70 to over 80, respectively (Tai et al., 2007; Thompson & Easton 2002). Management of breast cancer risk in male BRCA mutation carriers, however, remains controversial. Clinical guidelines that used to recommend mammogram have since retracted this recommendation due to insufficient evidence of its clinical utility in the literature. Despite this, some oncologists and family doctors continue to offer mammography to men with the BRCA mutations either to generate data in the literature or because there is not enough evidence to dissuade from its use (Lorentz, Liu, & Vesprini, 2018; Shiloh, Dagan, Friedman, Blank, & Friedman, 2013).

In spite of the use of mammography in men, there is a dearth of empirical literature on men's experiences of breast cancer screening. This clinical and empirical vagueness results in a sense of uncertainty which manifests in the doctor's office; if these men are counseled to undergo mammograms, what is their experience of this process? How does being at risk for a feminized and relatively unheard of cancer in men impact men's self-perception?

These were some of the questions that prompted a study of men who were enrolled into the Male Oncology Research and Education (MORE) Program at Sunnybrook Health Sciences Centre in Toronto, Canada. The MORE Program is an academic program which collects clinical information on men at increased risk for male-specific cancers such as prostate and male breast cancer (Lorentz et al., 2018). Through qualitative interviews, this study explored if and how men felt their bodies and identities were impacted by living with a BRCA gene mutation. This article reports findings relating to (a) the gender-specific language participants used to describe their breasts; (b) the ways in which participants' awareness of their bodies changed overtime; and (c) the participants' experiences of undergoing mammography. These findings are important as they highlight how men deal with surveillance of a part of the body most often associated with being female, their feelings about carrying a risk factor for breast cancer, their self-perceptions of their masculinities, and the language they use to describe their bodies. Understanding how men feel can help improve health-care providers' understanding of men's experiences of their embodied identities, as well as potentially lead to an evaluation of the ways in which mammogram are delivered to this population.

Background

There is a slowly growing body of qualitative literature on men with BRCA gene mutations. This literature contains explorations about men's fears of developing

cancer, experiences of seeking genetic testing, feelings after learning they have a BRCA gene mutation, and the process of disclosing positive genetic test results to family members (d'Agincourt-Canning, 2001; Hallowell et al., 2006; Hallowell et al., 2005a; Hallowell et al., 2005b; Strømsvik, Råheim, Oyen, & Gjengedal, 2009). Although these studies report that men worry about their daughters' risks for developing breast and ovarian cancer, they do not address how or if men's feelings about their breasts and their bodies changed after learning they had a BRCA gene mutation. To the authors' knowledge, there are no studies that explore men's feelings about their embodied identities after learning they carried a BRCA gene mutation and starting their own cancer screening.

Regarding research on the topic of men with BRCA gene mutations and mammography, the literature is scant. There is currently one case study on a male patient (BRCA2 gene mutation) who was diagnosed with a breast cancer that was identified on screening mammography (Freedman et al., 2012). This patient opted for a mastectomy to reduce future breast cancer risk, but the article does not explore the patient's feelings on either having mammograms or having a mastectomy. Articles on men with breast cancer without the context of a genetic predisposition are more plentiful. One article reported findings on the lived experience of men with breast cancer (Donovan & Flynn, 2007); one article reported men's experiences of attending a breast self-assessment clinic (Kipling, Ralph, & Callanan, 2014); and, another article was an opinion piece educating providers about the diagnosis of male breast cancer (Al-Haddad, 2010).

Within all these articles, a key theme is the gendered construction of breast cancer as a women's disease (Al-Naggar & Al-Naggar, 2012; McAllister, Evans, Ormiston, & Daly, 1998; Quincey, Williamson, & Winstanley, 2016; Thomas, 2010). This construction reinforces taken-for-granted assumptions that only women are diagnosed with breast cancer, and hence mammograms are for women only. For example, one qualitative study, which interviewed men who had a family history of breast cancer, reported that the majority of participants were unaware they could get breast cancer and hardly any participants raised the issue of mammography (Thomas, 2010). Similarly, in a qualitative study about men's experiences of having sisters with breast cancer, many participants expressed fear of developing some form of cancer, but only two participants were concerned about developing breast cancer (McAllister et al., 1998).

The gendering of breast cancer as a woman's condition is often connected to the theme of exclusion from family discussions about breast cancer, hegemonic masculine identities, and cancer resources (Donovan & Flynn, 2007; McAllister et al., 1998; Thomas, 2010). For example, men who had female relatives with breast

cancer, were often excluded from family discussions about the disease because breast cancer was described as a “girl’s problem” (McAllister et al., 1998). In addition to communication patterns, men feared that breast cancer would lead to their exclusion from hegemonic notions of masculinities; in other words, men who did not have cancer were concerned that being diagnosed with male breast cancer could negatively impact their sense of masculinity (Thomas, 2010). As well, men who required mastectomies felt emasculated by their changing body images (Donovan & Flynn, 2007).

Men with a history of breast cancer reported concealing their diagnosis to prevent the stigma of public disclosure. Conversely, other men conceptualized “coming out” with male breast cancer as an opportunity to resist social norms and redefine their masculinities (Donovan & Flynn, 2007). Reconceptualizing one’s identity was also considered an adaptive coping strategy (Kipling et al., 2014).

The theme of exclusion is also highlighted in men’s discussion of the lack of health-care resources available for men with breast cancer. The rarity of male breast cancer means that most educational information is geared toward women. Men with breast cancer expressed concern that they did not have access to relatable resources, such as photographs of male patients post-mastectomy, which could potentially help to normalize their experiences and support them in their healing process (Donovan & Flynn, 2007).

Since men’s feelings about their bodies had not yet been explored in the literature, the primary research question was: How do men, who learn they have a BRCA gene mutation and an increased risk for breast cancer, feel about their bodies and identities? This question was explored using qualitative interviewing and interpretive phenomenology.

