Resistance, agency, and liminality in women's accounts of symptom appraisal and help-seeking upon discovery of a breast irregularity

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ABSTRACT

In the breast cancer literature, “delayed presentation” is defined as a period of 3 months or more between the self-detection of a new breast symptom and the decision to seek help for it. Delay studies have overlooked the relevance of dominant medical discourses such as those concerning “proper” health. In this paper we use a critical discursive method to analyze interviews with 14 women about their symptom appraisal process to demonstrate how many inhabited a liminal space comprised of both “knowing and not knowing” about the symptom, and “acting and not acting” on it (interviews took place from January 2006 to April 2007). We describe three discursive themes that arose in the transcripts including “Doing the Right Thing”, “Deliberate Ignorance”, and “Passive Resistance.” These women’s narratives are juxtaposed with two commonly accepted medical discourses in relation to self-detected breast symptoms: That of the woman who was unaware of her symptom, or interpreted it as being insignificant, and therefore, not requiring medical attention; or that of the woman who noticed the symptom, interpreted it as threatening, and immediately sought medical attention. We suggest that such discourses are constricting and fail to account for the sizeable number of women who do not fit this mold (i.e., those who are both aware of the concerning change and delay presentation). We conclude that these constricting medical discourses effectively have a role to play in the contradictory reasoning or perceived irrationality of women’s delay behavior when it occurs.

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Introduction

Delays in seeking care for abnormal breast symptoms are associated with larger tumors and more advanced stages of cancer (Burgess et al., 2006; Hardin, Pommier, & Pommier, 2006; O’Mahoney & Hegarty, 2009). Defined as waiting three months or longer to seek help after detecting a concerning symptom (Facione, Miaskowski, Dodd, & Paul, 2002; Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999), delayed presentation is estimated to occur in 10–34% of women with breast cancer (e.g., Adam, Horner, & Vessey, 1980; Facione et al., 2002; MacArthur & Smith, 1981; O’Mahoney & Hegarty, 2009; Richards et al., 1999; Williams, Tortu, & Thomson, 2010). Patient, healthcare provider, and system related factors have been identified as potential causes for delay (Andersen, Cacioppo, & Roberts, 1995; Arndt et al., 2003; Bish, Ramirez, Burgess, & Hunter, 2005; Caplan & Helzlsouer, 1992/93; Potter, Mauldin, & Hill, 1996). In addition, age, cultural beliefs and attitudes, whether the symptom is a lump, perception of the symptom as serious, and presence of anxiety have been reported as factors influencing symptom appraisal, and possible delay in seeking care (Burgess et al., 2006; Gullutte, Brawley, Kinney, Powe, & Mooney, 2009; Meechan, Collins, & Petrie, 2003; Nosarti et al., 2000; O’Mahoney & Hegarty, 2009).

While these studies are useful and informative with respect to pointing to variables that might impede medical consultation, many of these stop short in terms of delving into the deeper processes — psychosocial and societal — by which such decisions are made. More specifically, the literature to date has not contrasted women’s narratives around delay with the dominant medical discourse to see how, and in what ways, women’s decisions regarding help-seeking may overlap, resist, challenge, or align with medical messages about appropriate help-seeking behavior (see also Barg & Grier, 2008). The present analysis examined how such discourses interact in order to enhance our understanding of this complex, and from the vantage point of the medical establishment, often perplexing, phenomenon.
In an article examining the dominant medical discourse around women and breast cancer, Davis (2008) analyzed 13 publications produced by the National Cancer Institute (NCI) on the topic of breast cancer and its treatments — some of which were revisions of earlier booklets. Davis (2008) noted that these pamphlets tell a specific story about the breast cancer patient that constructs an “idealized patient identity that serves a prescriptive function for women... The narrative articulates an early-cancer experience where the patient is treatable and cancer is cured or controlled” (p.65).

The dominant early-cancer narrative contained in these texts moves through six stages from pre-symptomatic through to symptomatic, diagnosis, treatment, and recovery to post recovery. All the texts emphasize that regular monitoring (through screening and self-examination) is the key to discovering breast cancer early, resulting in the best possible range of options and chances for a full recovery, and cure (Davis, 2008). In relation to these texts, Davis (2008) observed, the ideal female medical subject is,

diligent about engaging in early detection practices in the pre-symptomatic stage of the narrative. According to the texts, she regularly does breast self-examination, has an annual mammogram, and sees her physician for a manual examination. She also stays informed and aware of health issues... When the woman finds an irregularity, something that might be breast cancer, she immediately seeks out her doctor so that he or she can verify the symptoms. (p. 71)

Within the medical model, this type of healthcare behavior is presented as the ideal (Barg & Grier, 2008; Robertson, 2000; Roy, 2008; Willig, 2011; Wong & King, 2008). Within North America, health behavior tends to be situated within a rationalistic model that presumes that if individuals perceive themselves to be at a health risk, they will do everything in their power to seek out help as soon as possible so as to prevent illness, and/or to deal with what they perceive to be a threat to their well-being (Barg & Grier, 2008; Rosenstock, 1991).

