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Walking Each Other Home: Sensemaking of Illness Identity in an Online Metastatic Cancer Community

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Walking Each Other Home: Sensemaking of Illness Identity in an Online Metastatic Cancer
Community

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
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DEDICATION

This dissertation project is dedicated to the indomitable spirit that Ariane (Andy) is.

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ABSTRACT

Increasingly, online settings serve as primary social contexts for patient interaction, playing a crucial role in ways participants access medical information and turn to each other for support. Stage IV (metastatic) cancer patients like myself know what it is like to be overwhelmed by the complex array of medical tests, treatments, and information we are expected to assimilate. My late stage disease status necessitates I routinely grapple with not merely the kinds of support I think I need or how those needs will be met, but also what *meanings* I assign to my experiences. Consequently, as a member of *The Living Room (TLR)*, an online support group for metastatic breast cancer patients, I benefit from cyber-mediated connectivity with fellow patients who share many of the same psychosocial and informational needs. Because metastatic breast cancer (MBC) patients have different needs and communicate differently among themselves in online spaces, I conducted an ethnographic study of an online MBC community to study ways that patients make sense of and frame their disease, thus narrating their disease identity and survivorship. I used Weick's concepts of sensemaking as conceptual lenses and thematic analysis as a method to examine a variety of narrative and textual threads between members on *TLR*. I found that *TLR*'s group ecology was organized around the concept of 'shared values, shared support,' that *TLR* provided a platform for MBC patients to receive and give support from/to others who shared similar experiences, and that MBC patients negotiated a tension between the needs for social support and for distance from thoughts of cancer and terminal illness. In identifying the ways that MBC patients frame and make sense of their experiences in an online community, this project contributes to our understanding and appreciation of the improvisational

nature of illness and identity construction. This project also helps those living with MBC to manage the uncertainty of our disease and serves as a resource for clinicians who wish to learn more about patients' subjective experiences of their identities and illness.

CHAPTER ONE

INTRODUCTION AND REVIEW OF LITERATURE

Increasingly, online settings serve as primary social contexts for patient interaction, playing a crucial role in ways participants access medical information and turn to each other for support. In the early 1990s, disease-focused online groups began to form as places for “information exchange and mutual support” (Sharf, 1997, p. 66). Since then, the rapid growth of digital communication has fueled an explosion of cyber-mediated patient-to-patient disease support groups. An implication of this growth in connectivity is that it has enabled patients to fulfill support needs apart from or in addition to traditional face-to-face support groups and clinical care.

Stage IV (metastatic) cancer patients like myself know what it is like to be overwhelmed by the complex, often confusing and ongoing array of medical tests, treatments, and information we are expected to assimilate and with which we are to comply. I am also cognizant that there are things that medical professionals do not tell me (questions of quantity of life versus quality of life, alternatives to chemo and radiation, to larger questions of how to deal with loss or of how long I am going to live) and that it is up to me to educate myself outside of clinical encounters. Of major significance to me is that my late stage disease status necessitates I routinely grapple with not merely the kinds of support I think I need or how those needs will be met, but what *meanings* I assign to my experiences. Consequently, as a member of *The Living Room (TLR)*, an online support group for metastatic breast cancer patients, I benefit from cyber-mediated connectivity with fellow patients who (some half way across the globe) share many of the same

psychosocial and informational needs that I have. Through our Facebook™ platform web page, we exchange daily updates and discussions on members' health status, new treatments, disease progression, and yes, member's deaths. In other words, we engage in a discourse of survivorship.

In this research project, I first outline and support my claims about discourses of breast cancer survivorship and the rationale for why sites such as *TLR* warrant investigation. Ultimately, my dissertation project aims to examine an online support community's discursive constructions of cancer survivorship. In my introduction I begin with my impetus and rationale for this study. I follow with a review of the literature that shows the gaps in research on patient sensemaking of late stage disease in cyber-mediated spaces of social interaction. I then propose the research questions that guide this study, explain my methods of research, discuss some ethical questions raised by patients researching their own communities, and then discuss my analysis of data. Following is a section containing data samples which feature textural threads of online patient interaction from *TLR* highlighting these interactions as potentially functioning as modes and outcomes of sensemaking of survivorship by this community.

Impetus for Questioning Disease Discourse

As one of the breast cancer calendar¹ 'Angels' I remember standing at the railing aboard our parade float. All of us bedecked in pink, white, and silver, waved gracefully like pageant winners as we glided past the crowds. Multitudes of expressions of support flash-froze in my mind: hearty applause, wide, approving grins, cheering fist-pumps, gawking looks—and an overwhelming number of faces silently tearful or openly sobbing. I was pierced through by the public's open display of vulnerability that we, as survivors, had elicited. I was also struck by the

¹ A calendar project was created to raise funds for The American Cancer Society's *Making Strides Against Breast Cancer* initiative.

power that we had. Despite being an “Angel” on the float that day, as one who was fortunate to have survived, I felt neither virtuous nor victorious.

During those moments, I asked myself a number of questions. First, what did we represent to this crowd of tens of thousands? Were they celebrating with us, feeling sorry for us—or both? What specifically were they celebrating? Why was *this* cancer celebrated in this way? Finally, how did we acquire this power? These questions have remained with me through years of health communication research examining cancer survivorship. Principally, I have focused on ways disease discourse influences patient identity construction in relation to survivorship and subsequently how patients construct their own health and disease experiences. I establish the rationale for this study by situating my research in the aforementioned questions.

Identity Questions

My first question regarding what we represented to the crowd led me to examine the history of social constructions of breast cancer and the origins of the contemporary breast cancer survivor identity. Analysis of common representations of the breast cancer survivor identity found in biomedical, consumer, and philanthropic marketing texts and narratives reveal that they are rooted in the cultural motifs of valor and virtue (Loseke, 2008). Dominant images depict patients as victorious survivors and act as powerful cultural motifs. Combined with ubiquitous marketing messages and ritualized behaviors, these images script and organize breast cancer patients to perform as public models of courage. Implicit sets of required behaviors for patients and the public include: compliance with biomedical screenings, diagnoses and therapies; participation in charitable ‘fitness events’ (King, 2006); ethical, compassionate consumerism (Einstein, 2013); and an especially powerful unspoken edict—*not* to question any of these behaviors.

How and Why

Many of the reasons we as ‘Angels’ on the parade float inspired both pity and celebration from the crowd relate directly to socio-cultural perceptions of femininity, the breast, and cancer. A cultural shift away from viewing breast cancer as a humiliating and secret condition for women began 30-35 years ago with media narratives and representations that lionized the courage of public figures diagnosed with breast cancer such as Betty Ford (Dubriwny, 2009), Joan Lunden, and more recently Angelina Jolie, who, when faced with the genetic risks of breast and ovarian cancers elected to undergo a bilateral mastectomy and oophorectomy. These media depictions and women were celebrated around the globe. The first pink ribbon ad campaigns begun by Estée Lauder and Susan G Komen have led to decades of pervasive cause-related marketing of the disease (Einstein, 2013; King, 2006). Such awareness and fundraising campaigns have created the current social constructions of breast cancer as a disease of feminine empowerment, potentially undermining the emotional health of women who do not feel empowered by their illness experience (Sulik, 2012, 2014). Public sympathy and compassion are evoked by pink, maternal, feminine imagery. At the same time, outpourings of funds are elicited by showcasing the disease as one to be overcome through sheer will, fitness, biomedicine, and smiling. The two public responses of pity and hope are cultivated and co-exist in large part because of cultural beliefs and disease-marketing strategies. Because of a gendered co-construction of the discourse of survivorship socially and institutionally, public critique of disease discourse and marketing is silenced by virtue of long-held culturally iconic representations and beliefs about femininity, courage, and disease. Unfortunately, the public’s ritualistic performances of cheering on survivors through pink philanthropy in lieu of critique have, in effect, obscured and reified ongoing systemic issues regarding women’s health and

cancer. Often late stage disease sufferers are neglected or ignored. In light of social constructions of an iconic breast cancer survivor identity, I now turn to questions of ways metastatic breast cancer (MBC) patients are configured within those constructions and ways that their understandings of their identities and their health trajectories differ from the normalized breast cancer survivor identity.

‘Survivors,’ but Not Necessarily Optimistic

MBC patients are typically not the face of ‘optimistic survivorship’ and ‘awareness’ campaigns. Reportedly, more MBC patients are surviving longer because of newer target therapies and drugs; however, the ratio of patients dying from the disease as compared to the newly diagnosed remains relatively unchanged (ACS, 2018; NCI, 2017). Stage IV cancer patients are far less marketable under the current rubric of breast cancer awareness/survivorship discourse because, from a disease-marketing perspective, MBC patients represent incremental, but ultimate decline, in contrast to popular images of fit, feminine heroines whom the public hopes will conquer the disease. For instance, advertisements for the stage IV breast cancer therapy Ibrance© by Pfizer Corporation depict upper-middle-class white women coping with “the new normal” in muted, almost somber tones, and notably without promising a cure. Yet, sites like the Susan G Komen website feature hundreds of patient narratives, the majority of who are smiling, attractive, even chic-looking, as thriving stage 0-3 survivors. Stage IV survivors are found in a separate section. Their stories are less about “kicking cancer’s ass” and more about living with cancer, “the new normal”.

If available, breast cancer awareness discourse often obscures stage IV patients as marketable subjects. Given this scenario, a few questions come to mind: what might these patients be imagining about their health and illness, their gendered identities, and their futures?

in what ways are they narrating their disease identities in terms of commonly held ideas about survivorship, and how and where are they telling their stories?

Different Kinds of Survivorship

Based on the argument that similar to stage 0-3 breast cancer patients, MBC patients' beliefs about their disease are shaped largely by cultural definitions circulating through biomedicine, pink philanthropy, and advertising, how might they narrate survivorship? What discourse(s) might they use to make sense of their disease?

Discussions about breast reconstruction surgeries, short-term side effects and remission statuses, while common among earlier staged patients, rarely apply to MBC patients. Hopes of aesthetic wholeness or of being “cancer-free” are more elusive to them. Their own lived realities (many cannot have reconstructive surgery) rarely mirror the common scripts of disease remission and breast reconstruction (Crompvoets, 2012). Thus, many MBC patients do not avow to themselves the survivor identity as publicly constructed (Barel-Shoshani & Kreiler, 2017). Instead, they may expect unending tests, scans and procedures, harsher drug therapies, invasive surgeries, cascading side effects, significant changes in beauty aesthetics and appearance, and economic hardship.

Certainly, newer target and immune therapies for breast cancer offer hope for metastatic patients (Eng et al., 2017; Khosravi-Shahi, Cabezn-Gutierrez, & Custodio-Cabello, 2018; Li et al., 2011; Mohan & Ponnusankar, 2013; Monnot & Romero, 2018). And while more MBC patients may be living months and years longer, they must cope with different sets of side effects, impairments, and unique psychosocial needs (Niklasson, Paty & Ryden, 2017). How such patients talk to each other about survivorship while undergoing these challenges is of interest to both patients and providers (Mao et al., 2013; Kim, 2014; Kim, Hou, Han, & Himelboim, 2016).

Based on clinical interest and the increase of use by patients of platforms such as Facebook and other patient-initiated message boards, investigating peer-to-peer exchanges in cyber-connected communities of support warrants more research. According to the Miniwatts Marketing group, as of December 2017, approximately 1.97 billion people worldwide used Facebook. Hawkins, DeLaO, and Hang (2016), citing Lee (2015), maintain that more and more people are turning to Facebook as the dominant home for disease specific groups. Users' ability to ask anybody, any kind of question has facilitated an explosion of knowledge sharing among members of like-minded communities.

Health and Illness in “*The Living Room*”

As patients are increasingly seeking disease specific groups via social media platforms, it is fair to assume that MBC patients would naturally seek out support groups of similar patients; after all, MBC patients have unique treatment and psychosocial needs (Cardoso, Harbeck, Mertz, & Fenech, 2016; Lewis, Yee, Kilbreath, & Willis, 2015). And while MBC patients talk about things similar to earlier staged breast cancer patients, their instrumental needs are different, and their concerns about chronic illness and death contribute to and structure different discussions (Vilhauer, 2009; 2011). In addition to examining online patient-to-patient communication, doing so in absence of an expert biomedical facilitator will yield different kinds of data regarding framing of disease and survivorship. For example, online disease support sites are often removed from clinical care, existing on the peripherals of biomedicine with no ‘expert voice’ of medicine, either human (Pomery, Schofield, Xhilaga, & Gough, 2018) or algorithmic (Ranasinge, Bandaragoda, De Silva, & Alahakoon, 2017) moderating or regulating patients' narrations of health.

However, clinical researchers want to know what patients are saying to each other online

(that which they may not be saying in the clinical setting); they see OCSGs as spaces providing “a great wealth of qualitative information, in which patients freely express symptoms, side effects, treatment options and their ‘real-life’ experiences of undergoing cancer care” (Ranasigne, Bandaragoda, De Silva, & Alahakoon, 2017, p. 59). Researchers also acknowledge that a massive patient migration to electronic/social media for information and support from other patients necessitates the research of large amounts of textual data of patient-to-patient reported information (Ranasinge, Bandaragoda, De Silva, & Alahakoon, 2017).