Research Methods

Ethics

This study was conducted in partnership by researchers at the University of Toronto and Sunnybrook Health Sciences Centre. Ethics approval was obtained from both institutions (University of Toronto REB #31695; Sunnybrook REB #136-2015).

Theoretical Framework

The theoretical framework of interpretive phenomenology guided the process of data collection, coding and analysis (Wojnar & Swanson, 2007). Phenomenology is both a philosophy and research method, which focuses on understanding three aspects of embodiment: (a) the nature

of experience from the perspectives of people experiencing a phenomenon; (b) the essence of and commonalities among people’s experiences; and (c) the ways in which people experience the world through their bodies. Data were collected via in-depth interviews with a purposive sample of 15 male participants. The study’s sample size was based on the recommendations in the literature that phenomenology studies should have small and purposeful samples in order to gather rich and in-depth data (Armour, Rivaux, & Bell, 2009).

Data Collection Procedures

Recruitment. Eligibility criteria included male patients in the MORE Program who were over the age of 40, had a pathogenic BRCA1 or BRCA2 gene mutation, did not have a current cancer diagnosis, and had received one or more mammograms. While men in the MORE Program are atypical of the general population in the sense that they know their genetic risk, the study was specifically focused on the impact of the heightened risk of breast cancer and those individuals usually do know their genetic risk. At the time of data collection, fewer than 10% of the 120 patients in the MORE Program had received mammograms, and thus the list of potential participants was quickly exhausted. Because qualitative research is an iterative process, the inclusion criteria were broadened to include men who had not received mammograms, as well as men who had a past or current cancer diagnosis. The rationale was that men, who had not received mammograms, could speak about how the BRCA mutation affected their perceptions of their breasts and men with a history of cancer could discuss how the knowledge of having a BRCA gene mutation affected their identities before their cancer diagnosis.

Using a convenience sampling method, the recruitment coordinator at Sunnybrook Health Sciences Centre (J.L.) contacted clinic participants via telephone and invited them to participate in the study. If clinic participants expressed an interest in the study, they completed a screening tool and provided demographic information. In order to increase rapport, participants selected the date and time of the interview and were given the option of meeting in a confidential room at either Sunnybrook Health Sciences Centre or the University of Toronto.

All interviews were conducted by the first author (M.S.). Before the interviews, all participants provided written informed consent, as well as self-selected pseudonyms to protect confidentiality. Participants responded to a semi-structured interview guide of questions and prompts developed to explore participants’ journeys around learning they had a BRCA gene mutation, their perceptions of cancer risk, feelings about their prostates and breasts, experiences of mammography (if they had

it), and thoughts about female relatives' experiences with a BRCA mutation. Interviews lasted between 45 and 90 minutes and were digitally recorded. At the end of the interview, participants received an honorarium of a \$20 coffee shop gift card and a parking pass. After each interview, M.S. wrote field notes about observations, reflections, and emergent themes from the interviews, and these notes were analyzed alongside the transcripts.

Data Analysis

Digital recordings of all 15 interviews were transcribed by three research team members. After transcription, all identifying information was removed; transcripts were reviewed for accuracy and then uploaded into the qualitative software program, NVivo 10 (QSR International), for data analysis.

To ensure interrater reliability, the coding process began with all team members coding the same transcript, focusing on whether each person identified similar or different themes. This process of constant comparison was repeated with the next few transcripts until consensus was reached and a code list was established. Transcripts were then assigned for individual coding. Coding was reviewed in weekly team meetings. With time, patterns pertaining to men's lived experience emerged in the initial codes, which were then grouped into higher order codes. Through this iterative process of constant comparison, the code list was repeatedly revised and refined as new themes emerged and the team members' thinking evolved. The final code list included 13 codes and 65 sub-codes about lived experience. As previously described, interpretive phenomenology guided the research process and a thick description of participants' embodied experiences of having a BRCA gene mutation was the focus of analysis.

Findings

Participant Demographics

Participants' ages ranged from 40 to 76 with a mean age of 55. All 15 participants identified as Caucasian and had children. Thirteen participants were married and two were divorced. Most participants were Jewish or Catholic. Most participants worked in the fields of business, teaching, and medicine and four participants were retired.

Regarding health histories, three participants had a BRCA1 gene mutation and 12 had a BRCA2 gene mutation. All participants had strong familial cancer histories (especially breast and ovarian cancer). Five participants had a personal history of cancer: one had breast cancer, another had childhood leukemia, and three had been previously diagnosed with prostate cancer. Eight out of 15

participants had received at least one screening mammogram and one of those eight had received multiple mammograms due to his personal history of breast cancer.

Key findings that emerged from the interviews were body talk, changing awareness of breasts, and experiences of undergoing mammography.

Body Talk

"Guys don't have breasts." A key finding was that all participants used gender-specific language to talk about their bodies. In other words, participants found ways of describing their bodies that were different than the words that are traditionally used with regard to women. Fourteen out of 15 participants preferred using the word "chest" rather than breasts. Men said that "chests," but not breasts, were part of their physical essence, defining chests as a male body part and breasts as a female body part. For example, participant Sally¹ explained, "I don't think that I can say even now that I consider myself as having breasts." Participant M.A. also associated women with breasts and men with chests. He explained, "You know to me, chest, breast are synonymous... I think of the chest for male and... I feel when somebody says breasts I don't think of a male I think of a female." Another participant Mike elaborated on the differences between breasts and chests by explaining that doctors use the term breasts whereas lay people use the term chest.

In the medical profession, men have breasts. [But] in the world, men don't talk that way; they don't talk about their breasts. They talk about their chest... I just don't think it's something that the medical profession will ever change... there is just a bit of a disconnect between the medical profession and people in terms of how you name things.

Mike also reported that if he had breast cancer he would use the word chest in the context of disclosure to his peer group.

