



## HEALTH, CULTURE and SOCIETY

### Meanings of Breast Cancer Survivorship Among Members of Ethnically-Identified Support Groups

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Vol 9–10 (2016–2017) | ISSN 2161-6590 (online)

DOI 10.5195/hcs.2017.213 | <http://hcs.pitt.edu>



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## Abstract

Research on both cancer survivorship and support needs has been limited in its attention to survivors from culturally-diverse communities. This study examined the perspectives of members and leaders of ethnically-identified breast cancer support groups regarding the meanings and expectations attached to survivorship. Semi-structured interviews were conducted with 38 African American and Latina survivors in Central Florida. Participant narratives invoked themes of spiritual renewal and deepening religious faith, and deemphasized individual responsibility for personal change. Participants emphasized the importance of shared cultural identity in shaping the survivor experience, and some Latina women drew parallels between survivorship and the challenges of migration to a new country. An unwavering display of optimism was held to be paramount. These themes are interpreted within the framework of the interplay between dominant societal discourses of survivorship and locally-constructed meanings. Findings underscore the importance for healthcare providers to be cognizant and respectful of diverse perspectives on illness.

**Keywords:** *Cancer, survivorship, ethnicity, illness narratives, support groups*

# Meanings of Breast Cancer Survivorship Among Members of Ethnically-Identified Support Groups<sup>1</sup>

K. E. Dyer; J. Coreil

## I. Introduction

“Cancer survivorship” as a general concept is gaining increased attention in the United States. The term “cancer survivor” was coined in 1985 by a physician after his own cancer treatment, and has since gained currency (Kaiser, 2008), with the cancer survivorship movement generating momentum primarily in the late 1990s (Park, Zlateva, & Blank, 2009). In essence, survivorship refers to the long-term health and well-being of people who have been diagnosed with cancer, and views post-treatment quality-of-life and follow-up care as critical components of cancer care. This more holistic framework represents a deviation from an almost-exclusive focus in the past on physical survival above all else, and comes partly as a result of increasing survival rates in recent decades (NCCS, 2010).

In the ensuing years, scholars have focused on understanding the intricacies of life following cancer. Sociologist Arthur Frank has described this new state-of-being as the “remission society” (Frank, 1997, p. 9), in reference to any illness (not just cancer) in which the sufferers get better but are never considered fully healthy—just in remission. In this society:

Members [...] do not use one passport or another [to get from the land of the sick to the land of the well]. Instead they are on permanent visa status, that visa requiring periodic renewal. The triumph of modernist medicine is to allow increasing numbers of people who would have been dead to enjoy this visa status, living in the world of the healthy even if always subject to expulsion.

The study reported in this paper was undertaken in response to the recognition that cancer survivorship research has been limited in its attention to culturally diverse patients and survivors. Existing research on the meanings of life after cancer diagnosis and treatment, and on survivor identity, has been conducted primarily with Caucasian, middle- and upper-class American women diagnosed with breast cancer (e.g., Bell, 2014). Limited research has been undertaken on the ways in which diverse populations conceive of long-term engagement with cancer and its treatment-related side effects (Kaiser, 2008). Further, a survival gap between Caucasian women with breast cancer and African American and Latina women is well-documented, with the latter experiencing significantly higher mortality rates (Shavers & Brown, 2002; Newman & Martin, 2007). These disparities indicate that the experience of breast cancer and its treatment among women of color may be significantly different.

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<sup>1</sup> The views expressed within are solely those of the authors and do not necessarily represent the views of the Department of Veterans Affairs or the United States government

These differing diagnosis and treatment experiences may also contribute to differing support needs. Studies with breast cancer survivors have found that African American women have difficulty relating to mainstream cancer support groups and prefer attending groups organized specifically to meet their unique cultural needs (Erwin, Spatz, Stotts, Hollenberg, & Deloney, 1996; Moore, 2001; Mathews, 2000). It has been argued that these support groups, by potentially representing a different model of support, may serve to address the reported gap in support group participation among African American women (Michalec, Van Willigen, Wilson, Schreier, & Williams, 2004). In this paper, we argue that the meanings of “survivorship” and the expectations attached to the survivor identity will also vary, and that these expectations arise from life experiences and cultural values espoused by women who share a common social identity. These views of survivorship underpin the cultural models of particular support groups, and shape the characteristics of support and ideology offered to their members.