Because MBC patients have different needs and communicate differently among themselves in online spaces (Vilhaur, 2009, 2011) I conducted an ethnographic, IRB approved study of an online MBC community to study ways that patients make sense of and frame their disease, thus narrating their disease identity and survivorship. My aim, as a participant observer, was to examine textual exchanges between members of *TLR*, an invitation only group of approximately 145 stage IV breast cancer patients. Discussions between *TLR* members focus primarily on chronic conditions, impairments, and advancement of the disease. I used Weick’s (1995, 2005) concepts of sensemaking as conceptual lenses and thematic analysis as a method to examine a variety of narrative and textual threads between members on *TLR*. Identifying the ways that MBC frame their experiences and the discourses they use, through online exchanges leads to a greater understanding and appreciation of the improvisational nature of survivorship construction (Klein, 2014; Nachmanovitch, 2009) that patients use to narrate their cancer survivorship.

Literature Review

Survivorship

Illness: A social construction. J. R. Gusfeild (1967) argues, “Illness is a social designation, by no means given in the nature of medical fact” (p. 180). Rather, because individuals construct selfhood and their social worlds through social interaction they enact their illness experiences and endow them with meaning (Blumer, 1969; Conrad & Barker, 2010). The evaluative power by expert knowledge of what is normal and abnormal has created medical discourse (Foucault, 1977; Turner, 1996); however, there are consequences of illness independent of biological terms and effects. These consequences result from the assignment by physicians of an illness label upon a human body whereupon a human’s behavior is changed because a social state is added to a biophysiological state (Freidson, 1970; Conrad & Barker, 2010).

Historically, cultural understandings of a diagnosis of breast cancer have ranged from perceptions of a stigmatizing, disfiguring, and deadly disease (Batt, 1994; Leopold, 1999), to discourses of science shaping social construction of the survivor (Thorne & Murray, 2000), to disputed meanings of the survivor identity (Kaiser, 2008; Park et al., 2009; Morris et al., 2011), and more recently, to scholarship critiquing breast cancer awareness (Ehrenreich, 2003; King, 2006; Klawiter, 1999; Kosofsky-Sedgwick, 1999; Sulik, 2011). Socio-cultural understandings are largely embedded in disease discourse in government policy, feminist activism, breast cancer awareness campaigns, and corporate/citizen philanthropy. For example, Samantha King traces the trajectory of disease discourse beginning with the influence of breast cancer awareness over governmental policy springing from Betty Ford’s public disease experience to several years later in 1996, when breast cancer was being coined by *The New York Times Magazine*, as “This

Year's Hot Charity", based on the Estée Lauder™ corporation's branding of the pink ribbon (King, 2006, p. vii; see also Belkin, 1996). The public narrative of breast cancer had been transformed seemingly overnight from one of a horrific illness to one of feminine empowerment and nurture, with characters who are "rarely 'patients' and mostly 'survivors'". It had become a disease where the survivor "emerges as a beacon of hope who through her courage and vitality has elicited an outpouring of" consumer philanthropy and support (King, 2006, p. x).

Meanings of survivorship. The meaning of the term 'cancer survivor' has a variety of interpretations and is defined within numerous contexts. Until the 1960s the expression 'survivor' was attributed to grieving family members (IOM, 2006). Michael Feuerstein (2007) categorizes meanings of survivor as: policy related, disease statistics, adjustment/coping, and advocacy. The American Cancer Society (ACS, 2007) defines a survivor as "all those who choose to define themselves as survivors, from the time of their diagnosis and through the balance of life". After accessing hundreds of articles on breast cancer survivorship research, I found that the term 'survivor' was predominantly framed (throughout all disciplines of the arts and sciences) by biomedical measurements and outcomes. However, Dr. Fitzhugh Mullan's (1985) original definition of survivor describes the cancer patient as experiencing neither death nor the cure, but rather, struggling through inexact, yet predictable stages of a deadly disease. By and large Western advocacy group definitions of cancer survivorship, most especially breast cancer survivorship, have less to do with Mullan's reference to struggle and more to do with illness metaphors of war, heroism and victory (Ehrenreich, 2003; King, 2006; Sontag, 1978; Sulik, 2011).

From patient to survivor. Breast cancer as the chief cause of cancer, is "the second leading cause of cancer death in women" in the U.S. (Kelly et al, 2011, p. 159; see also

Cancer.org, 2016). Annually, 40,000 women (and men) die from metastatic breast cancer (Cancer.org, 2017). Although tens of millions of patients have entered the ranks of survivorship (10 year survival rates are currently at 80%) as a result of improved therapies and earlier detection, the number of annual deaths has remained static for two decades. This is despite unprecedented support in the forms of billions of dollars raised for breast cancer awareness messaging and research through advocacy groups and global corporate marketing (BCAN, 2015; Sulik, 2014). The enormous support given to this popularized disease coupled with static death rates leaves many survivors struggling to make sense of the meaning of survivorship. For instance, some patients who have varying definitions of survivorship feel current definitions alienating because of fears of recurrence and feel ambivalence toward the positive meanings ascribed to the disease (Helgeson, 2011; Kaiser, 2008; Kelly et al., 2011). Koczwara and Ward (2014) researched of the “hierarchy of cancer suffering” and the ways that ubiquitous media portrayals of the breast cancer survivor image normalize the cancer and makes it more acceptable to the public than other cancers. They maintain that positive bias has created a schism within the breast cancer world and is due to the status terminology used to celebrate certain types of breast cancer to the exclusion of others. The authors’ argument not only challenges the basis for meanings of survivorship but also brings into question why the ‘success’ of breast cancer treatment and survivorship should be considered a legitimate way to think about cancer survivorship in general.

The change in the meaning of survivorship began in large part with first lady Betty Ford’s public diagnosis in 1974, which signaled a discursive shift in which breast cancer patients reoriented their disease identity from one of suffering in silence to emulating the first lady’s publicized chronicled ‘battle’ as a ‘bright eyed’, feminine, fighter (Ehrenreich, 2003, Dubriwny,

2009). Women as patients, instead of medical diagnosticians, were given the responsibility of early detection through breast self-exams (BSE) and medical screenings billed as a form of self-empowerment (Fosket, Karran, & LaFia, 2000). The multibillion-dollar breast cancer industry, framed as Breast Cancer Awareness, emerged through government funding, citizen philanthropy (in the form of walks, fitness events, rallies, and pink consumerism), medical technologies and the pharmaceutical industry.

From survivor to she-ro. The grammar of empowerment and individualism found in contemporary definitions of the breast cancer survivor identity cast the patient as a resilient, self-determined, able-bodied archetype of femininity—what Gayle Sulik (2011) refers to as a ‘she-ro’. For instance, when attending a breast cancer survivor race or walk, the language or imagery used rarely suggests that the breast cancer sufferer is a victim of a lack of access to healthcare or of exposure to environmental pollutants, non-nutritious foods, and radiation from mammographies; rather, she is an inspiration to all who see her. She is the embodiment of an empowered member of an enshrined sisterhood of survivors. Not only is she victorious because she is a ‘survivor’—even if she is in the end stages of the disease and unable to walk. She exemplifies the transformative ability of this particular disease experience to provide a way of becoming a better human being. That ‘better human being’ behaves like an archetypically white, heterosexual, middleclass, fit, dressed in pink female. As such, she is the *fashioned survivor* (Ucok, 2007) who is robustly fighting the disease. Ozum Ucok (2007) refers to the *fashioned survivor* as a feminine archetype who is white, heterosexual, upper middle class, youthful, thin, and has a balanced bust line. As a result of the language and imagery of breast cancer culture, women of color who have breast cancer find themselves having to perform multiple forms of labor and identity work. Annette Madlock Gatison maintains that the fashioned survivor persona

is exclusionary to black survivors like her. She argues that the dominant white survivor representation, together with positive religious confession practices, and the ascription of the strong black woman archetype have imposed upon black women an “unhealthy trifecta of breast cancer culture, faith talk, and the strong black woman ideology” (Hall, 2009, 2015, p. 136).

Breast cancer culture consists of the nexus of connections between disease marketing, disease discourse, and the public imagination, which are centered within and manifested through the breast cancer survivor persona (Blackstone 2009; Broderick, Jogi, & Garry 2003; King 2006, 2010; Sulik 2011). This persona has been both constructed and deployed through master cultural narratives and the corporate marketing of those cultural codes of the disease (Loeske, 2008). These codes are evident when watching an NFL football game during October. Otherwise normalized masculinity is suspended temporarily in order to honor breast cancer awareness month where the viewer sees burly men—tossing pink footballs, wearing pink jerseys and pricy pink athletic shoes—exemplify compassion and support by playing their macho hearts out for all the feminine victims/she-ros of breast cancer. The heavily gendered, raced, classed, hetero-normative, and ablest cultural codes that are embedded in the breast cancer survivor persona and perpetuated through their participation in citizen philanthropy are not only tacitly accepted, but cheered by a compassionate and complicit public (Einstein, 2013).

Online Breast Cancer Support Groups

Being situated in the current survivor culture compels breast cancer patients to seek information and empowerment from sources such as the American Cancer Society, Susan G. Komen for the Cure®, and the National Cancer Institute. The social support needs of cancer patients have been documented for decades. Most cancer patients have unique physiological and psychosocial needs, and most experience the isolating effects of the diagnosis and treatments on

some level. Therefore, having social support in the forms of positive relationships and access to information is a determinate in better quality of life and overall coping with the disease (Bertero, 2000; Peters-Golden, 1982; Sjölander & Berterö, 2008; Ussher, Kirsten, Butow & Sandoval, 2005).

Social support. Social support is a fundamental human need (Cobb, 1976; Tilden, 1985; Sjolander & Bertero, 2008). Social support can be defined as a “set of personal contacts through which the individual maintains his (*sic*) social identity and receives emotional support, material aids, services, information, and new social contacts” (Walter, McBride, & Vachon, 1977).

Networks of social support exist in cultural scenes such as church groups, professional/advocacy groups, disease/injury related groups, informal networks, or family groups. People seek out support groups when pressed with a specific need. The very idea of support groups as a solution to loneliness and isolation is borne out by the words themselves: support, meaning sustenance and encouragement, and group, an assembly of like-minded individuals. Perhaps the greatest thing support groups provide is one-on-one emotional and social support as well as introductions to new social relationships. Social networks, both face-to-face and virtual, help people form bonds and foster a feeling of belonging (Ashida & Heaney, 2008; Keyes, Shmotkin, & Ryff, 2002) wherein a sense of commonality and connectedness lead to better psychosocial health and wellbeing (Fernandez et al., 2011).

Illness or disease support groups. When a patient receives a cancer diagnosis, fears of disease recurrence, death, social rejection, stigmatization, and fear of the unknown are common reactions (Ussher et al., 2005). Sick persons initially turn to family, friends, work colleagues, physicians, chaplains, and other patients for feedback, validation, encouragement, and hope. Illness support groups in the forms of professionally led or informal face-to-face and online

settings, are sought out by patients to alleviate some of the distress caused by diagnosis and treatment of the disease through informational, emotional, instrumental, and tangible kinds of support (Ahlberg & Nordner, 2006; Barg, & Gullatte, 2001; Campbell, Phaneuf, & Deane, 2004; Carlton-LaNey, Hamilton, Ruiz, & Alexander, 2001).

Both online support groups (OSGs) and face-to-face groups are of benefit to patients, but serve different functions (Thompson et al., 2016). Traditional face-to-face support groups, held at hospitals, clubs, churches and service organizations facilitate actual peer-to-peer interaction, are typically guided by a qualified discussion leader and are attended by older patients whose psycho-social needs are met by these types of interactions (Huber et al., 2017). Whereas, patients who largely use OSGs have a higher need for information, are more 'tech savvy', have a higher level of education, and are younger (Huber et al., 2017; Setoyama, Yamazaki, & Nakayama, 2010; Thompson et al., 2016). Additionally, the lack of constraints on cost, physical location, meeting times, and mobility issues influence patients' likelihood of participation in OSGs (Bambina, 2007; White & Dorman, 2001). Some research suggests that when given a choice, patients feel more positive about and perceive more social benefits from face-to-face support than online support (Van Uden- Kraan et al., 2011). Other research shows that by using both resources, patients receive more positive support and benefit more overall (Setoyama, Yamazaki, & Nakayama, 2010).