If I talk to my friends, and I haven't because I don't have cancer, but if I did I would I would talk about it as chest cancer. I wouldn't use breast cancer. So that would be the term I would use and in the conversation I would say that it is the same as breast cancer. It's exactly the same thing; it's just it's in my chest.

Mike explained that he rejected the term breasts for several reasons, including heterosexism, peer-pressure, and societal ideals about masculine appearance.

[E]ven when [doctors'] were talking about breast cancer when I was first diagnosed, I was thinking... "am I homophobic?" is that what is triggering this [dislike of the term breasts] and then I was like "no not at all". It's just the

word that we don't use. So that was it, but I was kind of shocked by my reaction to it... I spent a lot of time thinking about why does breast cancer bother me? It's the word. Yeah, guys don't have breasts.... when young boys or guys do have breasts they are kind of made fun of a little bit... When they are young men growing up, when they are not strong... Often times, if there is fat on their chest and it's not a good thing—"oh he's got boobs"—something like that. It's a negative connotation for a lot of men.

Only one study participant preferred the term breasts over chests. Ed believed that everybody—men and women—had breasts. He viewed the term “breasts,” and by extension the concept of a “breast cancer gene,” as objective realities rather than gendered constructs.

And the name itself [the breast cancer gene] lends itself away from the man. The *breast cancer gene* so when, if I mention it to somebody [and they say], “well you don't have breasts.” Well, first of all, I do have breasts; so does everybody. But then when you further explain to them, “well, it's not, it is a misnomer—breast cancer. It's a gene that restricts the ability of the body to fight cancer.”

Ed reported that he had cancer as a child and emphasized that he was an open person. Perhaps these two variables enabled Ed to comfortably talk about his body and use the term breasts.

Changing Awareness of Breasts

Many participants described that their awareness of their breasts changed over time and was tied to their life circumstances. Some participants' changing awareness occurred before learning their BRCA status due to aging or cancer risk while others developed awareness after learning BRCA status, experiencing cancer survivorship or other health conditions.

Awareness before diagnosis. Participants, who reported thinking about their breasts before undergoing BRCA testing, discussed their breasts in the context of desire for physical change. For example, M.A. reported that he observed changes in his muscle tone due to the aging process and physical inactivity.

I was getting a little soft in the area... I joke with my son and say “they're my moobs”—my man boobs—right... because the pectoral muscles, if you don't stay on it and keep them firm, they start to look a little more like breasts... I don't really think about [chest] too much other than that fact I probably should do some toning (laughs).

While M.A. associated “soft” breasts with aging, participant Alan linked having excess breast tissue with increased risk of breast cancer risk, a disease experienced by a family friend.

...because I am large so I did think about them [breasts]. I didn't think a lot about “did I have breast cancer?” or “could I get breast cancer?” but I did think about it a little bit. There was the brother of a reasonably close friend of mine when I was growing up who actually had breast cancer when he was young... So it wasn't an unknown thing to me; it was something that I was aware of and a little bit concerned about and I didn't know if the fact that I had breasts, relatively large ones, would put me more at risk or not.

Alan highlighted the connection between having “relatively large” breasts and cancer risk; there appears to be fear about what is growing/lurking in extra tissue. Alan reported that once he learned his BRCA status he changed his nutrition and lost weight to reduce his cancer risk, thereby increasing a sense of control over his future health status.

Awareness after BRCA diagnosis. While some participants thought about their breasts before undergoing BRCA testing, others described that this awareness occurred after learning their BRCA status and receiving mammograms for breast cancer screening. For example, T.C., who was having his first mammogram on the day of the research interview, explained that this upcoming procedure prompted him to reflect on how his self-concept was partly defined by his sense of masculinity.

T.C.: I mean the fact that I'm having a mammogram today. I never ever would have imagined that taking place... it's been difficult to kind of integrate that into the self that I've become over the last sixty years that was pretty much a male. Even though I'm surrounded by lots of—I mean I have lots of brothers-in-law as well too, but my siblings are all sisters and then raising a woman as well; I've always felt fairly secure in my masculinity so this has impacted that kind of traditional perspective, or perspective that I developed, that sense of self that I developed.

I: Can you say more about what that means, in terms of the traditional masculinity?

T.C.: Primarily the association of that part of the anatomy being female-oriented and not really... not very much attention on that part of the anatomy in the male body... my breasts haven't been a big part of my identity or my existence or my sense of self. So I'm becoming more aware of them and it's represented a change in terms of how I view myself and what parts of my body are important or the parts of the body that define me, as silly as that sounds.

T.C.'s description highlights that for 60 years his masculine identity has been based on two aspects of selfhood; his social self (being a man “surrounded” by sisters and raising a daughter) and his embodied self (having a “male

body"). The act of having a mammogram prompted T.C. to reflect on the ways in which he historically associated breasts with femininity and reconceptualize the meaning of his masculine identity.

Some participants reported an increased awareness of their breasts not because of BRCA per se but because of the physical changes associated with cancer survivorship. For example, Peter, who had a history of prostate cancer, explained he thought about his breasts due to changes in muscle tone caused by aging as well as the strain of cancer treatment.

I worked out so I had muscle there and which is now not muscle anymore but that's—you see, the other thing you got to realize at the same time all those treatments are going on, you're also aging, your body is falling apart and you'll get to that point [laughs] so which is it that's affecting your body this way, is it the aging process or is it treatment?

In comparison, Maple Leaf was a male breast cancer survivor who underwent a mastectomy. He thought about how surgical removal of his breast would be perceived by his peer group.

I'm a hockey player, so I play three times a week, so I had to stop playing hockey for... six months... I was thinking about the dressing room because you're obviously, you take everything off, right? So I was a *little bit* worried about what it would look like, you know the reaction to my—this—being gone, but to be honest they don't even look, so I kind of sloughed that off. I wasn't too worried about that part of it. I just think it's surgery, and yeah there's something missing, but so what?