For example, the widely used Andersen Model of patient delay reports that there are several stages that lead to a cancer diagnosis (Andersen et al., 1995). The first three stages include the movement from detecting an unexplained symptom, to inferring illness or a potential threat to one’s health, to seeking medical attention. The Andersen model adheres closely to the normative construction for optimal health behavior. That is, while providing a robust, empirically supported theoretical framework for the identification of various types of delay (Walter, Webster, Scott, & Emery, 2012), it nonetheless assumes as the norm or optimum, an unencumbered pathway from symptom detection to medical presentation, with incidents of delay being treated as deviations from that norm. Thus, it implies a preferred, everyday practice by identifying departures from it.

For a number of women, this preferred practice is achievable and straightforward and accurately represents the way they would manage their own healthcare if they found an irregularity. For others, however, this clear-cut trajectory from symptom discovery to medical presentation may be unrealistic, unfeasible, or undesirable even if *they are fully aware of the “right” steps to take* and even if they know rationally that early detection might lead to a better health outcome. Furthermore, when delay is examined through the lens of dominant medical discourses and what it means to be a “good” female medical subject, additional layers of complexity begin to emerge that are not accounted for by the commonly accepted models of delay (e.g., Andersen et al., 1995; Safer, Tharps, Jackson, & Leventhal, 1979).

Particularly problematic in our view have been traditional conceptualizations of denial as an explanation for delay behavior — that is, denial defined as the “disavowal of the perceptions” of reality that are disturbing to the self but nonetheless evident to others (Freud, 1938/1964, p. 204). In contrast to repression which is the warding off from consciousness of an unacceptable *internal* reality, denial is a defense erected against a threatening *external* reality (Freud, 1937). First in a list of four different types of denial in relation to cancer as outlined by Wool (1986) was denial pertaining to any physical manifestations of breast cancer. Although within the cancer literature authors have cautioned against healthcare professionals misinterpreting a lack of knowledge about a symptom as denial (Hacket, Casem, & Raker, 1973; Moyer & Levine, 1998), certain schools of psychoanalytic thought would suggest that the failure to attribute importance or a distressing meaning to a potentially threatening reality is still a form of denial intended to preserve a state of psychological equilibrium (Fenichel, 1945). Thus, the study of coping with cancer and the appraisal of cancer symptoms requires a more fine grained consideration of the process of denial and its definition (Matt, Sementilli, & Burish, 1988; Wool & Goldberg, 1986).

In the present study, we demonstrate how denial as a broad category is, in addition to its pejorative connotation, is inadequate as a dominant explanation for why women might postpone seeking medical evaluation for a self-detected breast change. We do so by seeking to understand the interplay between experiential and discursive processes by which women make decisions to seek help with the hope that the emergent understandings may point to ways in which the healthcare system may better meet the needs of women in the context of breast cancer care. This objective was met by listening to women’s stories, and examining these narratives as they were situated within medical and cultural discourses. A critical qualitative approach was adopted in undertaking this task (Marecek, Fine, & Kidder, 2001).

**Methods**

**Participants**

In a larger study using the grounded theory qualitative method, 14 women and the male partners of 7 of these women were interviewed separately about the process of discovery of a breast symptom up to the time that the woman sought medical consultation for it (see Fergus et al., 2011). The present critical qualitative analysis was conducted within the framework of this larger project but focused on the sub-sample of 14 women. For the women in the study, inclusion criteria were a diagnosis of breast cancer, a self-detected breast symptom (i.e., not detected through mammographic or other imaging procedures), involvement in a long-term intimate relationship at the time of symptom discovery, and the ability to speak and read English fluently.

The women’s disease characteristics ranged from a primary diagnosis of breast cancer to metastatic disease at the time of initial presentation to the oncologist. Out of the 14 women, eight had received a diagnosis of locally advanced breast cancer (LABC, defined below), three had metastatic disease, and an additional three women were classified as having aggressive disease but not LABC at the time of presentation. The average age of the female patients was 52 years (range = 41–67 years) and all the women were either married or in a long-term relationship with a male partner at the time of symptom discovery. The sample of 14 women was primarily white, with one African–Canadian participant, and two Asian participants. They reported college or university as the highest level of education. All but three participants were currently employed.

For four of the 14 women in the sample, their manner of presentation followed the expected trajectory for presentation whereby they sought help within a few weeks of symptom...
detection. In contrast, just under half of the women \( (n = 5) \) waited 12 or more weeks before presenting for medical opinion, including one extreme case where the woman did not present for 10 years. The proportion of women in the present sample who delayed presentation (36%) was slightly higher than the 10–34% estimated in the literature (cited above). The remaining five women in the sample saw a doctor within 12 weeks (but more than 3 weeks) of discovering a change in their breast. Although 12 weeks is considered the official medical definition of delay, we were interested in the women’s decision-making process to seek care more generally, and thus, included women with a range of timeframes from discovery to presentation.