Online cancer support groups. Preece (2001) defines online support communities as “any virtual social space where people come together to get and give information or support, to learn, or to find company” (p. 348). Increasingly online spaces are where cancer patients seek to gather information, feel connected socially, and increase their personal/collective sense making of their disease (Silence, 2013). Through the ubiquity and ease of access of online

communication (Wright, 2016), patients seek informational and emotional support from a legion of blogs and social media support groups/communities, such as Facebook. Clinicians are increasingly paying closer attention to patient-to-patient cyber-connected interactions. For example, Kim (2014) examines the connections between Facebook use and patient psychosocial wellbeing. Because cyber-mediated disease support groups are pervasive and so easily accessed, with few constraints on participation, the multiplicity of groups and individuals seeking self-help and resources is growing. A 2011 Pew Research report on *Peer-to-peer Health Care* showed 18% of internet users seeking others who have health conditions like theirs and one in four users with chronic health conditions seek others online with their conditions (Fox, 2011). Further, the study noted that over 50% of rare disease sufferers/caregivers seek out others online, highlighting that a worldwide pool of knowledge online was necessary in order to cope with a difficult condition (Fox, 2011).

Kinds of research on online cancer support groups. It is estimated that in 2005, there were 400,000 Internet cancer support groups (Im et al., 2005). Online support communities for breast cancer patients began to flourish in the mid 1990s (Sharf, 1997). Researchers at that time were (and in many ways still are) looking at how communities form and were mainly concerned with information control and how such information seeking would impact patient-provider understanding (Sharf, 1997, 2003). Physicians traditionally have been skeptical of the viability and accuracy of peer support group information; some initial concerns of the lack of reliable discussion have been found to be incorrect (Sillence & Mo, 2012).

To support this idea, Dutta (2007) argues that existing health communication research (Finn, 1999, 2000; Weinberg, Schmale, Uken, & Wessel, 1995; Wright, 2002) confirms numerous advantages of OSGs over face-to-face support groups including freer access in time

and space, anonymity, a mitigation of social anxiety brought on in face-to-face interactions, and the facilitation of ‘hyperpersonal’ communication (Walther, 1996, 2007). The hyperpersonal communication model involves the impression management intentions and behaviors of users working in tandem with computer mediated communication’s (CMC) technical capacities. The process of a synchronous interplay of sender, receiver, channel, and feedback loop works together to create communication events within a minimal cue environment in which it is easier to manage one’s online self-presentation. Such weak-tie (Adelman et al., 1987; Wellman & Gulia, 1999) connections between users may actually enhance a user’s sense of support because CMC interactions are not subject to the pressures that exist in face-to-face, closer tie relationships, thereby providing a certain objectivity to the user.

Users clearly search for support communities of like-minded members who can provide information. Rubenstein (2015) makes connections between social support and information exchange in an informal online breast cancer support groups finding the convergence of the sharing of information and feelings of support between group members’ displays of supportive information exchange to act as sensemaking tools..

Sillence (2013) examined ways the women in an online breast cancer support group constructed their advice requests to target like-minded members to draw upon each other’s experiential knowledge for decision-making and support. Oh and Lee’s (2012) study of an online chronic illness community showed how computer-mediated social support (CMSS) between members of a chronic illness community increased patients sense of empowerment and greater inclination to actively communicate with their physicians. Their findings seem to disconfirm physician’s fears that patients who use OSGs will be misinformed. Finally, Shim, Capella, and Han (2011) researched written emotional disclosure content and its benefits upon online cancer

support group's participants' overall health outcomes. Using keyword analysis, they found that women used more emotional language with women, men used more information-seeking language with each other, and that both men and women experienced web forums as private/intimate places of information exchange, despite web forums being quite public in nature.

While much research of health-related communication in OSGs has focused on participation, information seeking, support and health outcomes (Wright, 2016), less has examined online groups as spaces for alternative disease discourses. Sandaunet (2008) examined communication between members of an OSG of breast cancer patients to determine if the online setting provided freedom for expression of alternative discourses. Her analysis determined that offline dominant discourses were reified by members telling cancer "hero" stories, whereas participants' understandings of surrender and meaninglessness were not "woven into the communication" (p. 1631). Likewise, Garrison (2007) critiques the use of the war metaphor in breast cancer and chronic illness narratives as a culturally sanctioned rhetorical framework, arguing that its use delimits the ways breast cancer patients can talk about their own understandings of survivorship. Moreover, in researching specific topics of discussion among members of a leading OSG for breast cancer survivors, Zhang et al.'s (2017) study of topic classification asked among other questions, "Are there any differences of topic foci among patients of different cancer stages?" Examining OCSGs within which a variety of modes of communication are employed can provide glimpses into processes of meaning making and potentially differing discourses among disease communities.

In brief, OCSGs are spaces where information and support are sought. Members' disclosures (within the confluence of their exchanges of support) tend to contribute to feelings of empowerment. Research exploring ways metastatic breast cancer patients' discursively construct

meanings of survivorship and identity in an online community requires understandings of how they frame such meanings. This is done through individual and collective sensemaking.

Conceptual/Theoretical Frameworks

Framing “Reality” . . . Together

To conceptualize the communication processes that characterize OSGs I borrow Lanqvist’s (2016) notion of support groups as epistemic arenas within which understandings of the disease and of patient identity are understood. Regarding OSGs Landqvist (2016) asks the question, “How do information, knowledge and emotional support go together and contribute to the organizing of an open online health forum?” Landqvist theorizes that online health forums function as communities of practice (Eckert & McConnell-Ginet, 1992) within which are produced local knowledge and affect (feeling). Thus, OSGs existing as epistemic arenas are places where members agree upon what constitutes knowledge for them as well as enacting affect in response to such knowledge.

Mathieson and Stam (1995) contend that, “The narration of illness is often described as ‘trying to make sense of that illness’ and ultimately one’s life” (pp. 283-284). Bury (1982) maintains that the biographical disruption that occurs in cases of chronic illness or acute disease results in a search for meaning of illness and of the self and that these are similar. To circumscribe the domains of making sense of illness, we can apply Goffman’s (1974) *Frame Analysis*, where the implicit question “what is going on here?” is at play.

Borrowing from Bateson’s (1974) term, “frame”, framing analysis, as defined by Erving Goffman, refers to “the organization of experience” (p. 11) done through the primary frameworks of natural and social schemas. Building on the idea of James’s realms or worlds of reality, such schemas contribute to Schutz’s (1945) concept of ‘finite provinces of meaning’.

Schutz (1970) stated, “It is the meaning of our experience and not the ontological structure of the objects which constitute reality” (p. 230). Further, the commonsense world is really the sociocultural world wherein consensus of reality in relation to symbols is accomplished by its participants (Schutz, 1962). Ultimately, our ‘worlds of meaning’ (Stewart, Zediker, & Witteborn, 2004) are collaboratively agreed upon, produced, and reproduced based on symbols representing schemas of interpretation through which individuals understand and respond to events.

Susan Sontag (1978), herself a cancer patient, illustrated and critiqued the usage of the language and imagery of cancer as exaggeration and demeaning ascriptions—including her own public declaration in 1965—“the white race is the cancer of human history.” She rejected cultural interpretations of blame as a rationale for illness; instead, she counseled people to accept illness for what it is—illness. Sontag’s arguments effectively shattered dominant constructed frames of illness and disease by pointing to ways that misuse of language distorts and compounds actual human suffering. Later scholarship (Conrad & Barker, 2010) established the social constructions of illness confirmed the naturalistic and social frames that individuals create to explain illness thus acting as determinants of how they will act within whatever context they perceive the event to have occurred. It is with these frames that sensemaking of illness occurs.

Sensemaking

Sensemaking, as defined by Gephart et al. (2010), is “an ongoing process that creates an intersubjective sense of shared meanings through conversation and non-verbal behavior in face-to-face settings where people seek to produce, negotiate, and maintain a shared sense of meaning” (pp. 284–285). Whittle and Mueller (2012) depict sensemaking as a “. . . process through which people interpret themselves and the world around them through the production of meaning” (p. 114). Starbuck and Milliken (1988) characterize sensemaking as placing “stimuli

into some kind of framework” (p. 51). Such “frames of reference” guide interpretation (Cantril, 1941, p. 20). Putting stimuli into frames contributes to our ability “to comprehend, understand, explain, attribute, extrapolate, and predict” (Starbuck & Milliken, 1988, p. 51) what is going on in the event. It is recurring and contains a series of sequences of assumptions which “serve as predictions about future events” (Weick, 1995, p. 4).

Karl Weick’s concepts regarding sensemaking provide insight into factors that surface as members of communities address uncertain or ambiguous situations. Within illness support groups, particularly late stage disease or chronic illness, uncertainty is regular theme (Mischel, 1988, 1990; Hoth et al., 2015).

The human currency used to accomplish sensemaking of uncertain events, particularly events that are highly interpretive, is linguistic and most often done through the use of metaphors which act as structures of coherence (Shotter, 1993). This particularly applies to member’s interpretation of illness and events within cancer support groups where war, battle, and hero metaphors abound (Sontag, 1978).

Of interest to this project are four of seven of Weick’s (1995) properties of sense making: Grounded in Identity Construction; Retrospective; Enactment; and Social (pp. 20-42). In the social contexts of online discussions of disease, impairment, and death, the basic idea of sense making is that reality is an ongoing accomplishment that emerges from efforts to create order and make retrospective sense of what occurs. The key properties of sensemaking contribute to the formation of frames or metaphorical creations shaped through collaborative construction of what cancer patients determine as identity and survivorship.

Rationale and Research Questions

The goal of this study is to examine how an online support group of MBC patients create, sustain, and repair their own order through discourse(s), thereby framing their health and illness.

I previously outlined the rationales for why the discussion of disease identity and meanings of survivorship fundamentally connect to ways that MBC patients might frame their health and illness. The following research questions guide this study:

RQ1: What interpretive frameworks do members of *The Living Room* draw upon to view their disease identities and survivorship?

RQ2: In what ways do members of *The Living Room* make sense of living with advanced disease? Specifically, what discourses do they use to make sense of their disease?

CHAPTER TWO

METHOD

Research Context

TLR is an invitation-only group of MBC patients and was formed as a sister group of *Booby Buddies* (stage 0-3 breast cancer). The Facebook page for *TLR* reads, "This is a private discussion group for *Booby Buddies* with chronic breast cancer. Other women who are in the group are committed to praying for these women and their needs." Any woman who has MBC can join, but, for the purposes of protection of privacy and to enable more candid communication, prospective members, many of whom formally were *Booby Buddies*, must directly contact the founder and director, Jan James, to join." The membership count at the time of data collection was *TLR*, stage IV=156; *Booby Buddies*, stage 0-3=1062.

TLR was created in response to former members of *Booby Buddies* who had had new or subsequent diagnoses of MBC and who felt that much of the discussion found on the *Booby Buddies* forum did not reflect the challenges and concerns that they as MBC patients were experiencing. For instance, in *Booby Buddies*, discussions centered around questions and answers regarding newly diagnosed or earlier stages of cancer diagnosis, the trauma of hair loss, breast reconstruction, as well as participants' celebratory announcements of completion of treatment or remission status. Members with MBC were typically experiencing very different events regarding their own treatment and prognosis. For example, many of the impairments brought on by the disease, together with treatment side-effects for stage IV cancer patients can be harsher, more uncertain, and can go on in perpetuity. Women with MBC often cannot or do not

want to undergo breast reconstructive surgery, and very few of the members of *TLR* can look forward to a full remission status.

Participants

The participants were twelve women: nine with MBC, three with earlier stage breast cancer, all drawn from *TLR* membership list of 156. Inclusion criteria initially were membership, female gender and self-reported MBC (only). Recruitment difficulties (detailed below) necessitated an amendment to the study's recruitment protocol to include anyone listed as a member of *TLR*, including support members (who may or may not be MBC). The amendment was approved by the IRB. Participants age range was late 20s-late 50s, with one member, age 70 (mean=43 years). Race and national origin were not asked; however, most identified themselves as U.S. citizens and as white. Nine of twelve were married and lived with a spouse. Median income was not identified. Five of twelve (40%) were college educated and three (25%) had graduate degrees. Time since diagnosis of MBC ranged from 3 to 72 months (mean=42 months). Ten of twelve participants had been members of other online breast cancer support groups and five of twelve had been members of face-to-face cancer support groups. Participants were interviewed upon signed informed consent forms and entry to the study occurred over a seven-month period of online support group use.

Participant Observation

My history with *TLR* began in September 2014. A friend from my distant past contacted me to tell me about Booby Buddies. She was a breast cancer survivor herself and recommended the group to me. Truthfully, I was not interested. I have an aversion to groups and did not want to discuss my MBC with others online or face-to-face. However, because my friend invited me, I decided to look at the site out of curiosity. The director, Jan James, contacted me and asked me

to tell my story to the other members of Booby Buddies, which I did, and I then decided to join. I stayed in Booby Buddies for a month or two; but I felt unsatisfied as they were talking about things that I had already been through. A member from *TLR* contacted me and suggested I join them because I was a metastatic patient. I immediately joined because I felt more understood. I have spent the last four years in treatment and during that time have remained a member of this online support group. I have not joined any other support group until recently when I joined my hospital's face-to-face MBC support group.