Accordingly, in this paper we present themes from a study examining the perspectives of members and leaders of ethnically-identified breast cancer support groups on the meanings and expectations attached to the survivorship experience. Our desire to learn more about the study groups was sparked by our interest in the emergence of ethnically-identified breast cancer support groups in central Florida, USA in the years following a study we conducted in 2000-2001 (Coreil, Wilke, & Pintado, 2004). At the time of the earlier study, the only breast cancer support groups in that geographic area were sponsored by the American Cancer Society and local hospitals and served a general population of predominantly middle-class Caucasian women. Beginning in 2007 we conducted a follow-up study with these emergent ethnically-identified groups that focused on cultural models of recovery, perspectives on support group participation, and meanings of survivorship and the survivor experience. Findings related to successful recovery and support group participation are reported elsewhere (Coreil, Corvin, Nupp, Dyer, & Noble, 2012; Corvin, Coreil, Nupp, & Dyer, 2013). Here we describe the meanings of breast cancer survivorship emerging through the relationships and interactions of women who felt that ethnically-identified support groups fulfilled a common set of needs not addressed in support groups serving the general population, and for whom “survivorship” was seen to mean something distinct.

## II. Meanings and Discourses of Breast Cancer Survivorship

Little and colleagues (2002) argue that while cancer used to be “shrouded in social silence” (2002, p. 170), discourses around it have increasingly begun to circulate. While these themes primarily concern illness narratives and identity, rather than a focus on those who have survived, more recently narratives that reflect public understandings of cancer survivorship have appeared (e.g., Bell, 2014; DiGiacomo & Sumalla, 2012; Ehrenreich, 2001, 2009; Frank, 2012a; Segal, 2012; Sinding & Gray, 2005). Indeed, as Frank (2012a, p. 196) observes, over the past 20 years survivorship “has become an industry, trading in expectations and self-images,” which stands in marked contrast to the stigmatized silence on cancer and survivorship several decades ago. In most of these recent works, the term “dominant discourse” references widely-held ideas or assumptions about the nature of both cancer survivorship and cancer survivors themselves. These collectively-held assumptions have alternately been termed “cancer stories” or “cancer narratives” (e.g., Segal, 2012; Frank, 2012a). As Frank (2012a) further notes, some of these “will be dominant, others will be oppositional, and still others will be unspoken” (p. 206). We use the term dominant discourse in this paper to refer to these assumptions.

An important area of social science research has investigated the relationship between the dominant discourses that circulate in society and the “local” meanings of an experience that are constructed by individuals (Rappaport, 1990; Somers, 1994). For an individual, the meanings attached to an illness experience are shaped by particular sociocultural and historical contexts, such as ethnic background and identity. However, in creating a personal narrative, individuals may draw upon dominant discourses that often reflect deeply-held Western interpretations of illness, such as the importance of optimism and achieving control over illness through a positive attitude and “fighting spirit” (Wilkinson & Kitzinger, 2000).

Scholars have identified a number of dominant discourses relating to breast cancer survivorship, such as those of personal transformation, sisterhood, triumphalism and optimism, and the hero-warrior mystique (Brody, 2007; Collins, 2007; Gray & Doan, 1990; Honea, 1997). The optimistic, positively transformed, feminine, empowered, “immaculately groomed and seemingly at peace with the world” (King, 2006, p. 102) breast cancer survivor is an image that pervades both the media and advocacy realms (Ehrenreich, 2001, 2009; King, 2006), and has been the subject of both reverence and critique. For example, Bell (2014) argues that, because of the attention given to breast cancer by media and advocacy organizations, discourses of breast cancer survivorship have structured images of cancer in general, thus shaping the experiences and perceptions of survivors of other types of cancers.