Maple Leaf's quote highlights that he was a "little bit worried" about being judged and potentially socially excluded by his peer group due to the absence of breasts and the presence of scars: signifiers of gender difference and of surviving a disease that mostly affects women.

Some participants reported an increased awareness of their breasts because of non-BRCA-related health conditions that required direct medical intervention. For example, participant B. stated: "Well now I think about my chest because I have had heart problems but not from a BRCA perspective or cancer." Throughout the interview, B. reinforced that although he received annual screening for prostate cancer, having BRCA and living with an increased risk for cancer did not impact his daily life. However, living with a heart condition that required immediate and ongoing intervention did impact his self-perception.

Experiences of Undergoing Mammography

Acceptability of mammograms. Eight out of 15 participants had received mammograms. Out of the seven

participants, who had not received mammograms, six were receptive to having this testing if offered. For example, Andrew stated: "Yeah, I would enthusiastically sign up to have them if they made them available because my hope really is that if I get cancer from my BRCA mutation I'll catch it *early*, have it resected or whatever and just like beat it." The one participant who disagreed with the idea of a mammogram argued that a breast self-exam was sufficient and that a mammogram would be a waste of resources. H.M. stated, "I would probably resort to physical examination to see if I have a problem or not, which I could do myself so you know if something was growing there I would notice. I am very aware of my body so I would probably notice." H.M.'s quote highlights a masculinity discourse of self-control.

Many participants who received mammograms recognized that although it was rare for men to receive mammograms, this test was important for prevention. Derek discussed:

I don't know—a lot of men might get all wiggled out about it—but I just went in. Something I gotta do to make sure I am gonna be okay. And I went in and did it, had a few laughs about it when I was in there and it was all good and it all came back negative... I didn't think it was weird. I thought it was different in the beginning because I forget the percentage—three percent of the men ever have breast cancer and very few men have ever had a mammogram so it was very odd. I had asked everybody that I talked to after I was going to go did ever hear a man having a mammogram? No nope, nope, nope, nope, nope. There was the odd person... that had somebody in their family that had a mammogram, a male, so that was it but... that's what it takes to figure out what's going on and that's what I need to do. Doesn't matter whether it's a manly thing to do or not.

Derek's narrative highlights the gender norms associated with mammography and that although receiving a mammogram may not be a "manly thing to do" it was a form of cancer prevention.

The experience of the waiting room. Although most participants supported the idea of having a mammogram, the actual process of undergoing the testing was sometimes experienced as othering and excluding because this procedure is traditionally viewed as specifically for women. Many participants discussed that the waiting room was filled with patients who were women rather than men, and thus there was an awkwardness of sitting in the primarily women-patient waiting room. Participants used words such as "segregating" and "awkward" to describe the waiting room experience. For example, Alan explained, "I remember going to a waiting room, there was one other person, they called me in and the person was looking, I think you know it was... not embarrassing

but an awkward waiting room experience for anyone.” Similarly, Maple Leaf stated:

I find that dealing with the mammograms and the technical staff to kind of tiptoe around you and put you in certain places because they don't expect a male to be there, right, so they got women walking around in their gowns, so they don't want *you* in those areas... they kind of shunt you into an isolated, a more isolated area so you're not seeing the women walking by...

A participant reflected that women patients could be uncomfortable by having men patients in the waiting room. This participant described staff's helpfulness in making people of different genders more comfortable; strategies included bringing men in during less busy times and having minimal exposure to dressing room. As participant Sally explained:

Well, the first mammogram probably was the most uncomfortable because I wasn't familiar with the process, their equipment and I think they made an effort to bring me in off schedule and sort of through a different entrance. It may well be that they thought that it would make me feel more comfortable, and I don't know if it made me feel uncomfortable. I kind of just walked away thinking that I was probably going to make the other people in the waiting area uncomfortable. I mean they don't have a process for separating men and women in that kind of venue because most of the time it's women... So I thought it much as possible that it was to make the women feel comfortable in a situation where they were probably not so comfortable.

Some participants discussed the surprised reactions of women patients in the waiting room. For example, Maple Leaf described the assumption of fellow waiting room patients that men are sitting in the waiting rooms in the roles of partners rather than patients.

When you're in the waiting room and everybody thinks you're there for support or supporting somebody and actually [laugh] you're going in there to get tested... I think I got some funny looks from some of the other patients that are there. They wonder "why is he here?"

In comparison, Sally described:

I wandered into the waiting area, the breast exam area and sat down there with the women and when they came out they asked for Mrs. Smith, Mrs. This, Mr. [participant's last name] and so I stood up and there were a couple of giggles and titters and then we wandered in and they separated the women to one side and I went to the other.

Getting the mammogram. In terms of the actual procedure, some men described the process as uncomfortable.

For example, Sally explained, "The compression of the tissue and that, it's not painful, it's uncomfortable but it's just a medical test—kind of like having an X-ray, except you're in pain and you got to hold your arm up and same kind of thing. It didn't seem, it wasn't off putting."

In comparison, Maple Leaf described, "It's not easy because I don't have a lot to put in that clamp. So they have to push you and prod you pretty good but I understand that, from as I say, the family women I have talked to they don't like it either."

While some participants described the procedure as uncomfortable, others found it painful. For example, Peter explained:

I feel intensely *compassionate* for women going through it because, maybe because my breasts were small, it hurt like—my wife tells me it hurts—but I couldn't believe the pain and how long afterwards I still had—they were still sensitive and sore. In fact, I went to see my doctor about it and he said look you really got some bruising.

Regarding participants who reported experiencing discomfort, there was a general agreement that the experience was not as bad as other forms of discomfort. For example, Derek stated:

... I hurt myself a lot more doing things that didn't have anything to do with preventative health, it was oh well I wiped in my snow wheel or four wheeler or whatever and the pain was a lot greater than it was getting a mammogram so it isn't so bad.