As a patient, researcher, and a patient-provider teacher/standardized patient I have entered this research context with conflicted feelings. The researcher in me understands that as per IRB regulations, my study is putting my participants at minimal risk. I am not sure that very sick people should be in this category. The patient in me believes I am collecting data about people who are as vulnerable as me; and in some cases, they are facing imminent death. I am compelled by not only the ethical treatment of my research subject(s), but equally important to my project, I myself, as one of them am bound up within the worlds of meaning in which these women who have voluntarily joined the project live. Some big questions circulate often in my brain: How do I effectively and ethically study people who are dying, while I am one of them? Does my altered condition somehow disqualify me as an "objective" researcher? Is it possible to conduct "objective" research when one is living in an altered, seemingly compromised body/mind, while studying other altered, compromised bodies? I have been in the presence of post positivist researchers who almost deride participant research in health communication, calling it "Me-search." Such perspectives do not consider what I and others endeavor to do as serious scholarship, as they do their own research. Viewing participant observation with elements of autobiography (particularly health communication) as less rigorous, selectively

places such research in what some regard as less serious domains such as narrative medicine, autoethnographic writing, or some other type of humanity-based writing. Such thinking is not only illogical, it is seemingly dismissive of the humanness of human science. Admittedly, measuring academic rigor through the prisms of quantitative versus qualitative evaluation is an endless prospect. Rather, studying social and communicative processes in groups of patients is always invaluable to patients, clinicians and the public at large—especially in increasingly digitized, automated, and globalized commons. Who better to do it than one of their own? As an organic part of my community I speak the same language, feel others’ embodied pain and discomfort, have endured similar treatments, and have faced many of the same questions and complexities produced by this disease. Conducting interviews with fellow patients allows naturalistic observation, that is, natural phenomenon unfolding in its native environment. Moreover, as both a participant and observer, I am cognizant that I am co-producing the communication between myself and the interviewee. I am not the omniscient observer. I have composed the questions, I set the pace and tone of interaction, and no matter how objective or empathetic I endeavor to be, I am forever influencing the outcome of the interview event. What I am left to do as an interpretive scholar is to simply and yieldingly allow this relational event to unfold, moving as it will.

Recruitment

As a member of *TLR*, I had access to other members of the otherwise private group. While it was not necessary, I contacted the founder, Jan James (herself a breast cancer survivor, in remission) to request permission to conduct the study, which she granted. I then posted the IRB approved recruitment letter on *TLR*’s Facebook private page where only members could access it. After waiting two full weeks and receiving no response, I then Facebook instant

messaging each member individually, attaching the recruitment letter. After contacting all 155 members individually, I was able to enlist eight of twelve study participants. After more time passed and upon reconsideration, I submitted an amendment to the IRB changing inclusion criteria from members who are MBC patients to anyone on *TLR* membership list and the amendment was approved. As a result of this change, I was able to recruit three additional participants. One of the twelve participants is me. I decided to respond to the open-ended questions that were given to all participants. My responses are included in the corpus of data. The names of all participants (with the exception of me, Ariane) were obscured by the use of pseudonyms.

Difficulties in Recruitment

While the description of recruitment above seems straightforward, the process was more difficult than I initially thought it would be. After the posting of the announcement-invitation on *TLR* page, and getting no response after posting it several more times over a two week period, I then sought to personally instant message each of the 155 members. I tried to personalize each message by starting the message with the person's name and using more accessible language to preface the recruitment letter. Following the initial communication, I attached the recruitment letter. I received some responses and a few women decided to participate. A few others said they would, but when I tried to follow up, they failed to respond. After one or two more attempts to get the women to respond, I decided not to press them; I moved on. Something that I found a bit surprising was that the members who routinely post and seem to be very active-public participants online did not respond to my personal messages to them; and I could tell that the messages were read by them. I wondered how these individuals who could be so free about details of their lives to the group at large did not seem interested in telling their stories to a

fellow member (me). Meanwhile, some of the people who *did* respond to the personal messages said that they were breast cancer survivors, were support members of *TLR*, but not *MBC*. Of these support members several had expressed interest in participating, but they did not fit the criteria of recruitment letter.

To my knowledge, I had exhausted every avenue of accessing the population of this community. I wasn't sure if I needed to change my approach to the members. Did the language I use need changing or did I need to make a more direct appeal digitally? After consulting with my major professors and submitting an amendment to the IRB to include all members, not just members with *MBC*, I re-sent the invitation to all members noting that the criteria had been modified. I received a number of positive responses from support members and eventually the number of 12 participants was reached.

Overcoming Challenges to Recruitment

As I reflect over the access and recruitment process, I surmise that, while researchers may on occasion encounter difficulties recruiting research participants, there may have been some unique issues in mine that made recruitment more difficult. First, there appeared to be a tendency for people to be less responsive to or brush off general invitations, because virtually no one responded for the two weeks the announcement was posted and reposted. This is why I decided to send individual messages to each member. In doing so, I estimate that 35-38% of the members gave me various kinds of responses; I considered this percentage to be fairly normal. A number of the responders to my individual invitation agreed to participate. However, when I attempted to follow up through instant message or telephone, asking them to read over the informed consent, four of them failed to respond to these subsequent communications. It occurred to me that some members, upon consideration or reconsideration might not want to participate in the

interview because it might produce uncomfortable feelings; or maybe they were too busy or not feeling well physically. As a member, I put myself in their shoes, realizing that I, too, might have mixed feelings about talking about MBC to a researcher. As a result, not wanting to put any potential participant at risk, I did not press those members for further responses. Vilhauer (2008), in her qualitative study of the experiences of women with MBC points out that there are two reasons why women with MBC feel socially isolated: first because there is a reluctance to sharing their deeply felt concerns to friends and family and second, because friends and family, despite declarations of support, are not adequately supportive. The nature of online communication was something else to consider. Posting a “vent” or a question on social media is a lower stakes type of behavior when compared to discussing quality of life issues in the context of a personal interview—even if the interviewer is a patient herself. A semi-structured interview with open-ended questions presents a very different kind of feedback loop for the interviewee and interviewer versus an online post with users responding by clicking icons or giving brief responses. Something else to consider in the recruitment population is the state of members’ health. Members may be weakened and ill from the disease, the effects of active treatment and side effects from prior treatments and yet still agree to be interviewed. I am glad some members ultimately refused.

I submitted an amendment that opened the participant population to include all members of *TLR*. I was able to recruit three members who were support members of the community. While the process of recruitment was at times difficult for me (I had some ongoing troubling symptoms and newly discovered cancer and had to undergo radiotherapy) I believe that reaching the final number of twelve participants was good for this study; and the results section will confirm this.

Interview Process

The interviews were conducted over Skype. The length of each interview varied based on how much time each interviewee could devote to it; the shortest interview was 41:46 minutes, the longest was 1:27:30 hours. Each interview began with a short period of getting acquainted. In some cases the interviewee was fairly ill and unable to either breath consistently or was struggling for mental recall. In these instances, I deferred to each individual to allow them to set the pace and allow them to talk freely about what they chose to before launching into the interview proper and throughout the interview. I then went over each part of the informed consent form with each research participant and asked them if they understood and were giving their consent to the interview. Once each member verbally verified their already signed informed consent form I began the interview. After telling each participant that I had a cell phone recording device which I was going to be turning on for the duration of the interview, I pushed record on that device and began with the first of 19 questions (Interview questions can be found in Appendix A).

At certain points of some of the interviews I asked members who seemed to be struggling to breathe if they needed to end the interview. They decided to continue. In general, the flow of the interviews remained consistent. There were moments of laughter in all of the interviews and of tears both on my part and the part of at least one interviewee. I would occasionally note a sidebar to clarify what the interviewee had just said or to relate a short story. At times I had to remind myself to remain silent and conduct the interview question by question. Certainly, my emotions were impacted by the proximal effects of seeing the interviewees face-to-face on Skype and seeing their expressions within their personal surroundings and hearing their stories. These factors made me feel more connected to each of these members, such that, to this day, I cannot forget those connections. I cannot help but make the distinction between digital and face-to-face

communication among support group members as being stark. The interview experiences made all of our stories somehow 'more real.'

Thematic Analysis

The use of thematic analysis as the method by which data is analyzed was chosen for this study because of its accessibility and theoretically flexible approach to data analysis in qualitative research (Braun & Clarke, 2006). Researchers make their epistemological and ontological positions throughout the analysis, so long as clear explanations of the how and why of those positions are made (Holloway & Todres, 2003). For this study, I, as the researcher, chose an interpretive (latent, underlying), inductive (data-driven) approach to analysis of the data set. This does not mean that themes spontaneously emerge from the data for the researcher to discover, rather, it is an active process in that, "If themes 'reside' anywhere, they reside in our heads from our thinking about our data and creating links as we understand them" (Ely et al., 1997, 205-206). The decisions I have made to employ this method (along with the theoretical frame of Weick's sensemaking in organizations) are connected to the ontology of naturalistic observation, used to investigate and understand people's everyday experience. I chose to use the contextualist method, where the reporting of experiences and meanings rests between an essentialist (meanings made by participants) and constructionist (identifying the effects societal discourses have on such meanings), services both the reflection and unraveling of reality (Braun & Clarke, 2006). The interplay between meanings of experiences of participants and the ways in which dominant discourses shape participants' conceptualization of meanings demonstrates the recursive nature inherent in the contextualist method as a tool of thematic analysis.

In identifying a theme, the decision rests upon whether or not the theme captures something linked to the research question(s). Also, key, is the consistency of analysis of the

identified theme. Finally, coding the data from an inductive approach results in data-driven, rich description of the theme. I set about to identify initial codes related to discussion topics tied to the questions. Once I identified related codes I was able to make connections between meanings through the use of mind-maps and color coding. Larger codes were examined through the lens of Weick's (1995) seven properties of sensemaking. I then cross-checked, reviewed and refined each set of small, medium and large or broader codes with each other and decided-upon units of analysis—themes and subthemes. In order to connect the themes and subthemes to the research questions, I applied the epistemology that I use to guide this study: sensemaking of that which seems inexplicable or difficult to comprehend. My rationale for using thematic analysis as well as Weick's sensemaking in organizations (specifically for this study, communities or groups), was reconciled through the selection of clear, coherent, and compelling themes. I am confident that each theme tells a story and makes an argument in relation to the research questions.

CHAPTER THREE

DATA ANALYSIS AND FINDINGS

Sensemaking and Group Settings

Weick's (1995) work on sensemaking in organizations elaborates a process or sequence of characteristics that help serve as an explanatory method when people in groups or organizations experience threats to their identities through downturns, crisis, and inexplicable events. The seven sensemaking properties work in tandem, incorporating action and context. In this study, members come to the group having already experienced significant threats and destabilization to their identities through the diagnosis and ongoing treatment of late stage disease. Weick sums up his seven key aspects of sensemaking that members of groups use in these various settings as a process where: "people concerned with identity in the context of others engage ongoing events from which they extract cues and make plausible sense retrospectively, all the while enacting more or less order into those ongoing events" (p. 18).

It is important to establish *TLR* as the specific site of examination in order to analyze data through the prism of sensemaking. *TLR* (and other late stage breast cancer online communities) is the setting or what Shotter (1983) refers to as "local contingencies" i.e. circumstances, environment where chronically or terminally ill persons interact (pp. 28-30). Within this environment, participants have all experienced primary and ongoing biographical disruptions (Bury, 1982), because there exists for them an uncertain health trajectory. Questions of getting better are rarely asked, rather, the members already have been given to understand that they must anticipate an ongoing management of the ups and downs of their condition. Additionally,

members exist, at least in their other social spheres in a perpetual space of liminality (Turner, 1982) where they cannot return to the community of “the healthy”, for any number of reasons, but instead they interact with and are members of a new community of peers which include fellow patients, clinicians and caregivers. The limen or in-between space where one feels disconnected from normal, work-a-day living with others is a common place that even people in remission status describe as their experience (Little et al., 1996). The breach between health and disease is difficult for healthy people to understand, let alone cross. Therefore, members groups of fellow MBC patients find themselves among the community of the afflicted. They understand each other. They cannot forget that they are sick when they interact. They carry similar things in their bodies. They see themselves in each other.

The Context: Stage-Specific Groups

Like online earlier staged breast cancer support groups, MBC support groups have specific group norms, rules (written and unwritten), and rituals. Stage homogeneity among members in terms of prognosis may contribute to the types and quality of support that stage-specific group members give and receive, yet little research exists that supports this idea according to Vilhauer (2011). To illustrate that disease stage does matter, in her research on mixed-staged versus stage-specific breast cancer support groups, Vilhauer concluded that MBC patients felt silenced and alienated in mixed staged breast cancer support groups because earlier staged members feared becoming metastatic. Yet, MBC patients reported being able to express themselves more fully with each other and felt a greater sense of hope in dealing with their specific issues. Some obvious explanations for this could be that MBC patients have treatments, side effects, surgeries, and psycho-social needs that are unique to later staged patients. Beyond the obvious somatic concerns and seeking of health information by MBC support group

members, are thoughts of permanent loss of health and eventual death—which are things that they are reluctant to disclose but will share more openly in the safety of peers who have experienced them as well (Cella et al., 1993; Dennis, 2003; Gray et al., 1997; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Petersson, Berglund, Brodin, Glimelius, & Sjoden, 2000; van Uden-Kraan et al., 2008a). Research indicates that being among like-minded others in illness support groups impacts patient’s psycho-social health positively. In the following part of this chapter, I present an analysis of the collected data through three main themes: Group ecology, Support: from others just “Like me”, and Distancing.