Critiques of these survivorship discourses—emerging from both academic circles as well as individuals affected by cancer themselves—have pointed to their potentially negative implications. As Deimling, Bowman, and Wagner (2007) note, “even among those who are likely to survive cancer, the expectations created by the survivorship orientation risks creating a ‘blame the victim’ situation where individuals feel overly responsible for their own survival” (p. 764), a situation that may be aggravated in the event of recurrence. Indeed, existing narratives of cancer as a “battle” to be fought and conquered are laced with notions of personal responsibility and victory, suggesting that those who lose this battle have somehow fallen short and are undeserving of the title of “survivor” (Pertl, Quigley, & Hevey, 2014; cf. Stoller, 2004). Indeed, dominant discourses are not accepted uniformly and uncritically: Wilkinson and Kitzinger (2000) found several areas of resistance to the expectation of optimism in their study with breast cancer patients, while Sinding and Gray (2005) detailed how participants in their project consistently challenged several assumptions about survivors, most notably the expectation for positive self-transformation. In a study on cancer-related fatigue among survivors (Pertl et al., 2014), participants often rejected the depiction of a cancer survivor as a “strong and positive individual who has battled and prevailed rather than someone who . . . has gone through a difficult ordeal that has left them weakened or with continuing problems” (p. 149). In our earlier study of breast cancer survivors participating in mainstream support groups (Coreil et al., 2004), we found that some participants contested the dominant recovery narrative of unwavering optimism. They expressed negative views of the “cheerleading” components of meetings, and challenged leaders’ efforts to steer discussion away from alternative perspectives.

### III. Methods

The themes presented in this paper are drawn from a mixed-method study conducted with ethnically-identified breast cancer support groups in the Tampa Bay and Orlando, USA areas. As part of this study, semi-

structured interviews were conducted with members and leaders of four groups. Two of these groups were formed to serve African American women with breast cancer, and the other two served Latina Spanish-speaking women. Our methodological approach was drawn from naturalistic inquiry (Lincoln & Guba, 1985), in which we examined the perspectives of members of naturally-occurring groups in their own context (Coreil, 1995). This methodological approach complements our interpretivist epistemological framework, which holds that “what people know and believe to be true about the world is constructed or created and reinforced and supported as people interact with one another over time in specific social settings” (LeCompte & Schensul, 2010, p. 67). We included in our sample all active ethnically-identified breast cancer support groups in the study area. A total of 38 interviews were conducted, 33 with group members and five with group leaders. Nineteen participants belonged to the two African American-serving groups, while 19 belonged to the two Latina-serving groups.

All of the groups functioned independently of the health care establishment and were peer-led. One of the African American support groups was the local chapter of a breast cancer organization serving African American women, and the other group was faith-based and met at a local Baptist church. A regional cancer center provided meeting space for one of the Latina groups; the other was based at the private office of an obstetrician-gynecologist. Each was organized by a charismatic leader who reported seeing a need for support groups that serve culturally distinct communities. Three of the five leaders had been treated for breast cancer themselves. The fact that all groups were peer-led is important given the occasional tendency in the support group literature to gloss over the distinction between peer-led and professionally-led groups. As Gray and colleagues (1997) assert, the “self-help approach [tends to emphasize] member empowerment and avoidance of hierarchy, while professionally led groups emphasize leader guidance and intervention” (p. 280). The significance of this characteristic in the context of our study is a point to which we return below.

Interviewees were recruited on-site at weekly meetings of the four support groups, and given a choice of location for their interview. Most interviews were conducted in participants’ homes. The interview guide was translated into Spanish by a professional transcription/translation service for use with Spanish-speaking participants. All Latina participants were interviewed in their preferred language by a bilingual (English/Spanish) research assistant; 16 of the 19 Latina interviews were conducted in Spanish. The University of South Florida Institutional Review Board approved all aspects of the research and maintained ethical oversight of the study, and interviewees gave informed consent for participation. Participants were paid \$30 each to compensate them for their time.