Suggestions for improvements to mammogram services. Several participants, who reported experiencing discomfort during the mammogram, had suggestions for how to reduce this discomfort. For example, Jordan explained that it would have been helpful to have a technician explain the procedure so he could anticipate the discomfort.

I: What was the procedure like?

Jordan: Very uncomfortable, again just because of the anatomy... if somebody could prepare me beforehand to say listen "not necessarily made for you... This is going to be sort of uncomfortable." Managing expectations are always *better* than not... if a technician would have [explained] "here's what's going to happen, here's how the test is done, you know, you're going to feel uncomfortable but you know it's not long" and all of that kind of stuff.

While some men discussed ways to improve current services, others suggested changing the type of technology altogether and replacing mammogram with MRI. Alan stated:

...the MRI experience is a great experience. I mean, it's very uncomfortable because it's, it can be claustrophobic and it's loud and all of these things but it's this total feeling of non-invasiveness. Like they are taking a complete look at whatever it is they are going to look at... that's the kind of test that people are very comfortable with. A test that you feel like, this is really advanced science and it's not a feeling of invasiveness and it's going to see a problem if I have any.... Especially because the, not only is the mammogram uncomfortable but it has a reputation of being uncomfortable so people shy away from it a lot whereas an MRI has this reputation that okay it's something that's hard to get and it's really not painful and yes it can be a little claustrophobic but you know they can give you a drug for that or something and you just go and do it and I think that would be a great direction if that's where the health system ended up finding good results...

Discussion

This study examined male BRCA carriers' experiences of their embodied identities in relation to their breasts and to mammography. The focus was how men experienced their cancer risk and their treatment differently from women. The current report is the first on men's feelings about their bodies in relation to carrying BRCA mutations and one of the first discussions of men receiving a mammography. From the perspective of gender and health, men with BRCA do not simply have a condition but they have a condition that is often gendered female and is related to a higher risk of breast cancer. The majority of participants were healthy and had elected to enter the medical system for the purpose of risk reduction and disease prevention. They were also motivated to be part of the MORE Program to contribute to academic knowledge on genetic risk and men's cancers. In this sense, most participants can be considered "previvors" (Frank, 2012). Frank argues that in this era of biomedicalization "designation as a BRCA mutation carrier is now seen not simply as a risk, but as a diagnosis that requires a corresponding treatment" (2012, p. 183). However, in comparison to women BRCA previvors who may opt for the "actionable treatments" of prophylactic oophorectomies and mastectomies, men previvors only have "passive treatments" of surveillance and watchful waiting to manage cancer risk (Frank, 2012, p. 184). By choosing to undergo surveillance, participants in this study knowingly or unknowingly accepted medicalization. They also deviated from the traditionally gendered patterns of help-seeking behaviors whereby "male members of breast/ovarian cancer families are less likely to participate at every level of the counseling, testing, and communication process" (Shiloh et al., 2013, pp. 417–418).

Themes that emerged from the interviews were: body talk, changing awareness of breasts and experiences of

undergoing mammography. These, in turn, revealed: (a) the gender-specific language participants used to describe their breasts; (b) the ways in which bodily awareness changed overtime; and (c) the participants' gratitude for the opportunity but discomfort with the experience of mammography. Participants had concrete suggestions for improving the delivery of male breast cancer screening services.

Body Talk

We listened to the language that men used to talk about their bodies and found that most participants believed that "guys don't have breasts." Instead, participants preferred the term chests, as this was the accepted term used in their daily lives by their families and peer groups. These narratives highlight the ways in which bodies are languaged with social meanings. These meanings can be hidden or gender neutralized within the realm of biomedicine, which posits that, anatomically speaking, all men and women have breasts. In our "gendered world," however, breasts represent femininity, sexuality, and motherhood (Donovan & Flynn, 2007). Following this thinking, breasts are more than physical anatomy, but also comprise the gendered tissue of sociocultural values and beliefs. Given these sociocultural associations, it is not surprising that most study participants rejected the term breasts and instead chose to define this body part with the more masculine-sounding term "chest." The preference of the term "chest" over "breasts" function as a gender binary by creating comparisons between men's and women's bodies; these comparisons also imply that if men have breasts, then they are at risk of being emasculated. This is in concert with O'Neil's (1981) conceptualization that to be seen as masculine men will often define themselves in opposition to women. Interestingly, the one participant who reported that everybody has breasts used the discourse of science to de-gender and hence legitimize the use of the term breasts.

The cornerstones of hegemonic masculinities—anti-femininity, homophobia, and aging (O'Neil, 1981)—are evident in the research findings. For example, participant Mike questioned whether he was homophobic when reflecting upon his preference for the term chest rather than breasts. He explained that his word choice was based on socialization and childhood peer pressure, whereby boys' and adolescents' stereotype their peers who are overweight and "have fat on their chests" as effeminate. Aging is added as a negative touchstone to hegemonic masculinity when participant M.A. associated "soft" breasts with aging and discussed the importance of exercise to offset the aging process.

The term chest masculinizes not only the male body, but also the condition of carrying a genetic risk factor for

breast cancer. It creates distance from the concept of breast cancer—if men don't have breasts, then they are also less likely to be diagnosed with breast cancer. This distancing makes sense given the stigma of male breast cancer; this stigma is based on the public misperception and mislabeling of breast cancer as a women's disease, the low incidence rate of breast cancer in men, and the lack of public awareness that men get breast cancer (Al-Naggar & Al-Naggar, 2012; Donovan & Flynn, 2007; McAllister et al., 1998; Shiloh et al., 2013; Thomas, 2010). In this light, perhaps the use of the term chest is an unintentional method of gaining control over and coping with the reality of having a gendered gene and gendered form of cancer. This is in line with literature reporting that men, who have familial histories of breast cancer, use avoidance strategies to cope with genetic information and the implications of the disease (McAllister et al., 1998). The theme of control also emerged in a qualitative study about male BRCA carriers' reactions after learning their genetic status; the authors discuss that men's gender identity is often tied to feelings of "control and invulnerability," and thus "and being identified as a mutation carrier may conflict with this identity. Being a male identified with a mutation associated with female cancer may further increase this identity conflict" (Stromsvik, Raheim, Oyen, Engebretsen, & Gjengedal, 2010, p. 367).