Group Ecology

Understanding how members of *TLR* came to join the group and their levels of participation helps in determining their specific group ecology. Likewise, assessing the group ecology is vital to answering the first research question that asks how member’s online participation affects their understanding of their illness. In assessing the group ecology of *TLR*, one has to access the group’s mission/purpose statement. The group’s founder, Jan Owen, states on the Facebook page: “This is a private discussion group for Booby Buddies with chronic breast cancer. Other women who are in the group are committed to praying for these women and their needs.”

One does not need to be a Booby Buddy to join *TLR*; however, earlier staged members of Booby Buddies who have found that they are currently metastatic are referred over to *TLR*. There are currently 151 members in *TLR*, with the number remaining between 150-170 over the past five years. As noted in the Methods section of this study, accessing and interviewing research subjects among such a population was not without its challenges due not only to the precarity of

members health statuses, but also because numerous members who were active online participants failed to respond to requests (for various reasons) for one-on-one interviews.

As with most online communities, the utilities of digital communication such as 24-hour access, instantaneous responses, alternative texts such as emoticons, GIFs, Memes, videos, etc. are also employed by members of *TLR*. Additionally, as an invitation-only group, this peer-to-peer community has a layer of privacy or protection which enables members to more freely discuss their disease experiences. Interviewees expressed that they do not feel judged, that they can share just about anything with each other, and experience a high level of support by and connection to other members. As they seek information and social connection, the unspoken rule that ‘we don’t give advice unless specifically asked for’ contributes to interviewees stating that they are able to ask the hard questions and to vent emotions. Further, this group of later stage patients, by virtue of having already been through early stage treatments, is able to tolerate a higher level of ambiguity and uncertainty; this might explain why supportive messages and offers of prayer are offered instead of medical advice or litanies of alternative cures.

Shared Values, Shared Support

Interviewees all expressed the need for support by others like them and reported receiving it from the group. Jaime, a young mother said she joined specifically:

Knowing there was a group for other terminal ladies and I hoped I’d find support since I was so newly diagnosed and so very you (35, and with a 3 yr old and a 7 yr old) . . . I am definitely a ‘vent’er. Sometimes TLR are the only ones who understand. I can go in and vent about how much dying sucks and how I’m so afraid to do it and leave my family and they understand. It’s not the early stagers, so they (TLR) have to deal with the same

issues I do. Making a will, worrying how my kids will adapt when I'm gone, how much pain Neulasta (for bone loss) brings: all things they know and understand.

Shoshanna, a founding member (seven years), talks about support in terms of information seeking:

Think the connection, like we said, I think for those of us that participate more or even those of us who are kind of on the sidelines (who just read through comments and things) its information and finding out what worked for somebody, what didn't work. What new things, newer things people are doing—we can share that with each other, as much as we want or as little as we want. The online part allows you to either be really involved or less involved, whichever you're comfortable with. I think that information trading and experience is the biggest benefit of it.

And Talia, a recently diagnosed member who came over to *TLR* from Boobie Buddies, defines the group's purpose as:

Well, I was going to say to provide support but I think it's more to validate each other and their experiences so that you don't think you're crazy. I mean I don't really see it as any other way. I don't think it's different than a parent support group or anything else it's you're putting something out there because you hope and you want to know that somebody else has gone through that same thing and you're not crazy. . . and I try to be a little bit more active for people who are seeking out if it's something that I know or something I can relate to, I try to be a little bit more active there, to let people know yeah, people are reading, people are watching.

The enactment of some sense of order is a key to an understanding of participants seeking and realization of support. Members conceptualization of their identities as MBC patients shapes

what they expect to find when entering this digital space of interaction. There appears to be an immediate expectation to find specific means of support from two of the relatively new members as well as the five-year member. Naturally, when one joins a support group, they expect support; but Jaime's comments show that this group is one where she can safely vent and fellow members are not like the "early-stagers," but instead they know and understand what she is expressing. Jaime is selecting cues to act a certain way (venting about fear of death) in relation to her online community lending support. Members identities as enacted as MBC patients gives her confidence to act; their online textual cues are implicitly constructed and interpreted so as to reinforce the idea that Jaime will find support for venting her very real fears of death and all that goes with leaving her family behind.

Harkening back to *TLR's* statement of purpose, prayer is mentioned. It is difficult to know how many members consider themselves believers in prayer, but the existence of two prayer coordinators (who switch off every month) signals to members that prayer (requests) is a tool at their disposal. Members who declare themselves atheists, while not agreeing with declarations of faith in a higher being, nonetheless, express a desire to show solidarity with members who share news and requests for prayer by sending "vibes" and thoughts. The use of thoughts, vibes, prayers, wishes, hopes, through textual exchanges is a prominent means of response in this group's ecology of relating. Tacit acceptance by members of the use of prayer is exemplified by Penny commenting about the group:

I don't think it's too religious, I think its pretty general. I mean, you don't have to participate. You can send—uh, what do they say? Vibes. If you don't want to say prayers, you can say vibes. I think that's people that just can't say prayers. That's their opinion. Nobody shoves that down their throat. You don't have to comment. And it's not real

religious based, it's just on there because some people want to be prayed for. . . You can't totally be about nothing about that on there.

Jaime, expresses feeling rage towards God but she explains that there may members who are "very churchy" who might not be very receptive of such raw, honest expressions of anger toward God. She assumes that such members might respond with a platitude such as "God never gives us more than we can handle" and so she shies away posting about her anger toward God. However, Jaime expresses a desire to see *more* interaction on *TLR* because she misses it. What she perceives as a certain type of religiosity from some members has not discouraged her from being an actively participating member.

There is a tension that *TLR* members experience regarding the need for support and regular participation. On one hand, a majority of interviewees expressed a need to feel connected to others who understand (believing they are in a judgement-free zone), and to overcome feelings of isolation. On the other hand, the reluctance to consistent participation is connected to the very nature of having a chronic and terminal disease. Seeing other member's declining health status and deaths acts as a mirror to them. Interviewees reported the difficulty at losing multiple members in relatively short spans and a need to not go online and check other members' status. Vonda, who leads prayer support every other month, says:

I am pretty bad when it's not my month. It's more of an emotional thing. I haven't known the ones that have passed recently, but it gets really hard when like when I am on a month that somebody is not doing well and then that next month, things get worse. . . I tend to get on not as much as when I am doing the prayer requests. Just so emotionally, I can come back in a month.

Vonda's rationale is that in order to lend the best support she can, she needs a break from the intensity and of what other members are experiencing as well as fatigue from caretaking member's news and prayer requests during any given month by taking the following month off. Similarly, Penny, a member who, in addition to MBC, has an interstitial lung disease (stemming from a medicine given to her to initially treat her breast cancer) which is a terminal condition, routinely interacts online to lend support, occasionally to "vent," and to seek information, explains that there are times that she has to stop logging on to *TLR*, "backing off" because, "Ok, I just can't do this. I can't watch all these people die."

And Talia, a recently diagnosed member expresses distress over other members stories about financial and occupational crisis's—not uncommon occurrences for late-stage patients:

Well that has been the more alarming thing that I've read on the Living Room and on Booby Buddies is the amount of women who have lost their jobs, who have lost their homes, who are in financial ruin because of this and that scares the bejesus out of me because I just think wow, I'm so fortunate that I have a job, and that my job provides me insurance, and that does worry me, it worries me at any time. I think it puts me in a different category at work that if they were tired of paying for me I could be targeted...but that's very scary so when I read these things I'm like well how are we not raising money for these people who need that?

Because online interaction can be thought of as transactional communication where the benefits should outweigh costs (as evidenced by predominantly positive online presentations of self [(Goffman, 1959)], as well as the allure of clickbait), it would follow that late-stage cancer patients with significant challenges on multiple fronts might be less inclined to socially engage with others who are facing significant challenges themselves.

My results indicate that needing to engage, but “backing off” of consistent engagement is a feature of the group ecology as enacted by the majority of the study interviewees. As interviewees expressed a need to protect themselves from the effects of reading other member’s decline of health status or deaths as well as other content that may traumatize them, their sensemaking process of ongoing protection of identity construction is evident. Talia, in particular, reveals the threat to one’s identity when she cites stories of members losing their jobs and ability to work because of the disease and how this makes her afraid as she questions whether something can be done amongst members to prevent this threat to identity. This is an example of what Weick (1995) says of sensemaking of identity construction, “How can I know what I think until I see what I say?” (p. 20). Talia’s discursive identity construction implicates her and others together as vulnerable chronic cancer patients. Acting off of cues of stories she has read about patients losing income, job, and insurance, and remembering (as retrospective) that she herself may be occupationally and financially vulnerable, she invokes collective action (enactment) to socially repair what she perceives as a real need or breach for patients. She is cognizant that it could happen to any one (plausibility) on *TLR* or Boobie Buddies: including her.

Overall, this group’s ecology as shared by interviewees is informed by the utilities of digital communication and the seeking of emotional support and information from others who are MBC patients. Important features of this group’s shared values and motivations to note are the consistent offering of prayer support and in spite of a consensus that *TLR* is a highly supportive group, numerous members express a need to “back off” when there are perceived threats to their identity as patients.

Support: From Others Just “Like Me”

MBC patients live in the context of “contracted time” (Bell & Ristovski-Slijepcevic, 2011, p. 629). Qualitative researchers identify the isolating effects of the disease as impacting MBC patient’s overall psycho-social health (Butler et al., 1999; Hall et al., 1996; Oh et al., 2004; Davies & Sque, 2002). Certainly, a cancer patient’s perception of his or her own contracted health trajectory contributes to the already isolating effects of having the disease. Therefore, the need for social support is identified as an important strategy for patients living with MBC, specifically in terms of women being able to share their thoughts and feelings (regarding living with the disease) to family members and close friends (Willis et al., 2015). As a highly supportive online environment where women with MBC seek out other women with MBC for support and hear each other’s stories (Mayer, 2010), *TLR* fills numerous needs for support for members among which are: a need for connection, a need to give and receive support, a need for information, and a need to construct or restabilize one’s identity.

A Place to Feel Less Alone

All but one interviewee expressed the need for social support as a reason for being a member of *TLR*. Many expressed the need for information as a part of that support. Based on their comments, their need to be literally (digitally) and figuratively (emotional and instrumental support) connected functioned as a deliberate strategy to cope with effects of MBC as well as to establish some sense of normalcy. Penny describes how her twin conditions, her “double trouble” cause her to feel isolated:

One of the really weird things with this disease is even though you don’t try, you’re secluded. Because, you don’t feel like getting out. And when I go back to my hometown, I don’t want anybody to see me with this thing on. I just don’t want to get into it with

them, I don't want to talk about it. I don't want to hash it over. I don't want them going, Awww, Awww—NO. I don't want sympathy about this. I don't feel like that. I don't want them looking at me like that. Forget it. I'm not doing that.

She goes on to explain how her daughter-in-law plans family vacations, rarely taking into consideration Penny's limitations of not being able to keep up physically because she cannot breathe and therefore cannot walk up hills or steps. She sees her adult children and her grandchildren as going on with their busy, eventful lives and feeling separated from them. Being told by people who are well that she looks great for having cancer only contributes to further feelings of isolation. She wants to feel included without feeling like a patient. After joining *TLR*, because she believed that everyone there was just like her, she was surprised at how "good" it ended up being for her because of the care that members show each other in their responses. She didn't think it would be as personal. Selena, a nurse in her late twenties who deals with significant issues from brain tumors, joined when she was diagnosed with metastatic disease:

How I fell into the Living Room though was after I turned metastatic, that was darkness—black—I did not know where to go, I had no compass, no roadmap, totally didn't see it coming, didn't know what the next step would be, so I was reaching out to anyone with brain cancer. . . I was able to connect with people that had breast cancer that metastasized to the brain so even though it was in different parts of the brain—and that also ultimately affects...I don't want to say your outcome, but I don't know what the word I'm trying to say is. Sorry, I'm blaming the brain tumor on that. You know how different parts of your brain affect different things, like speech, vision, hearing, mobility, creative thinking, speaking, all that, so you're not going to find someone who's exactly like you because we're all so different. But being able to hear how those people have

lived through it and how they've dealt with it and how far out they are, that gives me a certain sense of hope.

Selena expresses the need to know the worst of the worst, so, that way, she can anticipate it. She believes, that as both a nurse and a patient, having this information will help her cope with the unknowable when it comes to brain metastases. But she also expresses a need for hope to be able to hear other patient's stories, and live through what others have gone through, thus living her best life with MBC and brain tumors. In her case, information is a tool of support but is contingent on the stories of others outcomes.