Interviews were audiotaped and transcribed verbatim; text files were imported into MaxQDA, a qualitative software program, for coding and analysis. We used an inductive analytic approach that captured themes emerging directly from the interviews. Research team members developed a codebook, and transcripts were coded using the constant comparison method wherein new categories emerging during coding were compared to previously-coded transcripts and incorporated until no new themes emerged (Bernard & Ryan, 2006). Each transcript was coded by a pair of analysts, including one person who had participated in the interviews and one person who had not. Spanish-language interviews were coded by the bilingual interviewer and by a bilingual, native Spanish-speaking research assistant. Inconsistencies in coding were discussed and reconciled in meetings. Coded transcripts were then analyzed for commonly expressed themes and areas of dissent to gain a clearer picture of the important areas of agreement

relating to survivorship. Finally, preliminary findings were presented to three of the four support groups (two African American groups and one Latina group); feedback from these sessions helped to refine the interpretation of results.

### **Participant Sociodemographic Characteristics**

All participants self-identified ethnically in concordance with their respective support group membership: in other words, all members of the African American-targeted groups self-identified as “African American” or “black” themselves, while all members of the Latina groups self-identified either as “Latina” or “Hispanic.” Thus, ethnic identification was participant-driven and not assigned by the study team; what we refer to as an ethnic group is based on self-identification with “ethnoracial” categories (Dressler, Oths, & Gravlee, 2005).

The average age for African American participants was 59.5 years, and for Latina participants it was 51.9 years. Half of the participants were married (eight of the African American women and 11 of the Latina women), although an equal number of African American women also reported being divorced (eight versus six Latina women). The average number of children for both African American and Latina women was two.

Differences between African American and Latina participants were found in educational attainment, religion and birthplace. African American women on the whole had higher levels of educational attainment—the largest proportion had received some secondary education (eight), a college degree (five), or an advanced degree (two), versus some high school or a GED (four). The most common level of educational attainment for the Latina women was a high school diploma or GED (nine), followed by a college degree (six), an advanced degree (two), or some secondary education (two). The vast majority of both groups described themselves as adhering to some form of Christianity; however, while 15 of the African American women identified as Protestant (and none as Catholic), about half of the Latina women described themselves as Catholic and the other half as Protestant. Only one of the Latina women was born in the United States; the rest had moved to the country as children or adults. All but one African American woman had been born domestically.

## **IV. Findings**

The present study investigates the meanings and expectations attached to survivorship among women who participate in ethnically-identified breast cancer support groups. Major themes emerging from the interviews include participants’ identification with the survivor terminology, growth and rebirth, sisterhood and bonding, and the importance of optimism and a positive attitude. In the discussion section, we examine these themes in relation to dominant discourses on breast cancer survivorship in order to better understand how multiple social identities shape survivorship beliefs and experience.

### **Survivor Identity and Terminology**

Ten African American women and nine Latina women used the term “cancer survivor” in response to interview questions, either in reference to themselves or to someone else. Because we did not use the word “survivor”

in the interview guide, this identification was unprompted. That slightly over half of the participants spontaneously used survivor terminology points to its growing significance in diverse populations for framing cancer narratives. Participants explained:

Once a cancer survivor, always a cancer survivor. I survived. And because I survived I want to help somebody else survive (African American, age 63).

One of the things is that we don't speak of remission. It's gone. It's not in remission. We don't live by the five-year rule that you are sitting waiting for five years to say you are going to be a survivor. No. You are a survivor the day that you are diagnosed. And every day that you live after that, you are a survivor (African American, age 49):

[The support group leader] explained to me: "starting today, you are a survivor." Many people think that you are a survivor after five years . . . and she said to me, "no, because today you're battling cancer, and it is one more day that you survive this disease" (Latina, age 53).