Procedures

Research Ethics Board approval was obtained prior to beginning the study. Participants were recruited through a cancer center situated in Toronto, Ontario and primarily through the Locally Advanced Breast Cancer (LABC) Clinic. Technically defined, LABC tumors are 5 cm or greater in size directly involving the skin or underlying musculature of the chest-wall and/or with extensive lymph node involvement. Eligible women were identified from medical records and approached on the day of their hospital visit by the research assistant in the waiting room. Women were informed about the nature of the project and if they expressed an interest in participating, were provided with written information about the study. The research assistant then followed up by telephone and set up a time to interview the participant in person.

A semi-structured interview guide was used asking participants to elaborate on their thoughts and feelings at each stage of the process from awareness of the symptom, to seeking help from a medical professional. Questions were phrased neutrally, in a non-blaming manner and pertained to the process of symptom discovery and relationship dynamics regarding the symptom that may have influenced the woman’s decision to seek help. Interviews were conducted by the research assistant in the hospital or over the telephone, were audiotaped, and transcribed verbatim. All participants reviewed and signed an informed consent form before taking part in the interview. In the case of telephone interviews, participants were sent two copies of the consent form in advance of participating, were provided with written information about the study. The research assistant then followed up by telephone and set up a time to interview the participant in person.

Data analysis

The purpose of the original, grounded theory analysis was to understand relationship dynamics that may hinder or facilitate timely presentation for a self-detected breast irregularity. The grounded theory analysis revealed two main processes that a woman negotiated within herself in relation to her partner upon discovery of a breast symptom. These were mutually influential and entailed a tenuous form of knowing in relation to the symptom itself, as well as an intentionality around disclosure (or concealment) in relation to her partner and the broader social and medical systems (Fergus et al., 2011). It was over the course of conducting the grounded theory analysis, that we began to note the higher level discursive practices and influences also embedded in the text. For the present analysis, the text was analyzed using a critical discursive approach to understanding the themes that emerged from the transcripts with a wider cultural and societal lens. The authors LG and KF, experienced qualitative researchers and psychologists, analyzed the data. Both LG and KF maintain a critical, non-pathologizing and humanistic epistemological approach in their research endeavors. Moreover, both LG and KF have extensive experience working in the field of psycho-oncology and in particular, with women with breast cancer, and have published elsewhere on the topic (Fergus et al., 2011; Granek, Fitzgerald, Fergus, Clemens, & Heisey, 2012). The inclusion of two analysts contributed to the rigor of the analysis through ongoing discussion and debate, which allowed for the constant interrogation of the emergent interpretation and its plausibility in relation to both the broader social structures and the women’s personal narratives.

Discourse analysis is an interpretative methodological frame that uses tools from the interdisciplinary area of discourse and conversation analysis (Potter, 1996; Wilkinson & Kitzinger, 1995). Willig (2011) noted: “discourses make available to us particular (historical and culturally specific) ways of ordering and making sense of the world including ourselves. They make available discursive spaces, or ‘positions’ which we can occupy and this has implications for how others perceive us and how will experience ourselves” (p. 898). Interestingly, Willig is both a well-known discourse analyst (Willig, 1999, 2008) who has in more recent years been diagnosed with cancer and has written papers at the intersection of both of these identities. Of her own experience, she wrote, “upon being diagnosed with cancer, I quickly realised that not all available ways of making sense of my experience were helpful to me” (Willig, 2011, p. 897).

In our study, the discourses with which the women engaged in telling their stories of decision-making around seeking help for their symptoms were examined not only with an eye toward what the women reported, but also how these understandings were immersed in, and negotiated within dominant medical and gender discourses (Cheek, 2004). We were interested in Willig’s notion of the available “ways of… making sense” of the experience of decision making about breast symptoms, while focusing on what other types of experiences women drew on and articulated in explaining their thinking and behavior that may have fallen outside of the available ways of making sense. We were concerned with how texts, or in the case of this study, women’s narratives as expressed during the interviews, were situated and constructed within social, cultural, political and historical contexts.

Selections of the text that referred overtly or by implication to dominant healthcare injunctions, or to participants’ self-appraisal or self-judgment in relation to the choices they made to present for medical evaluation were extracted for further analysis and discussion. Contradictions and tensions in the transcripts were noted, discussed and memoed about throughout the analysis of the transcripts. Corresponding with Potter and Wetherell’s (1995) distinction between discourse practices and discursive resources, the guiding questions in rereading and reanalyzing the text included: What are the women saying implicitly and explicitly about their experiences of decision-making around seeking care?: What do the contradictions and tensions in the text reveal about what was and was not being said about delay?: What was the social context in which these women were telling their stories of seeking care for their breast cancer symptoms?: In what ways did these women’s narratives draw on the “available ways for making sense” and what ways did their stories about their experiences fall outside of these norms?