Kasandrea, who has survived with breast cancer for twenty-eight years total (MBC for five years), is a member, but chooses not to participate in discussions. She sees the purpose for her need for support among MBC patients as a need to build on the intimacy we all share regarding a shared diagnosis. She says she is a private person, doesn't have social media down to her own comfort level and has mixed feelings about online communication while admitting its importance. She sees support groups and this particular online space as a place to be able to say anything and a place for group members to be curious: to think of their diagnosis not in terms of waiting to die, but to ask themselves, "what exactly do I want to do with time I have right now?" Her ideas of support revolve around living a vital life while coping with the uncertain trajectory of the disease.

The Need to Show Support

Members of online illness communities are most often motivated to log on to their sites to seek information or support (Preece, 2003). Interviewees responses regarding support and interaction on *TLR* indicate that the *giving* of support is also a need that members have from time

to time. For example, when I, Ariane, a five-year member, age 59, mother of five, answered my interview questions, I stated that I viewed the group's main goal as:

To respond to the unique needs of MBC patients who are members. To have a space to discuss things that virtually no one else, except a fellow MBC patient might be able to understand about living with MBC. To support members through response, feedback and prayers.

My response here is two-fold, to get support from others and to lend it. Indeed, as I have moved through five years of living with the disease and participating with my online community, I have found that in equal parts, I seek out answers to dilemmas, request prayers for test, procedures, new chemo treatments while, at the same time, I scroll through each member's status and posts and seek for ways to support them through prayers and words that don't minimize what they are going through, but instead respond with something meaningful to show that I have not just clicked and emoji, but that I share their concerns. I do this because I am constantly aware that I could be them and they could be me. I see sharing my empathy as employing a kind of shared support.

As mentioned previously, members usually refrain from giving advice or offering hope for recovery. Not having any easy answers or the ability to fix other's dilemmas provides an environment where members produce support through what Kaufman and Whitehead (2016) describe as 'reciprocal empathy' where the sharing of empathy produces strong supportive effects. Empathic responses to unfixable circumstances is a form of action or enactment used by interviewees. A potential by-product of reciprocal empathy is a sense of normalization where peers, having shared similar stories, strengthen their disease identities by doing emotional identity work together. The showing of empathy is an enactment which is the result of

retrospective memory—a lived, figure-ground experience—within which members in the present see through a backwards cone of light and thus impute meaning onto their present environment (Weick, 1995, p. 30). What is happening in the present certainly affects the meaning built into the retrospective event. Hearing other’s difficulties and uncertainties (as well as their good news) and responding with empathetic responses is what Weick, speaking about enactment, would characterize as “How can I know what we did until I see what we produced?” (p. 30). Here the action is the showing of empathy. In terms of respondents act of empathizing it is with the hope for each other’s (and could include their own) more uncertain rather than predictable futures.

As a support member of *TLR*, Laura, is a long-time member of Boobie Buddies (six years), in her 50s, and is in remission. She sees her participation, in addition to giving helpful information (if asked), as offering prayers, input, encouragement, and to tell stories of what has happened to her. She says that she currently accesses *TLR* more regularly than in the past when she was authoring devotional books for breast cancer patients. She describes herself as having a sense of urgency in giving immediate support to members because she has seen many women from the site die.

Connie, a founding member, former breast cancer patient, early 40s and a mother of five, and a former military service member, provides direct support to MBC members of *TLR*. She conducts numerous fundraisers to directly fund patients as well as providing direct support to members online. She explains her history of involvement with *TLR*:

So, *TLR* was started and I just grew into it. One, because I saw—I had seen ladies come in, and then move over (from Boobie Buddies). You know, you switch over to *TLR* when you are stage IV. And I just love them, and I want to do whatever I can to support them. . . because I could be them tomorrow. And, there go I but for the grace of God.

You know. I am in Behavioral Health, so what I do for my job, I am doing for the ladies. So, let's visualize our next life; let's visualize our next plan, like a second act, whatever. And I am really trying to do that for them. And in the Pink Sisters yard sales, I am poor cause I have five children, that's what funds everything. Because I get all this stuff donated for these care packages, but then it's 200.00 to mail them all out. A yard sale will fix that. So, I kind of like, creative. . . I love them. Every day has a TLR or Boobie Buddy girl in it in some way.

Weick's properties of sensemaking apply here because identity construction is a facet of the giving and receiving of support. Cancer is the "it" that is foundational to the dialogic events that occur in *TLR*. The direction between causality and events through which individuals think about themselves is contingent upon what one thinks "it" is and how "it" defines the self. Connie's identification with cancer and her connection to it serves as her rationale to be directly involved with members on a seemingly daily basis; so too does Laura's sense of urgency. The self is involved in both the receiving and giving of support and informs the unmistakable identity work that is happening. Members like myself engage in the giving of support as a way of reinforcing the idea that I am still able to be on the "outside" of patienthood when giving encouragement and solidarity to others. I see my identity from a place of greater strength. Admittedly, I find it harder to be on the receiving end at times because I may feel very weak or afraid and less autonomous. But I also am aware that allowing others to give me feedback and encouragement contributes to their own sense of autonomy. In this multi-directional relationship of the definition of events and self within the setting, we all as members find ourselves adapting to our own need for what Erez and Earley define as (1) a need for a positive cognitive and affective state about the self; (2) motivation to see the self as efficacious and competent; and (3) the need for self-consistency—to

experience coherence and continuity. These three modes of self- efficacy motivate us to construct a patient identity that is not merely a victim or subject, but rather an active participant who can give and receive support.

Information as Support (Or Not?)

It should be noted that the distinction between support seeking versus information seeking behaviors is not being made in this study. The research literature examining each of these dominant online illness forum behaviors is vast. Based on participants responses, I identify the need to seek information by any of the participants as serving the dual purposes of both fact finding and social interaction for them. For example, Talia states she asks questions of members because online is immediate and to confirm information previous information which might be construed as fact seeking, but she needs confirmation from her peers:

The questions I ask are about things that are happening in this moment that I need an answer to, for example: I have this cold. Am I going to be sick longer? You know what I mean? Because the doctors just kind of look at you and say, Well, you should be fine. and I'm like, mmmm but am I?

Selena, a nurse, has been helped by asking for information because:

They answer a lot of questions for me and things that I don't expect. . . I like to fall back to where there's more of a population and I can just ask everybody and they can give me their input. . . I want to hear everybody's take on what I am wondering.

The need for information and to connect with other's stories (other's "take" or experiences) is intertwined. Lisa, who is in her late 40s and a five-year MBC patient, expresses the need to log-on and read others stories of good news, yet she purposely avoids logging on because she doesn't want reminders every day of the mostly difficult things that MBC patients are going through.

Initially it appears that Lisa does want social interaction; speaking about other *TLR* member's good news she says: "Actually that is nice, cause that does give me hope. I say to myself, okay, I'll be there one day. It's okay. It's the other stuff that I know that I might be there someday, that I just don't want to think about." However, in response to the word "support," she says:

Yeah, right, as soon as I see the word support or, what's the word, social? Immediately, I don't want to know. I don't want to hear, I don't (want) nobody to give me, psychobabble that you think you know what I feel because—nobody does.

Lisa is making her own clear distinction between her consumption of positive versus negative stories, updates and statuses. She gains emotional support, hope, from positive news, freely admitting that she "might be there someday." Yet, her definition of support is decidedly a negative one of emotional prescriptions or platitudes, "psychobabble", despite her knowing that the group consists of MBC patients like herself. This distinction may stem from past negative feedback from others regarding her diagnosis, or any number of reasons for not wanting to interact with fellow patients. Her desire to maintain this distinction is rooted in her desire to maintain normalcy, to cope in her own way; yet this is identity construction in relation to others, nonetheless.

The need for information sharing according to Shoshanna is a form of connection:

I think the connection, like we said, I think for those of us that participate more or even those of us who are kind of on the sidelines (who just read through comments and things) its information and finding out what worked for somebody, what didn't work. What new things, newer things people are doing—we can share that with each other, as much as we want or as little as we want. The online part allows you to either be really involved or less

involved, whichever you're comfortable with. I think that information trading and experience is the biggest benefit of it.

Whether or not Shoshanna defines connection as being social and supportive or purely digital is not clear; however, she goes on to relate that the “dynamic of everybody being in different places” yet always being available is a crucial feature of being a member of a social media group like ours. Having another member available at 3:00 or 4:00 in the morning to talk to when she can't sleep—having another MBC patient like her—always to chat with, has been very important to her. This indicates that she feels social support when she cannot sleep, is perhaps anxious about something, and needs to chat.

Weick's (1995) discussion of enactment of social environments ““where the activity of “making” of that which is sensed”” results in people producing part of the social space they are a part of (p. 30; see also Pondy & Mitroff, 1979). In cyberspace, we use texts of all kinds to represent our interactions. We make visible or tangible to ourselves and others what we are all producing in digital common spaces to the effect that we can all see what we are thinking. The giving and receiving of support by MBC patients in online groups serves as a form of coping with the ups and downs of chronic illness as well as contending with uncertainty. As Shoshanna points out, knowing that she can connect with someone like herself, someone who is “out there” at any given time, an “encountering” of her online environment is an enactment of her faith in what she will find once she connects, even if she chooses to not interact and merely sit on the sidelines.

The need for and displays of support on this site are socially acceptable and encouraged. As such, this illness community a decidedly social space for members to enact their perceptions of their illness and their expectations of other MBC patients while accessing their shared

knowledge base in ongoing ways that serve to stabilize and redefine their identities. This ongoing need for connection, a need to give and receive support, a need for information, is made sense of by members in tandem with how they view their identities as individuals, patients, and members of *TLR*. But members also indicate that there is also a need for space from interacting. This can be understood as distancing.

Distancing

“Sometimes with all this going on, ignorance is bliss”

—Vicki, MBC participant and nurse.

The benefits of accessing online support groups are numerous: ease of utility, instant access, rapid response and connection within multiple time zones to name a few. Additionally, users can easily display different presentations of the self on multiple platforms and still remain relatively anonymous. And then there is what is called lurking. Lurkers, according to Technopeida (2019), are:

Internet users who, rather than participating in interactive websites such as social media platforms, only passively observe information and do not reveal information about themselves. These passive users may view text and images, download information, visit other people's profiles or request information through the Internet, but do not post, update their profiles, share links, use social media indicators or otherwise create an online or social media footprint.

Participation in support groups or group forums has its share of lurkers, perhaps more than average users realize. In fact, most of us do some form of lurking ourselves at one time or another and most online users lurk. Research on the role of lurking in online health support group contexts reveals it as both an active participation process (Han et al., 2014) and also as

contributing to more positive health outcomes (Fullwood et al., 2019). In other words, there is a cost attached to engaging publicly whereas, choosing to watch and collect information may be beneficial to the lurker. Such research argues against a lurker/engaging dichotomy. Through my analysis of *TLR* interviewees I identified a propensity (of eleven out of twelve members) to avoid engagement with fellow MBC patients online at various times and for various reasons. These eleven did not act as pure lurkers, per se, as much as they were at times disinclined to participate—to put distance between themselves and thoughts of their diagnosis. The following examples and analysis will include the sensemaking rationales that members employ as they navigate a tension of needing support and avoiding connection.

Social Exchange and Support Groups

Communities of late stage cancer patients are formed for these two reasons primarily: firstly, for participants to talk about and begin to grasp the physical and social challenges of their diagnosis; secondly, to probe for meaning and lessen some of the socially isolating aspects that late and end-stage disease brings. These two primary reasons are why I sought out a face-to-face MBC group to join at my area cancer center. Prior to joining this group, I had been skeptical and resistant. Instead, I held myself at a distance for several years and chose to interact with other MBC patients via an online community. There, online, I could sit on the sidelines and scroll and observe and occasionally comment, without any real discomfort. It took me years to place myself, physically and emotionally, in front of others like me and hear their stories of pain, unresolvable issues, ups and downs, and to experience their potent emotions. I could not click off. I had to sit and feel. This was new for me. Honestly, I wanted to run out of the room a few times. Their stories and the presence of their bodies were beyond potent reminders of what I was

living in at those precise moments. Seeing the marks of cancer and treatments on their and my own bodies was at times too much to take.

I tell this not to merely illustrate the very obvious difference between digital and face-to-face support group communication—I personally do not prefer one over the other because I see each providing distinct means of support for very different needs—but to say that having now experienced both kinds of communication helps me to understand why people like me need to distance ourselves from our disease experience in the ways that my interviewees describe when engaging in online with other MBC patients. To take a breath, a pause, to assess and to ask ourselves who and what we want to be today.

If one applied Emerson and Cook's (1976) social exchange theory to online support group (OSG) membership behaviors, one could conclude that there are different social commitments respecting cyber-connected versus face-to-face engagement. Less time between exchanges would be one difference; another difference might be users' sense of obligation to each other primarily because digital communication affords us more privacy and anonymity if needed. For example, I might feel a greater sense of social obligation (cost/benefit) to my face-to-face group members because I attend my weekly group regularly, spend an average of 2 hours devoted to getting there, and participate because they *see* me and I *see* them. Whereas, if I log on to *TLR* a few times a week spending most of those brief minutes scrolling through news and posts and responding to a prayer request or two, I do not feel as obligated to stay in regular contact with my online MBC members primarily because of my time investment. Beyond that, my face-to-face engagement may seem more real to me thus more future investment on my part.