These identity issues can be taken into account by health-care providers working with men. For example, one strategy for building rapport and increasing men's comfort in accessing health-care services could be mirroring men's wording by using the term chests. This strategy fits with research on the use of metaphor as a counseling technique to explore men's feelings and emotions (Genuchi, Hopper, & Morrison, 2017). Shared words provide an entry point for asking questions to better understand the meaning behind the language.

Changing Awareness of Breasts

In spite of men's distancing themselves from the concept of breasts, men did report thinking about the significance of their chests/breasts and it was primarily with respect to changes in life contexts. Before learning they were BRCA carriers, some participants reported that they never thought about their breasts while others had given thought to their breasts because of dissatisfaction with their appearance, bodily changes due to aging process, and knowing others with breast cancer. Other participants described increased awareness of their breasts because of bodily changes due to other medical conditions or previous cancer diagnosis.

This finding is significant because the existing qualitative literature on men with BRCA discusses men's temporal narratives of the process of seeking genetic testing

and their emotional reactions to learning they carry the BRCA gene (d'Agincourt-Canning, 2001; Hallowell et al., 2006; Hallowell et al., 2005a; Hallowell et al., 2005b). However, this literature does not explore how men's experience and perceptions of their bodies change over time and through the process of living with the knowledge they are BRCA carriers. Health-care practitioners may view body parts as static and fixed in time especially in the present moment of the clinical encounter but just as symptoms and diseases evolve so does awareness of the body. This finding has relevance for health-care practitioners working with men because often time clinical encounter may focus on the presence and/or prevention of symptoms, and how symptoms change over time. However, it is also important for practitioners to build rapport by understanding the whole person within their evolving social and psychological contexts and this includes learning from men about how they view not only their embodied identities but also the ways in which their experience of their identities change over time. The literature on gender and accessing health-care services reveals that men often seek help later than women (Daly, 2009). If men think about their bodies prior to seeking health-care resources, then perhaps practitioners can harness this knowledge to develop strategies to support men in accessing resources sooner than later.

Experiences of Undergoing Mammography

In addition to men's shifting experiences of their bodies, participants' reported their experiences of undergoing mammography from the moment they walked into the waiting room to the getting the actual procedure. This is the first study that focuses on men's experiences of mammography. Although there are several medical reports on the efficacy of mammograms in men (Hines, Tan, Yasrebi, DePeri, & Perez, 2007; Muñoz Carrasco, Álvarez Benito, & Rivin del Campo, 2013; Patterson, Helvie, Aziz, & Nees, 2007; Tukul & Ozcan, 1996), there is a lack of literature on men's (general populations and BRCA-carriers) experiences of mammography.

Due to the dearth of literature on men and mammograms, the authors turned to the literature on women's experiences of mammograms (Brett, Bankhead, Henderson, Watson, & Austoker, 2005; Engelman, Cizik, & Ellerbeck, 2006; Fine, Rimer, & Watts, 1993; Hamilton & Barlow, 2003; Morris, 2014; Nekhlyudov, Ross-Degnan, & Fletcher, 2003; Watson et al., 2005). There are parallels between this body of literature and the findings of the current study related to the waiting room experience and anticipation of the procedure.

First, the current study identified that men experienced the waiting room to be awkward and excluding due to the lack of other male patients given the infrequency of male

mammograms. In a study on women's satisfaction with mammography facilities, participants reported that comfortable waiting room could help to put them at ease and suggested ways to improve the atmosphere such as creating a spa-like atmosphere (Engelman et al., 2006). With regards to men's experiences, participants reported that staff tried to increase their comfort by scheduling them at less busy times and minimizing exposure to women's dressing room areas. Based on these findings, additional strategies could be adopted to increase patients' comfort, including displaying in the waiting rooms posters and brochures about male mammography to both normalize and increase awareness of the fact that people of all sexes and genders get mammograms.

Second, the current study reports that many men experienced discomfort and pain during mammography, also noted in the women's literature (Engelman et al., 2006; Hamilton & Barlow, 2003; Morris, 2014). In order to reduce the experience of pain and discomfort, a number of study participants suggested replacing mammograms with MRIs. Others recommended that technicians could improve the ways in which they prepared patients for what to expect in terms of the potential pain and discomfort of the procedure, a finding also echoed in the women's literature. One study (Brett et al., 2005) has argued that women should have the mammography procedure explained before they have their mammogram and that they should be told that they might normally experience some discomfort. Another study (Hamilton & Barlow, 2003) has reported that the quality of the mammography service depended on the behavior, professionalism, and interpersonal skills of the technicians all of which helped decrease women's anxiety about the procedure. Also noted is that women appreciated when technologists made them comfortable by engaging in small talk and showing a caring attitude toward them (Engelman et al., 2006). Interestingly, women patients were less concerned with verbal communication but more with technician's body language and sensitivity about level of breast compression (Morris, 2014). Taken together, findings about women and the current study's findings about men suggest that although MRI may not be a viable economic alternative to mammograms, it would be worthwhile for mammogram facilities to explore the process of how mammography procedures are explained to patients of all genders and the professionalism of their staff.

Consequences for clinical practice. In summary, the study's findings have the following consequences for clinical practice. First, health-care practitioners should mirror men's words in order to promote rapport and explore the meaning and feelings behind these words. Second, therapeutic rapport can also be fostered by taking a wholistic approach to understanding the evolving social

and psychological contexts of men's experiences and embodied identities. Third, mammographic clinics should display educational information geared toward all genders to increase men's comfort and sense of inclusion. Fourth, technicians should thoroughly explain the process of mammography to help men anticipate what to expect during the procedure.