This interplay between text and context meant that at every instance, we tried to:

1. understand what the women were saying within the framework of their own lives, and;
2. situate and interpret their responses within the larger cultural discourses that constrain and shape what the women felt they
could and could not say about their decision-making process (Parker, 1997).

Findings

Our analysis revealed that many of the women in the sample inhabited a kind of double liminality while making decisions around seeking medical care. These women tended to oscillate back and forth between knowing and not knowing about their symptom within the personal realm, and between acting and not acting on it in the medical realm. This oscillation between knowing and not knowing, acting and not acting was situated and framed within the larger dominant discourses that outline and dictate the available choices for women who find an abnormal breast symptom. Within this context, there were three discursive strategies women drew upon in negotiating this liminal space between unappealing choices when it came to seeking care for their breast cancer symptoms. These were: (1) “Doing the Right Thing,” (2) “Deliberate Ignorance” and (3) “Passive Resistance,” each of which are described in more detail below. (The use of words such as “passive” and “ignorance” are not the moral judgments of the authors but are intended to reflect the analytic themes in the data.) While four of the women in the sample were more straightforward in their decision to seek medical care, their interview discourse was nonetheless revealing of various injunctions, assumptions, and psychological processes related to one or more of these discursive strategies.

“Doing the Right Thing”

The use of moralizing language in descriptions surrounding seeking care for breast symptoms was prevalent. Women spontaneously brought up the notion of knowing about the “right” healthcare behavior that they felt they were supposed to be engaging in. This included the idea that deviating from the immediate presentation trajectory was considered “wrong” and “shameful.” Some women also seemed to be self-critical about not presenting sooner, spoke about “failing” at proper healthcare behavior, and about feeling guilt and shame over failing their partners, themselves, and their doctors by not seeking care right away.

One participant, for example, described seeking care within two days of finding her symptom because she was worried about what her partner would think of her if she waited. Speaking about her husband in relation to her own healthcare practices, she said,

No, he’s a very responsible, person and ... I’m not as responsible, and having him ... just thinking about how he would do it influenced ... me being very responsible about it. I need to be very honest with you that even the self-examination is something I do more often because he naggs me to do it. I’m the kind of person who just flies through life, I don’t stop to do the right thing ... to diet, to exercise, to do any of those things. Nor to examine myself. And every now and then he’d remind me and I’d do it, and I think ... if I’m not wrong, I think he reminded me sometime around the time I did it, I think he might have even nagged me that evening, and as I was sitting there at the computer, I thought, well I’d better do this. (Alice, 41, dx: Locally Advanced Breast Cancer (LABC), Italics are the authors)

Words and phrases such as “responsible,” “be honest with you”, “nagged”, “do the right thing”, and “I’d better do this” are moralistic utterances eliciting a sense of obligation, shame, confession, and guilt over acting or not acting responsibly when it comes to self-care in the context of breast symptoms.

Another participant similarly spoke about waiting to tell her partner about her symptom and then waiting a few months to see the doctor. Although she was conscious of the reasons she chose to wait, she described how her partner influenced her decision to seek care. She noted, I figured, now that he knows about it, I would be foolish not to act on it, because then I would just bring about feelings of, she doesn’t care about our family, she doesn’t care about herself, and I really do. So I didn’t want that to come out of not getting treated. I didn’t want that to seem that I didn’t care about the whole... our relations and my family. (Betty, 52, dx: Metastatic)

Although this woman described a number of motives for waiting to seek care such as not wanting to disrupt a promotion she was about to get at work that she had been waiting for 25 years; wanting to deal with her grief over losing her mother to cancer; and not wanting a possible diagnosis of cancer to influence her contemplation over whether to seek a divorce from her partner, she ultimately attributed her help-seeking to the guilt she felt about acting irresponsibly and the fear of being seen as “uncaring” to her husband and her family.

What both of these examples illustrate is that women may be aware of what they perceive to be the “right” behavior when it comes to their healthcare and this awareness results in shame and guilt when they fail to live up to the accepted standard. As outlined in the introduction, the dominant medical discourse of seeking care immediately or else being considered an irresponsible patient, and therefore, a “bad” medical subject or a “bad” woman was a theme that emerged in the transcripts. Moreover, this awareness of the medical discourse is internalized and seems to exert pressure on the women’s conscience even when no one else knew about the symptom.