Distancing to Avoid

In western polite society there are topics that are routinely avoided: death, disability, sex, bodily functions and disease to name a few. To work around our discomfort, we employ the use of euphemistic terminology to soften the blow of stark reality i.e., “So sorry he passed away” Instead of “So sorry he’s dead.” Or, “Um, that’s interesting behavior for a chairing a meeting.” Instead of, “Um, he is an incompetent moron.” Further cloaking of language occurs with women, such as myself, who have had mastectomies being told by healthy others, that the “up” side to having cancer is that they can get a new set of breasts or thank God we don’t have brain cancer. We rationalize to ourselves that we speak in these ways to protect others, but is that all there is to our supposedly innocuous statements ostensibly spoken to mitigate discomfort in the other? Such communications are used to maintain facework (Goffman, 1959), both our own and others, as part of the practice of politeness theory (Brown & Levinson, 1987). It is hard for a disabled person or disease sufferer to hear: You have a disease that I am terrified of. Conversely, it is hard to say to someone else: I am dying. And so, we avoid such talk. Online illness support groups exist as places where participants can write, post, hear, see, and respond to similar others, things that they may normally not say in polite company.

Connie, a support member, highlights what she sees as an important feature and purpose of *TLR*:

To give women a voice. A place where they can be honest and say these raw feelings—that you can’t say to your family cause you’re being brave for your family. Your doctor, you don’t have a lot of time with your doctor and he doesn’t have this, so in the case that nobody knows but you, you are the only one that truly knows what Jasmine and Rachel (or whomever) are going through. I don’t. Cause my fight ended. And you guys are still

at war. So, you guys are the only ones that know that and you guys need that place to talk about it.

Connie's reference to raw feelings can be interpreted as intense emotional disclosures by members to each other. In this online space, it is safer to disclose such things whereas it may not be face-to-face with one's family or oncologists. While it may be considered axiomatic that personal disclosures in online illness support groups (because of anonymity and distance among other features of online exchanges) lead to increase psychosocial benefits for patients (Shaw et al., 2006, 2007), distancing through avoidance (a subtheme) for the majority of these MBC participants helps them control information flow.

Lisa, a member who chooses not to participate in *TLR* says she purposely avoids all support groups:

When I go in to FB, I don't want go to see about how we need to pray for this one person because she was just rediagnosed or she's gonna start up chemo. I mean, I understand everyone and all of them need prayer at one time or another and I do understand that but for me, selfishly, I don't want that reminder everyday and to me, it's everyday.

Lisa does want to influence the flow of information she receives about others. She does not want to know all the details of other MBC patient's negative experiences nor does she want reminders of her disease—that she could easily be them. There is no way of knowing whether or not Lisa lurks; however, based on her previous comment about her responding hopefully to positive news and posts, she may not completely avoid online activity regarding other MBC patients. She would like to manage the information about her disease and prognosis that she gleans on her own apart from what she may perceive as negative stories or statuses. Even though Lisa is a non-

participating member of *TLR*, her perspective of managing what information she exposes herself to serves to preserve her self-efficacy and is grounded in identity construction (Weick, 1995).

Likewise, Vicki, a nurse, who is being treated for acute pleural effusions and finds it painful to breathe states a need:

to hear from other people who've responded to treatment with a plural effusion. But I am just afraid to put it out there. Cause what if I hear back from them and they were not successful? Cause I don't want to hear that. So that's what prevents me from putting that out there.

Vicki clearly has a need for information but is afraid of the answer(s). Later in the interview she returns to this discussion:

I wanted to say one more thing about that Facebook thing and why I don't want to go on making myself vulnerable to anyone else with this particular diagnosis or treatment. It's the same thing why I don't google pleural effusions, you know, I've never done that from day one. And I caught myself last night doing that, and I was like, "Just step away", That's what I always tell anyone who's recently diagnosed, do not go on google or Facebook.

Vicki avoids new information and struggles with controlling what she accesses despite the professional advice she gives to her patients. Her vulnerable condition causes tension between her need to know and desire not to know. Both Vicki and Lisa's sensemaking are examples of enactment of sensible environments where what they do next, that is, the activity becomes the making of the cognition that preceded the action (Thomas et al., 1993; Weick, 1995). As they state what they think out loud, it does not matter if it is contradictory or perplexing. For them it is a way for them to *see* what they said and thus do the next action that seems logical to them.

For Vonda, a prayer support coordinator, distancing through avoidance for her is quite simply the need to recharge emotionally to be able to meet the challenges of the next month.

I am pretty bad when it's not my month. It's more of an emotional thing. I haven't known the ones that have passed recently, but it gets really hard when like when I am on a month that somebody is not doing well and then that next month, things get worse. . .I tend to get on not as much as when I am doing the prayer requests. Just so emotionally, I can come back in a month.

Some members expressed guilt feelings (survivor guilt) for sharing with other members their good news of being NED (no evidence of disease which means remission). Jaime explains that she avoids time spent on *TLR*:

It used to be daily, but then I just stopped. I still see the posts on my Facebook feed, but I rarely comment. I think I don't comment or interact because I'm not currently in any treatment and responded so well to my first line treatment that I'm now NED and I feel like a fraud giving advice to others who are fighting for their lives still. I do still check in sometimes to see if there's anything I can help someone with or to mention that I'm praying for them. Or to check if people have died and I just haven't realized it, since I'm being honest.

Jaime engages with member's posts to remain connected to them, but she freely admits that she distances herself because being NED puts her in a different space from those who are not. Yet, she too lives with the fear of recurrence and requires as much support as those who are in active treatment. Her status as both a survivor in remission and a "mester-sister" as she describes herself, exemplify the interplay and complexity of member's identity negotiation and construction in this community.

Distancing as Protection

When asked, “What posts, discussions, or news have been the most upsetting to you and why?” I, as a participant, answered “Obviously, the deaths of or members going to hospice.” While members going to hospice does not necessarily mean they will die, my thoughts almost immediately go to ultimately the death of that member. As if to confirm this, I usually look to see if that person has had a prior series of decline in health status to determine if they will be able to leave hospice. If I read a notification that a member has died, I am devastated emotionally. I feel shook up, as if psychically displaced. If I am honest with my feelings and attempt to grieve, I immediately log off. Many times, however, I ignore those feelings and instead feel an obligation to extend comfort by posting what words come to mind. What is better? To feel the raw grief of fresh loss and dread of death myself? Or to throw my feelings into making others feel better? Many of us walk this tightrope regularly. We feel the push and pull of the weight of our illness and the specters of what we imagine awaits us. Our cognitive reasoning and our social interaction are so enmeshed (Walsh & Ungson, 1991), that we often forget that we are making sense of our illness and losses together and that this is an ongoing process to which we adapt.

Protection and Loss

As a founding member (six years), Shoshanna demonstrates the ongoing sensemaking she makes when exposed to loss. She sums up what numerous interviewees expressed about needing to distance oneself and assess what is happening to others, thus oneself:

I’m on FB all the time. TLR is one of my, they update it regularly, so I see it all the time. But I’ve been lately and what not sort of the watcher. An outside view and don’t comment too much or put too much feedback in. I think the other part of the difficulty is when we do lose so many and that’s just all we’re seeing for several days is this one

passed and the next day we've lost another one and lost another one. It's hard in the idea that you think about their family, you think about what they've gone through and the people that are left behind, but it's impossible to not turn it back to yourself and think about that, we do it all the time. Sometimes it gets too much and so I just sit on the sidelines and kind of watch them. And unfortunately for my own protection, if it is about somebody, I just kinda scroll by.

Shoshanna's disinclination to interact is the result of her sense of the ongoing flow of life and death. Weick's model would suggest that she is singling out this moment here and that moment there (as focused on and extracted cues) from the complexity and enormity of loss of life. She needs a map, *any* map (Holub, 1977) to help ameliorate the feelings of hopelessness that could overtake her. Rather than avoid going online, Shoshanna says she logs on to Facebook most days. Her *map* directs her to sit on the sidelines as "a watcher," and scroll while she avoids news of people's decline or death. This is her understanding of engagement with her feelings of loss and grief (for others and herself). Notice that she has no intention of completely "unplugging" either temporarily or permanently.

Talia says she doesn't post very much on *TLR*, in part because she considers herself an independent soul: "it takes a lot for me to want to be with a group of women and just groups in general and then here's this sensitive subject and it's like, argh!" Talia's reluctance toward engaging in this group and its discussion topics is borne out of a need for self-preservation. It could be characterized as, "How can I know what I should avoid if I see what I shouldn't see?" to paraphrase what is going on here. When asked about why it is hard to participate Talia responds to Ariane in this exchange:

Talia: I think for some people they don't participate because they fear the answers they're going to get. I think the Living Room for me...uh...that's hard. *Talia tearing up*

sympathy from Ariane

Talia: Yeah. So I don't post there a lot either because that's just hard.

Ariane: Yeah, it is hard. The unknown...

Talia: Because it's not like going first class getting upgraded. It's an upgrade because it's more serious. So I wonder if people don't connect there because it's just too hard.

Ariane: Yeah, I agree. If we are...

Talia: I wasn't going to cry at this. But yeah, that's my answer to that question.

The raw emotions expressed by Talia as she considers the cost of participating in a group of fellow MBC patients indicate meanings that lie just below the surface of her mental and emotional life stemming from coping daily with metastatic disease. Her mention of people refraining from participating because of fearing answers that are too hard to take may be something she, herself, is afraid of; this statement opens her up to emotions that she may be protecting. As she finds herself in the middle of the ongoing-ness of sensemaking (we are always in the middle of things, that we make into things through language), Talia's language is creating the situation she and she assumes others find themselves in (Weick, 1995, pp. 43-44). She goes on to describe MBC status as not being promoted up (to first class), but instead, being given a serious status that truthfully, no one would ever choose, let alone talk about with regularity.

TLR member's ongoing sensemaking helps them explain the need to distance themselves through self-protective behaviors such as avoidance of loss and death, perhaps the ultimate threat to one's identity. This idea is tied closely to identity construction and is also a function of ongoing sensemaking: ways these participants understand the term survivor.

Survivor of What?

Meanings of breast cancer survivorship have gone through a stark metamorphosis in the last 50 years, ranging from a once private and stigmatized disease to contemporary disease discourse which evokes the cultural metaphors of fighting, war, heroism and virtue. Such metaphors have fueled enormous public support of the breast cancer survivor identity. Images of predominantly white, physically fit, upper middle class, heterosexual females who triumph over the disease by sheer optimism and willpower have overshadowed the stark reality that despite billions of dollars spent for Breast Cancer Awareness marketing and initiatives for races for the cure and early detection, death rates for breast cancer have remained relatively static. The differences between representations of breast cancer awareness and survival statistics leave some breast cancer patients struggling to reconcile their own personal experiences with dominant images of survivorship. For instance, MBC patients consider current definitions alienating because of their own fears of the disease progressing in the context of the positive entailments of metaphors of fighting and beating the disease. One response to isolating messages on the part of MBC patients is to formulate their own discursive ideas about survivorship.

Current Definitions of Cancer Survivor

The term cancer survivor has been refined over the past forty years due in part, to more patients living with cancer as a chronic condition. Today, Fitzhugh Mullan's (1983) definition seems to be one commonly adopted definition: *“survivor”—anyone diagnosed with cancer—from the time of diagnosis through his or her life.* Similarly, The National Cancer Institute defines a survivor as *“One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor*

from the time of diagnosis until the end of life.” (NCI, 2019). And the American Cancer Society currently adheres to the following definition:

The definition of cancer survivorship has evolved from a focus on three phases (the time from diagnosis to the end of initial treatment, the transition from treatment to extended survival, and long-term survival) to encompass a wide range of experiences and trajectories. For example, some individuals may live cancer free for the remainder of their life after initial treatment, while others may live with cancer as a chronic disease or experience recurrence or a subsequent cancer. (ACS, 2019)

Mullan’s rationale for his original definition is better understood when he says, “A lot takes place after treatment, and that is the recuperation phase. You’re dealing with uncertainty, your identity and vocation” (Cure Today, 2006). The ACS extrapolates Mullan’s rationale out to include chronic disease, recurrence or a subsequent cancer (Mullan more than likely may have included these threats with which cancer survivors routinely contend). Metastatic patients are conscious that more than likely they must live and die with their disease which includes living with uncertainty, and threats to their identities, vocations and financial solvency. For many metastatic patients/survivors, the term cancer survivor extends beyond perpetual therapies well into all domains of survival. When asked what the term *breast cancer survivor* meant to them and why, members’ responses were broken down into two categories: an embrace of current definitions, with a subtheme of distinctions; and a resistance to current definitions, with subthemes of distinctions and alternative definitions.