Implications and Conclusions

The current study begins to address a gap in the literature on men with BRCA by contributing in-depth understanding about men's language choices for describing their bodies, changing awareness of their breasts/chests and their experiences of mammography. Participants provided concrete strategies for improving mammography services, and these suggestions have the potential for application in clinical settings both in terms of building therapeutic rapport with male patients and addressing how mammography procedures are explained to patients.

Qualitative research strives for in-depth understanding of a phenomena rather than generalizability to larger populations. That being said, there are two limitations regarding the generalizability of what is learned from the sample. First, men who carry BRCA gene mutations are a subset within the small population of men who either have or are at risk of breast cancer. This population of genetically vulnerable men does not discount the importance of the sample or the study. However, the study is restricted to the men known to have the cancer-risk gene mutation, focusing on a specific population to understand breasts and masculinities. Future studies could compare the experiences of different groups of men who deal with breasts and masculinities such as: men who have the BRCA gene mutation and a known risk, men who have had breast cancer and are not able to assign etiology to genetics, and men who live with gynecomastia.

Second, the sample was also a small group of homogenous, Caucasian, heterosexual, cis-males from one tertiary care center; only eight of whom had received mammography. Despite this small sample size, in-depth knowledge about a specific group of men has been obtained. To further the findings, future studies should consider employing mixed or quantitative methods to broaden the type of participant and sample size. A quantitative study with a larger sample may be helpful in understanding the larger variation in men experiences of their breasts/chests and mammography. A framework of intersectionality would also be useful in understanding how differences in ages, socioeconomic status, education level, and social supports could impact men's perceptions of their bodies, as well as their experiences of mammography (Hesse-Biber & An, 2015).

This study identified that men, who carry BRCA mutations and have sought health care in the form surveillance to monitor their cancer risk, incorporated what is seen as more feminized condition into a masculine identity. Understanding the ways in which men reconcile living with a gendered condition has intrinsic value for health-care practitioners who work with men with BRCA, as well as for those providing services to men with other gendered conditions. This understanding could potentially lead to the development and implementation of programs that increase men's attendance in health-care programs.

Note

1. All participants self-selected pseudonyms; some played with gender by selecting names traditionally associated with women while others selected initials or nicknames.

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References

- Al-Haddad, M. (2010). Breast cancer in men: The importance of teaching and raising awareness. *Clinical Journal of Oncology Nursing, 14*(1), 31–32. doi:10.1188/10.CJON.31-32
- Al-Naggar, R. A., & Al-Naggar, D. H. (2012). Perceptions and opinions about male breast cancer and male breast self-examination: A qualitative study. *Asian Pacific Journal of Cancer Prevention, 13*(1), 243–246. Retrieved from <http://dx.doi.org/10.7314/APJCP.2012.13.1.243>
- Armour, M., Rivaux, S., & Bell, H. (2009). Using context to build rigor. *Qualitative Social Work, 8*(1), 101–122. doi:10.1177/1473325008100424
- Brett, J., Bankhead, C., Henderson, B., Watson, E., & Austoker, J. (2005). The psychological impact of mammographic screening: A systematic review. *Psycho-Oncology, 14*(11), 917–938. doi:10.1002/pon.904
- d'Agincourt-Canning, L. (2001). Experiences of genetic risk: Disclosure and the gendering of responsibility. *Bioethics, 15*(3), 231–247. doi:10.1111/1467-8519.00234
- Daly, M. (2009). The impact of social roles on the experience of men in BRCA1/2 families: Implications for counseling. *Journal of Genetic Counseling, 18*(1), 42–48. doi:10.1007/s10897-008-9183-y
- Donovan, T., & Flynn, M. (2007). What makes a man a man? The lived experience of male breast cancer. *Cancer Nursing, 30*(6), 464–470. Retrieved from <https://doi.org/10.1097/01.NCC.0000300173.18584.37>
- Engelman, K. K., Cizik, A. M., & Ellerbeck, E. F. (2006). Women's satisfaction with their mammography experience: Results of a qualitative study. *Women & Health, 42*(4), 17–35. doi:10.1300/J013v42n04_02
- Fine, M. K., Rimer, B. K., & Watts, P. (1993). Women's responses to the mammography experience. *Journal of the American Board of Family Medicine, 6*(6), 546–555. doi:10.3122/jabfm.6.6.546
- Frank, E. (2012). "More than boobs and ovaries": BRCA positive young women and the negotiation of medicalization in an online message board. In J. Jacobs Kronenfeld (Ed.), *Issues in health and health care related to race/ethnicity, immigration, SES and gender* (pp. 181–199). Bingley: Emerald.
- Freedman, B. C., Keto, J., & Rosenbaum Smith, S. M. (2012). Screening mammography in men with BRCA mutations: Is there a role? *The Breast Journal, 18*(1), 73–75. doi:10.1111/j.1524-4741.2011.01185.x
- Genuchi, M., Hopper, B., & Morrison, C. (2017). Using metaphors to facilitate exploration of emotional content in counseling with college men. *The Journal of Men's Studies, 25*(2), 133–149. doi:10.1177/1060826516661187
- Hallowell, N., Arden-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C., & Watson, M. (2005a). Communication about genetic testing in families of male BRCA1/2 carriers and non-carriers: Patterns, priorities and problems. *Clinical Genetics, 67*, 492–502. doi:10.1111/j.1399-0004.2005.00443.x
- Hallowell, N., Arden-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C., & Watson, M. (2005b). Men's decision-making about predictive BRCA1/2 testing: The role of family. *Journal of Genetic Counseling, 14*(3), 207–217. doi:10.1007/s10897-005-0384-3
- Hallowell, N., Arden-Jones, A., Eeles, R., Foster, C., Lucassen, A., Moynihan, C., & Watson, M. (2006). Guilt, blame and responsibility: Men's understanding of their role in the transmission of BRCA1/2 mutations within their family. *Sociology of Health & Illness, 28*(7), 969–988. doi:10.1111/j.1467-9566.2006.00515.x
- Hamilton, E., & Barlow, J. (2003). Women's views of a breast screening service. *Health Care for Women International, 24*(1), 40–48. doi:10.1080/07399330390170015
- Hesse-Biber, S., & An, C. (2015). Within-gender medical differences in medical decision making among male carriers of the BRCA genetic mutation for hereditary breast cancer. *American Journal of Men's Health, 11*(5), 1444–1459. doi:10.1177/1557988315610806
- Hines, S. L., Tan, W. W., Yasrebi, M., DePeri, E. R., & Perez, E. A. (2007). The role of mammography in male patients with breast symptoms. *Mayo Clinic Proceedings, 82*(3), 297–300. doi:10.4065/82.3.297
- Kipling, M., Ralph, J. E. M., & Callanan, K. (2014). Psychological impact of male breast disorders: Literature review and survey results. *Breast Care, 9*(1), 29–33. Retrieved from <http://doi.org/10.1159/000358751>