Deliberate ignorance as a form of resistance

The cultivation of being deliberately ignorant, or the swinging back and forth between knowing and not knowing about one’s symptom until one was ready to present to the physician was a common theme in the transcripts. Deliberate ignorance seemed to serve as a useful psychological mechanism for the women in the face of sometimes severe physical symptoms, those that to an outsider, would seem hard to ignore. One participant, for example, described the process of both knowing and not knowing about her symptoms that included fatigue, shortness of breath, breast pain, and secretions from her nipple. When asked, “what were your reactions when you found the breast secretions?” the participant responded,

P: I was just hoping that it was nothing, and I went into denial.
I: How serious did you think it was?
P: I didn’t think it was serious.
I: Were you concerned about cancer at the time?
P: A little bit, but at the same time I didn’t want to deal with it. (Betty, 52, dx: Metastatic)

In this short passage, it becomes evident that this woman was not ‘in denial’ (as the term typically means) about her symptoms even though she herself used that terminology. On the contrary, she was aware of her symptoms, concerned about them, and thought they might be cancerous. However, she could not simultaneously admit to knowing it was serious and not act on it, and so, described herself instead as being “in denial.” In other words, she claimed ignorance about her symptom in order to meet her need to delay seeking medical care, while simultaneously holding on to
a culturally acceptable notion of proper healthcare behavior (i.e., it’s ok not to seek care if it’s not serious). This dilemma – this liminal space between discourses – later became fully articulated when the participant spoke about the timing of these symptoms in her life.

P: No, [the timing] was just not good, and the timing is never good when you’re not well. But you know, when you have that (strong head) control, you just tend to… like I just tended to forget it, like I just wanted it totally gone. Didn’t want to deal with it at all…

I: How do you think that the breast symptom would affect you in doing what you wanted to do?

P: I think it would have hindered me… that’s [the reason] I didn’t tell anybody. I just didn’t want all that to, like any part of the illness or whatever, the symptoms or whatever I had, I didn’t want them to influence my own decisions and my future… because of all the guilt feelings, and all the feelings of, you know, that I owe people, that I owe my partner, that are part of my adult life… I was afraid that if I really wanted to leave that I couldn’t, because of everything that was happening. And so I just totally blocked everything out. (Betty, 52, dx Metastatic).

From the outside looking in, it may seem at first glance that this woman is in denial about her physical symptoms. Upon closer inspection, however, it becomes clear that “blocking everything out” cannot be considered denial in the pure sense of not knowing something is there because of the degree of intentionality behind the action. Moreover, such deliberative ignorance is productive, meaningful, and purposeful on the part of the woman who is not ready to present to the physician because she had other areas in her life that required attention “unhindered” by the weight of breast cancer. Ignoring the symptom in this way became both a form of agency and a form of resistance in relation to the dominant mores around seeking medical care.

Another participant in the study who struggled over the course of the interview to retell her breast cancer narrative, insisted that she forgot the process by which she discovered her symptom, and then went on to reveal bits and pieces of the story over the course of the dialog – possibly an indication that she did not forget what happened, but was struggling to tell a coherent, ‘responsible’ story instead. When asked by the interviewer how serious she thought her lump was, she remarked,

P: I had no idea, I didn’t think of it in those terms.

I: Were you concerned about cancer?

P: Yes.

I: What made you think of cancer?

P: Well, a lump in your breast is unusual, what else can you think of but cancer?

…I went for a mammogram in the middle, or toward the end of August. So, I think I sort of went into denial for a little while, I just ignored it. Or tried to. And then realized by the feel of it that this was, it couldn’t be ignored…

I: In all this time, did you think underneath that it was cancer?

P: Well I certainly knew it was a possibility, but, I’m a bit of a shallow person, so I put it out of my mind. (Meghan, 53, dx: Grade 3 Tumor)

The presentation of self as being “shallow”, “in denial for a while”, and “trying to ignore it” are in contradiction to this participant’s behavior which included monitoring and feeling her breast lump daily and having cancer at the forefront of her mind when thinking of what her symptom might be. Indeed, later in the interview, it was reported that delaying care had more to do with her teenage son being “off track” and her husband being unemployed at the time – both stressful situations that contributed to the participant’s waiting until she was emotionally ready to take on another stressor such as a diagnosis of breast cancer. In this scenario, she resisted care until she was emotionally and psychologically ready to deal with the consequences. Since she could not come out and outwardly say this, she constructed herself as not knowing, as being “shallow,” or as being in “denial” (i.e., the only explanation available to her for not presenting in the straightforward manner assumed and promoted by the medical care culture (Davis, 2008).

The last example of this phenomenon came from a participant with a long history of benign breast lumps. The lump was discovered by a nurse at an annual check-up and was locally advanced by the time she was diagnosed. Although the participant described being unaware of any unusual breast symptoms, she had stopped wearing a bra for 18 months prior to this check-up because the underwire was cutting into her breast and was causing severe pain. When the nurse first pointed out the lump during her check-up, the participant was surprised that it was there, but simultaneously described knowing it was serious and probably cancer.