Embracing Current Definitions

Fewer than three of interviewees responded in terms of confirming the currently understood breast cancer survivor discourse. These members used metaphorical terms of

understanding, such as warrior, fight, battle, beating cancer, a journey, as well as characterizing their cancer diagnosis as a transformative, redemptive event in their life. Respondents who see their survivor identity as primarily defined by current disease discourse still maintained their own discursive elements. For example, Vicki, a nurse, says:

I consider myself a survivor from that moment I felt the lump in my breast. Because that's when the game starts. You know, that's when the nightmare begins. And you're already, um the waiting and the diagnosing. And so, I've always considered myself a survivor. And I've tried to live my life that way. Those first few years out of treatment you really live with that fear of it coming back. And it kind of goes away a little bit. I mean, I was seven years out; I was hiking mountains, doing, I mean, living life.

She goes on to make a distinction apart from the traditional idea of survivor from the moment of diagnosis: "I'm striving to thrive. Now, you know, the thriver term is so big now. And, so, I just, I absolutely believe I'm a survivor. And, and until my last breath, I'm a survivor." This last statement comports not only with survivor from diagnosis to death, but with an alternative definition that has become more popularized since MBC issues have received more coverage in news, research and marketing. Vicki, as a health care provider and a patient finds herself living between two discourses—a predominantly bio-medical/marketing discourse and a more recently adopted identity, as a "thriver."

Laura, a support member, who herself was diagnosed stage 3 and has been in remission for seven years, responds positively to the question:

Wow. It means it involves a total change in my life that I had no idea, a new road that God had for me to walk down. I was a science major. I was not an English major. I never in my life thought of writing a book. But I ended up writing one and then two more and

now I speak and do retreats with my daughter and I have countless notes from women tell me what my book, the cancer book, meant to them. It's been an unbelievable blessing to me.

Lisa sees her experience as transformative symbolizing a change and a new road. Her perspective is fundamentally rooted in her faith in God, therefore redemptive. What is considered a curse for many is considered by Lisa as a blessing. Academic scholarship that critiques the marketing of the breast cancer identity as a positive, transcendent experience, would argue with notions of seeing a deadly disease as a blessing, especially without interrogating the structural inequalities and environmental causes of the increase of the disease (Ehrenreich, 2003; Goodman, 2013; King, 2006; Sulik, 2011; Youde, 2009). Laura goes on to say that she is a survivor, "Because I have no cancer in my body anymore." Penny, who contends with lung disease and MBC says:

To me, I feel like I am a survivor, but it's weird with that title breast cancer survivor. Cause survivor means you beat it. But I know we're all considered survivors because we're here. But to me. . . it's a battle. It's a battle you have to fight every day. It's like a part-time job. If you let it, it can consume your whole life.

Penny casts the definition from day of diagnosis until death in terms a battle and a vocation that can consume one's life.

Vonda, a stage 3 survivor in remission for five years, responds to the question making some distinctions:

. . . It's like the world will say, "Oh, you're a survivor only if you beat it." I don't see that as that. I see it as somebody who has had to deal with that diagnosis, regardless of their beating it or if they are still in chemo or if it's taken over their body, or whatever, we're

all survivors. I mean, every day you survive you're a survivor. So, I think, I know that a lot of people with metastatic, they don't necessarily call themselves survivors from what I've experienced. I think the better term is warriors, it's someone who has been diagnosed and has given it all their all, no matter what they decide to do. If it be herbs or chemo. . . Or nothing at all. It's kind of whatever you decide to do, but once you get that diagnosis, you are a survivor no matter what you decide to do.

Vonda's definition alternates in a variety of ways between current and alternative definitions. She includes all people in all stages of breast cancer as survivors, every day—a current definition. Yet, she concedes that MBC members might not want to be called survivors and ascribes warrior as a better term, characterizing them as having given it their all no matter what they choose to do. At the end of her statement, there is an element of patient autonomy given to MBC patients who decide to “give it their all” by choosing alternative treatments or none at all.

Speaking of giving it your all, several members said that they are routinely told by healthy others, “You look great!” MBC patients find that these comments marginalize them as survivors because people are looking for outside markers of being in active cancer treatment such as being bald, being in a wheelchair, or some other signal of impairment. Connie, as a stage 3 patient, said she enjoyed tremendous support from her fellow soldier in her army unit when she was bald. But when she returned to the unit, experiencing great pain from neuropathy (a permanent effect of chemotherapy) which disabled her from PT, she found that the same unit was far less supportive to her. She maintains that having had her hair grown back in made the difference of people's level of support shown.

For the past five years that I, Ariane, have been a MBC patient, I have been told that I look good or great, usually by well meaning, healthy others. I do not recall such statements when

I was undergoing treatment as a stage 3b patient. When I was bald, swollen, had sores all over my face from the ravages of chemo, displays of pity were more common. It is not that we MBC patients are offended by this. We get it. But we do we realize that people who are not afflicted the ways in which our bodies are naturally have trouble grasping impairment, disability, and living with a deadly disease. We should also understand that as humans we all are governed in social interaction by the powerful cultural symbols of health and illness (Blumer, 1969). As a result of pink culture, we do not find ourselves being celebrated by the public or viewed as survivors in the ways that earlier staggers are. Even so, being misunderstood or overlooked because we do not always carry bodily markers that typically evoke sympathy is the least of our problems. Most of us, when and if we can, get up each day and try to live our lives in more meaningful ways as we manage our disease and all that goes with it.

Resisting Current Definitions

Nine out of twelve respondents, all MBC patients, responded with answers that run counter to the motifs found in discourses of courage, strength, heroism, virtue, and ability. With those perceptions and distinctions, some members had alternate names for breast cancer survivor. Jaimie calls herself a Metaviver. She unequivocally says:

Nope. Not at all. Even with 3 years of NED under my belt, I still don't feel like a survivor. Lana told me I'm a survivor from day 1 of diagnosis, but I just don't feel that way. I'm a Metavivor. I have a disease that will kill me. Sure, right now I'm uber lucky and I'm in remission. But that can disappear in a heartbeat. How can I be considered a survivor if I always have that lurking over my head? A survivor would get over it and move on. I feel like I'll never really move on. I'm trying, and doing a decent job at it, but I still don't feel like a survivor. The only thing "survivor"-y is the survivor's guilt.

Jaime's alternative construction of how she is living with the identity of a MBC survivor in remission is decidedly clear that Metaviver means she has a disease that will kill her. Despite being in remission for three years, she feels she can never really move on. Other members express similar perspectives of not being able to move on, always being in survival mode, not being able to "ring the bell" when completing a course of chemo or radiation (because more than likely, you'll be back for more), and being a full-time patient.

Kasandrea comments that about the term breast cancer survivor: "I hate the word and its implications of winners and losers." She rejects the term and the consequential effects it has on the ways others might orient themselves to the disease. In an earlier comment about her need to be "normal" and not need any more than others (people without a chronic disease) highlights ways that Kasandrea views her disease experience and identity:

I've been extremely lucky to be living this long and with amazing medical care. I've felt special in my care and always well listened to and respected. I've been continuously treated at XXX for 28+years, through thick and thin. I know I'm not different than anyone else, it's just I never thought cancer would kill me or given it all the attention it often demands. As I've gotten older, I have no idea. I know I'm living with too much information about myself, I am tired of so many doctor's appointments and deal daily with very high degrees of ambiguity and uncertainty all the time. It's hard to make plans.

Varying alternate ways of understanding their disease experience ranged from making distinctions to actual critique of pink culture. For instance, Selena, a young survivor, a nurse, is also a writer and public speaker. She characterizes much of what she does as a MBC in terms of fighting and persistence. "I consider myself a Metavivor or a lifer or a breast cancer patient, but I would not say I am a survivor anymore." Talia, a mother of preteens says, "We've actually

banned the pink. I told everybody after day one: I can't do pink. We're not subscribing to pink. I can't do it. We do cardinal red because I am huge baseball fan." Lisa calls the term, "Just a slogan." I (Ariane) note, "I think putting the burden on the breast cancer patient to fight by following all the prescriptive behaviors (so the public doesn't have to feel so bad) is a shitty way to frame and market disease." Shoshanna, who is a mother and whose mother was diagnosed with breast cancer at the same time that she was, says this about the term survivor:

Yuck! I don't think it necessarily gets taken away when we get our MBC diagnosis, but I don't consider myself a survivor anymore, because I won't survive this. We won't. And the stuff, the pieces and parts that we go through now are different. It's ongoing, it's all the time, and the survivor part has to go somewhere else. I really like Thriver. I've heard that one a lot in some of my groups. I like that one a lot better because we're living with MBC and we're always going to be living with it as long as we're here. And that encompasses a lot of things as far as the treatments and being patients and everything that comes with that. But survivor is a little too victorious and sunshine and rainbows to what MBC is.

This member eschews the term survivor because of the ongoingness of the disease experience as well as the metaphorical understanding she has about early stage disease compared to late stage. One inference to be made is that if MBC is *not* sunshine and rainbows, then it is perhaps the different pieces and parts that we go through constitute something less bright and promising to the MBC patient. Since we won't survive this, we have the choice to view our identities as Thrivers.

I Am Gonna Be Okay

Lisa tells a story about people who told her that she was in denial about her view of survivorship:

. . . Here locally, the breast cancer foundation, I don't know, Susan G Komen, had this thing where they go get the cancer survivors and go dress you up and put a wig or pretty hair thing on and they put make up on you, you know, they beautify you and take a picture of you. And, when you're done with that, then they post that picture out there. In our situation it was at a mall. And everybody's picture, and underneath you're supposed to put down what advice you've got or what are your thoughts, something like that. And I think my response was something like "pretend that it is a really bad cold, that its going be like having a really bad cold, that I'll get past it," or something like that. People would respond like, "She's in denial." No, I am not in denial. Because I know whatever it is, I am gonna be okay. And, I am. I am. It's not denial. Tomorrow, they say, "Sorry, no, it's over," well, that's not today. So I am okay.

Lisa's sensemaking about her identity as a MBC flies in the face of the ACS and well-known breast cancer awareness industry leaders such as Susan G. Komen. She rejects being beautified and having to say things like fight, strength, and victory—all things that a feminized disease discourse expects from women and mothers. "Having a really bad cold" is not usually found in the lexicon of breast cancer awareness inspiration-speak. Lisa resists feeling the pressure to inspire others, refuses to participate in breast cancer awareness survivor discourse and, in essence, has gone off on her own to say, "I am gonna be okay."

Members responses illustrate their attempts at making the word survivor sensible to themselves and other MBC patients in relation to their identities. Their commonsense world is

really a sociocultural world wherein the consensus of reality is reached by the perceptions of participants using the affordances of language and symbols (Schutz, 1969). Metaphors are powerful examples of this, as they are sites for authoring of experience. As Sontag argues in her classic work on *Illness as Metaphor*, the commonality of war and battle metaphors has meant that cancer (and the term survivor) is entangled in a social context of the entailments of winning and losing. Within their own epistemic arena (Landqvist, 2017) participants expressions of their ideas about survivorship act as tools with which they are negotiating and renegotiating their metastatic identities; this is because in organizations there is a need to maintain a consistent narrative of self. In settings such as *TLR* where mutability of the self is especially fluctuating, texts of the self are informed by texts of the other and environment—in this instance, the text that members are responding or reacting to is the dominant survivor discourse. Interviewees in their responses to this question maintained their own coherence and consistency in their attempts to understand the current definition of survivor while at the same time constructing alternative terms/names for and understandings of breast cancer survivor.

CHAPTER FOUR

CONCLUSION

Understanding the discursive ways frames emerge and how sensemaking is constructed within those frames is the goal of this study. Examining the framing of illness/disease and the construction of survivor discourse and identity in an OSG of MBC patients will fill several gaps in health communication research. First, exploring ways disease discourses influence patient identity and notions of survivorship in an online space among members who are chronically and acutely ill is needed for patients like me. I acknowledge that I and other members of my community may either embrace or eschew circulating discourses that construct breast cancer victims or she-roes or something in between. However, identifying the functions of the properties of collective sensemaking in this community is a way to potentially help us to manage the uncertainty of our disease.

Secondly, my research addresses a crucial area of research needed by clinicians. I maintain that clinicians are indeed interested in patient's subjective understandings of their patient identities and their illness overall. To illustrate, in my work with healthcare providers as an intimate women's health examination instructor, clinicians routinely affirm in our sessions the need for patient perspectives. Acting as a liaison as both a standardized patient and teacher, I see my position as literally filling gaps of clinical encounter communication with my live body on the table, my health communication expertise, and the communication of my patient subjectivities. During debriefing, participants express appreciation for patient feedback being

given through this unique training encounter. Being able to identify sensemaking constructions in a peer-to-peer OSG like *TLR* may provide new insights to patients own understanding of their experiences thus contributing to patient-provider communication scholarship.

Ultimately, I write to a general audience comprised of patients, potential patients, clinicians, academics and the general public. I want my work to be accessed by all.

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