- Lorentz, J., Liu, S., & Vesprini, D. (2018). Male Oncology Research and Education (MORE) program for men at high risk for prostate cancer. *Current Oncology, 25*(2), 170-175.
- McAllister, M. F., Evans, D. G., Ormiston, W., & Daly, P. (1998). Men in breast cancer families: A preliminary qualitative study of awareness and experience. *Journal of Medical Genetics, 35*(9), 739-744. Retrieved from <http://dx.doi.org/10.1136/jmg.35.9.739>
- Morris, N. (2015). When health means suffering: Mammograms, pain and compassionate care. *European Journal of Cancer Care, 24*(4), 483-492. doi:10.1111/ecc.12272
- Muñoz Carrasco, R., Álvarez Benito, M., & Rivin del Campo, E. (2013). Value of mammography and breast ultrasound in male patients with nipple discharge. *European Journal of Radiology, 82*(3), 478-484. doi:10.1016/j.ejrad.2012.10.019
- Nekhlyudov, L., Ross-Degnan, D., & Fletcher, S. W. (2003). Beliefs and expectations of women under 50 years old regarding screening mammography. *Journal of General Internal Medicine, 18*(3), 182-189. doi:10.1046/j.1525-1497.2003.20112.x
- O'Neil, J. M. (1981). Patterns of gender role conflict and strain: Sexism and fear of femininity in men's lives. *The Personnel and Guidance Journal, 60*(4), 203-210. doi:10.1002/j.2164-4918.1981.tb00282.x
- Patterson, S. K., Helvie, M. A., Aziz, K., & Nees, A. V. (2007). Outcome of men presenting with clinical breast problems: The role of mammography and ultrasound. *Clinical Imaging, 31*(2), 145-146. doi:10.1016/j.clinimag.2006.12.009
- Quincey, K., Williamson, I., & Winstanley, S. (2016). 'Marginalised malignancies': A qualitative synthesis of men's accounts of living with breast cancer. *Social Science & Medicine, 149*, 17-25. Retrieved from <https://doi.org/10.1016/j.socscimed.2015.11.032>
- Shiloh, S., Dagan, E., Friedman, I., Blank, N., & Friedman, E. (2013). A follow-up study on men tested for BRCA1/BRCA2 mutations: Impacts and coping processes. *Psycho-Oncology, 22*(2), 417-425. doi:10.1002/pon.2106
- Strømsvik, N., Råheim, M., Øyen, N., Engebretsen, L., & Gjengedal, E. (2010). Stigmatization and male identity: Norwegian males' experience after identification as BRCA1/2 mutation carriers. *Journal of Genetic Counseling, 19*(4), 360-370. doi:10.1007/s10897-010-9293-1
- Strømsvik, N., Råheim, M., Øyen, N., & Gjengedal, E. (2009). Men in the women's world of hereditary breast and ovarian cancer—A systematic review. *Familial Cancer, 8*(3), 221-229. doi:10.1007/s10689-009-9232-1
- Tai, Y., Domchek, S., Parmigiani, G., & Chen, S. (2007). Breast cancer risk among male BRCA1 and BRCA2 mutation carriers. *Journal of the National Cancer Institute, 99*(23), 1811-1814. doi:10.1093/jnci/djm203
- Thomas, E. (2010). Original research: Men's awareness and knowledge of male breast cancer. *American Journal of Nursing, 110*(10), 32-37. doi:10.1097/01.NAJ.0000389672.93605.2f
- Thompson, D., & Easton, D. F. (2001). Variation in cancer risks, by mutation position, in BRCA2 mutation carriers. *The American Journal of Human Genetics, 68*(2), 410-419. doi:10.1086/318181
- Thompson, D., & Easton, D. F. (2002). Cancer incidence in BRCA1 mutation carriers. *Journal of the National Cancer Institute, 94*(18), 1358-1365. Retrieved from <https://doi.org/10.1093/jnci/94.18.1358>
- Tukel, S., & Ouzcan, H. (1996). Mammography in men with breast cancer: Review of the mammographic findings in five cases. *Australasian Radiology, 40*(4), 387-390. doi:10.1111/j.1440-1673.1996.tb00432.x
- Watson, E. K., Henderson, B. J., Brett, J., Bankhead, C., & Austoker, J. (2005). The psychological impact of mammographic screening on women with a family history of breast cancer—A systematic review. *Psycho-Oncology, 14*(11), 939-948. doi:10.1002/pon.903
- Wojnar, D., & Swanson, K. (2007). Phenomenology. *Journal of Holistic Nursing, 25*(3), 172-180. doi:10.1177/0898010106295172