P: Once (they) touched it, I couldn’t figure out why I wouldn’t have known it was there before that, because… once I knew where it was and how to touch it, I couldn’t understand why my husband or myself hadn’t discovered it before then, because other little cysts that have been a lot smaller, between the two of us, we’d always discover them first… But this one… I don’t know, I had stopped wearing a bra because the underwire hurt, I’d have it on for a couple of hours and I’d think, this is so uncomfortable. And I’d just take it off… So that was a way of solving the problem… because that’s right about where the lump was, where the bra had been cutting into it. So I had been aware of it, (without) actually knowing that there was something there, I just thought… from whatever, I put on weight, or whatever, the bra was just too tight, uncomfortable. (Maria, 60, dx: LABC)

“Being aware of it, without actually knowing that something is there” captures the essence of deliberate ignorance in that it simultaneously allows for awareness and for abdication of action. To have awareness and to not act appropriately is not a culturally acceptable option within the dominant discourses of appropriate medical behavior and appropriate gendered behavior for women. Instead, they resisted these injunctions while retaining a morally acceptable narrative by cultivating a deliberative form of ignorance around their symptoms.

Passive resistance as a form of agency

The notion of passive resistance accurately captures the final form of resistance and agency employed by women in this study in their decision-making around seeking care for their abnormal breast symptoms. Loretzen (2008) coined the term, “passive resistance” to describe women who avoid succumbing to medical pressures and injunctions by refusing to engage with medical practitioners in ways that do not suit their needs.

Passive resistance was prevalent in two separate, but connected spheres when it came to decision-making and could be subsumed under the general concept of avoiding external pressures. In some instances where the woman discovered the change in her breast, she did not immediately disclose this finding to her spouse. Instead, she often strategically waited to tell her partner until she was ready...
to seek care from a physician. She withheld information about her symptom in order to “avoid the pressure” of her partner who she expected would push her to seek care immediately (also see Fergus et al., 2011). These women thus retained control and agency over their bodies by resisting disclosure to their intimate partners until they felt ready to move forward.

The second type of passive resistance in women had to do with avoiding the medical gaze by refusing to engage with a medical professional at all, and in the process, accommodating to her physical symptoms until the benefits of medical care outweighed the costs associated with seeking care (e.g., undergoing invasive and prolonged treatment).

For example, one participant presented to the physician at the point where her symptoms were so serious, she was admitted to the hospital right away and scheduled for immediate surgery. Her symptoms included an inverted nipple, intensifying breast pain and significant discharge from the nipple, which she had tried to treat with Polysporin (an over the counter antibiotic cream). When she eventually did see a doctor, it was for another matter, but was immediately diagnosed with breast cancer. When asked to speak about her breast symptom, she recalled being worried about it, but also dismissing it as being a skin rash.

I: What was that like for you?
P: Mm, some concern. There seemed to be a bit of oozing, or crustiness. I simply thought I’d developed some sort of skin rash or skin irritation, you know, I didn’t think anything more of it than that, and I used Polysporin on it... Well, I never thought cancer, really. It wasn’t until coming home in April and the pain got so bad. (I still felt like) it was mastitis, but... I was starting, at the back of my mind, entertaining some thoughts, I wonder (if) this could be cancer. I can’t say that it... it wasn’t my main thought.

I: Now is there any particular reason why cancer never crossed your mind at that time?

P: Well because I’d had identical symptoms over 20 years before, (some) years before, and it had been mastitis. And at that time I had worried about cancer and was basically kind of laughed at and... and I felt foolish about how I’d been so worried.

I: So that was a negative experience for you then?
P: I guess it was, yes.

I: And this was your doctor, or this was like family and friends that reacted?
P: Family doctor.

I: He reacted that way?
P: Yeah. And then he kidded me that the only people who got mastitis were women who didn’t bathe well or often, like homeless women which made me feel very embarrassed. But then, I guess he must have realized I was upset by that, because he then on his own did some research and called the county medical officer and he knew that we went out in our boat a fair bit and went swimming, and we learned, back where we like to bath well or often, like escherichia coli. So (we) then figured out that was how I got the infection. But no, I was very humiliated, I was very embarrassed.

I: Did you tell him anything about how you felt, the family doctor?
P: No, I don’t think so. It’s a long time ago...But I was very humiliated. (Donna, 63, dx: LABC, Grade 2)

This story about feeling humiliated by the family physician was such a prominent narrative in her life, her husband also recalled it in his own interview about his wife’s pre-diagnosis experience. He described the incident as occurring thirty years earlier and causing his wife embarrassment. The humiliation and shame of being dismissed thirty years earlier by her family physician was so traumatic that this participant chose passive resistance or avoiding care altogether rather than risk being dismissed and ridiculed again by another healthcare professional.

Discussion

Several authors have noted that there is a dire need to take the social and cultural context into account when examining women’s experiences with breast cancer in order to better understand their needs and desires within the healthcare system (e.g., Barg & Grier, 2008; Robertson, 2000; Roy, 2008; Thomas-MacLean, 2004; Wong & King, 2008). Kaiser (2008) noted, for example, that good research on cancer needs to “acknowledge the variation in responses to breast cancer” (p. 86), and that in her study of breast cancer patients she found that, “the failure of our cultural conceptions of cancer to adequately reflect lived experience and highlight how individuals actively ‘craft’ illness meanings” (p. 86) was readily apparent. Similarly, in another study looking at communicating prevention strategies about breast cancer for minority women, Barg and Grier (2008) concluded, “Our results stress the importance of identifying and addressing “deep structure”, which involves the cultural, social, historical, and environmental factors that influence minority health” (p.340). Finally, Willig (2011), in writing about cancer in general explained it is important, “to acknowledge that the struggle to find meaning after a cancer diagnosis always takes place within a very specific social-historical and cultural context. Such a context makes certain discourses more or less available; it highlights particular constructions of meaning and obscures others” (p. 901).

Our study examined the “deep structure”, or the social, historical, and cultural discourses that shaped women’s accounts of decision-making to seek help for their abnormal breast symptoms before they were diagnosed with cancer. By taking the wider societal discourses into account in our analysis, we discovered that this process is a more complex, variegated, and layered than has been previously allowed for in existing published accounts and explanations of delay.

A useful frame for understanding our participants’ pre-diagnostic experience is that of being in a liminal state. Frank (1990) has described liminality in the context of cancer to refer to the threshold state between illness and wellness where the sick person either recovers from the disease or dies from it. In his conceptualization, liminality is a kind of existential state of constant oscillation between ‘normality’ and disease. Little, Jordens, Paul, Montgomery, and Philipson (1998) described liminality as a major subjective category of the cancer experience. They suggest that all cancer patients experience liminality as a process “marked by disorientation, a sense of loss and of loss of control, and a sense of uncertainty” (p. 1485) that comes from inhabiting the ‘in between space’ of everyday life and facing one’s mortality when diagnosed with cancer. Our findings suggest that there is also a pre-diagnosis liminality where women experience two different, but intertwined and related types of “threshold states” before they make a decision to seek care.

The first state involves the liminality between knowing and not knowing about their cancer symptom. Here women may go back and forth between awareness of a change in their breast (often worrying that they have cancer), to dismissing their symptom as being normal, benign, or there, but not significant. In other words,
oscillating between interpreting the symptom as “something” or as “nothing”. Interestingly, only two of the women in the sample made direct reference to fear and anxiety as playing a role in their pre-diagnostic experience. For the majority of women, their anxiety was implied when they spoke of their concern that the symptom was “something.” The second stage involves liminality around action and inaction where a woman may be caught between acting or not acting on the symptom while knowing that the former is the ‘correct’ choice. As we have attempted to convey, inaction around the symptom is a form of action, but one that is not considered acceptable.

The dominant medical discourse (see Robertson, 2000; Roy, 2008; Willig, 2011; Wong & King, 2008) thus allows for two culturally acceptable explanatory narratives: The first is that of the woman who was unaware of her symptom, or interpreted it as being insignificant, and therefore, not requiring medical attention; the second is that of the individual who noticed her symptom, interpreted it as potentially dangerous, and immediately sought medical attention. The one possibility that is unavailable in these binary discourses is that the woman was aware of her symptom, recognized that it might be threatening, and yet chose not to seek care immediately. This paradigm of what constitutes acceptable symptom-appraisal and action is constraining and problematic on two levels: Firstly, it does not adequately account for the proportion of women who are aware of their symptom and do not present within 3 months of symptom detection. Secondly, it breeds shame and embarrassment in women who have delayed making it more difficult for them to present for medical care (Facione & Facione, 2006).

For women who do not ally with one of the two culturally acceptable options, they end up inhabiting that “in between” or liminal place vis-à-vis their own understanding and handling of a breast irregularity. This liminal orientation (in relation to self, body, and medicine), is often viewed by external observers (i.e., healthcare providers, family, and close friends) as perplexing or unfortunate at best, or psychopathological at worst. In this analysis of women’s accounts of seeking care, we sought to demonstrate how the broader societal messages concerning healthcare (i.e., the sense of obligation and responsibility to care for one’s health and enact the proper health-behavior such as presenting immediately to the doctor upon finding an abnormality) are taken up by the individual, and effectively have a role to play in creating the apparently “flawed or contradictory” reasoning (see Facione & Facione, 2006) or perceived irrationality of women’s delay behavior when it occurs. On an intrapsychic level, such messaging contributes to a woman’s experience of, at best, embarrassment in relation to not following the clear cut presentation trajectory, and at worst, deep shame and guilt over seemingly choosing to not prioritize her health over everything else. Once again, the latter especially, presumes that rationality reigns supreme in the help-seeking process and that a failure to enact that rational behavior is worthy of disgrace and humiliation.

Women for whom their anxiety motivates presentation (rather than impedes it) are fortunate in this regard, because their coping style is in keeping with the dominant, accepted help-seeking discourse. Women who cope with anxiety through avoidance, however, must work around or challenge this natural tendency in order to seek out medical evaluation (see Steifel, 2006). Those who are unsuccessful and end up ‘delaying’ are often perceived by healthcare professionals as being “in denial,” irresponsible, and/or utilizing other defense mechanisms (Wool, 1986). Denial has been defined as a disavowal of a threatening external reality (Freud, 1937) or as a “distortion of negative experiences so complete that it can block out memory of the experience altogether” (Taylor, Colins, Skokan, & Aspinwal, 1989, p.117). Our analysis illustrated that none of the women in our study were in denial in the way that it is traditionally conceptualized. The women who postponed seeking medical care were in the main, conscious of their symptom, were monitoring it, thinking about it, reflecting on it, interpreting it, and assessing it, often with great concern over what it might be, but at the same time were dismissing it, or choosing not to seek help for it. Not only is the concept of denial insufficient to capture this complex process, but the label also carries with it a heavy burden for women because of its negative connotations of blame and irresponsibility. Our analysis suggests that individualistic characterizations are not sufficiently complex and tend to overlook the sociopolitical and cultural factors at play in this process.

At a recent meeting, one of our colleagues working in the medical field, exasperatingly asked us why women would delay seeking care if they knew that early detection would lead to a better health outcome. She asked, “Do they not care about their health?! In many ways, this question echoes the concern of one of the participants quoted earlier who was worried that avoiding medical attention would be misconstrued as “not caring.” As she articulates, she is aware of how her decision to avoid medical care may appear unacceptable from the outside, but for her, the formula does not fit. For this participant, avoiding medical attention does not equal not caring. There are other factors that unsettle this equation.

One such factor has to do with the intersection of two dominant discourses when it comes to health: that of the moralizing aspect of self-care in the medical context and that of the gendered aspect of being a “good female subject.” This healthcare behavior or self-care is assumed to be the responsibility and obligation of the individual agent — a model which has been termed “healthism” in the social science literature (Lupton, 1995; Robertson, 2000; Roy, 2008). Some scholars have noted that cancer, in particular, is situated within a discourse that regards the disease as a moral issue where prevention, treatment, and help-seeking are placed on the shoulders of the individual, and that those who deviate from this model (e.g., those who smoke, are obese, do not take care of themselves in general) are held morally accountable for their ‘negligence’ (Ehrenreich, 2009; Roy, 2008; Willig, 2009, 2011).

In our study, the expectation to self-regulate via an “internalized medical gaze” (Loretzén, 2008, p.53) was bound up in a moral pressure to act like a “good” medical subject, purportedly on behalf of oneself and one’s own good. However, as was evident from participants’ narratives, this imperative was also constraining and delegitimizing — effectively serving to dissuade some women from enacting the very health behaviors they were expected to uphold. Failing to self-regulate as a good medical subject meant for a number of participants, being irresponsible and uncaring — two characteristics that are especially problematic for women (Bebko & Krestan, 1990; Fine & Carney, 2001; O’Grady, 2005). Indeed, in line with other research in the area of women and cancer (Badr, 2004; Fergus & Gray, 2009; Meyerowitz, Watkins, & Sparks, 1983) the participants in our study were aware of their families’ needs, perceptions, and anticipated responses to their decision-making around their health. This simultaneous awareness of knowing what one ‘should do’ and one’s actual behavior are the very tensions that led to feelings of shame and embarrassment about their decision-making process because it fell so outside of the received behavioral ideal for women.

Conclusions and implications

The goal of this analysis was to offer some insight into what we have come to view as a liminal period prior to presentation;
that deeply personal moment when a woman happens upon a potentially threatening reality, and the myriad of feelings, reactions, wishes, and cognitive processes that come attached to that reality. We have attempted to elucidate the discursive positions that are available to women upon self-detecting a breast irregularity and how these might be taken up by a woman who does not enact normative help-seeking practices in relation to its discovery. In doing so, we hope to expand ways that healthcare providers may make sense of women’s hesitation to seek help despite an awareness of ‘proper’ help-seeking behavior. Delay behavior is not, de facto, the product of irrationality or psychopathology—mild or extreme. Our aim in offering this alternative construction (Willig, 1999) was not to polarize understanding along psychological versus sociopolitical and social constructionist lines, but to reveal the complex interaction between personal and sociological discourses; an interaction which may shed light on how women may both know and care that they are in danger, yet not enact, unproblematically, the received view of proper health behavior.

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