For many women, "survivorship" had varying timelines. For example, a Latina participant believed that survivorship began after her treatment was completed, reflecting the myriad ways in which the concept was interpreted and managed:

I've only been out of treatment one year. The doctor told me "the minute you get it until you are alive, you survive," but to me it's just a year because that's when I finished my last treatment. So, October 6th of last year is only one year off finishing my treatments. I'm very fresh (Latina, age unknown).

One striking aspect of the interviews was the reliance on and importance attached to being around other survivors. According to many women, only other survivors could understand the experience of treatment and survivorship, and their support was seen as qualitatively different from that offered by family or friends.

You need somebody who knows exactly what you've gone through . . . You need somebody there for you who knows what you are going through, who knows what you need (African American, age 63).

My baby sister, she tells me, "I know how you feel, don't worry about it, we are here for you." I looked at her and I said, "you do know how I feel? When was the last time you had chemo?" She goes, "Oh no girl, I'm not talking about that feeling." Don't use it on me, then! . . . I told her, "You do not tell a person 'I know how you feel.' No. You don't." Now I can tell that to a person who is going through it. I DO know how you feel because I went through it (Latina, age unknown).

The importance of shared experience is particularly salient considering that three of the four peer leaders of these support groups were breast cancer survivors themselves. A participant in an African American group reflected on the significance of this:

It's a great encouragement having our leader, and I'm not sure whether it could have been any other leader if they had not had cancer, but having our leader to have had [cancer] and to be such a nice person and willing to donate her time to do this [is appreciated] (African American, age 73).



A related aspect of this perspective was the idea that family and friends cannot truly relate to an individual's experience with breast cancer. Indeed, significant others often just want to "fix the problem right away," leaving other survivors to fill the void left by that lack of support.

The family, okay, they support us, but they have not gone through what we have. But those [other survivors] . . . they know because they went through what you have. The family could say "ah forget it, it will pass, the pain." They say it, but they are not feeling it. Those [other survivors] did feel what you feel, which is different (Latina, age 57).

Only a few participants claimed that cancer had not affected their lives. This may be a function of where recruitment took place—in support groups, where women are seeking help and support through a process because it has ostensibly impacted them somehow. However, it is significant to note these cases: perhaps they are important precisely because they are less likely to occur in this particular context.

Well, for me it didn't affect so much. When I was under treatment I was really feeling uncomfortable, feeling bad with the whole experience, but after that sometimes I don't even remember that I had cancer. I heard some people really kind of lingering, "oh, I had cancer." It's part of my life. It's part of my past. And let's go on with life (African American, age 50).

No, no. No, no. Cancer changed nothing in my life . . . I have had a normal life, and I haven't been depressed or anything like that (Latina, age 60).

In order to establish a positive identity as a survivor, some Latina women felt that they had to first deflect any question of moral culpability, a disclaimer not mentioned by African American women. These narratives invoked a discourse of moral rectitude, refuting the idea that past "improper" behavior, physical trauma, or other lifestyle choices not conforming to social norms might be linked to breast cancer etiology. Anthropological studies of Latina cultural models of breast and cervical cancer have reported such beliefs (Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995; Hunt, 1998), where "breaches in the social order, and of proper and improper behaviors. . . [and in particular] interpersonal aggression and improper reproductive behaviors" (Hunt, 1998, p. 303) are attributed to the development of cancer in individuals. Some of the Latina women we interviewed made reference to these etiological explanations in affirmations of their own virtuous lives:

The first thing one thinks is that this is a punishment from God . . . This is important. It is not a punishment. I think one tells oneself: "He is punishing me for having done this or that in the past." You know? I learned it is not a punishment [from God] (Latina, age 43).

Yes, they had more defined ideas and they came to me with some stories, like "when I was young I hurt myself" or "I carried my grandson on my shoulder and he hit me with his head" . . . And none of that, none of that will cause it. Then I had to bring them books, because my word wasn't enough. That's when I started changing a lot of their beliefs and when someone new came with the same story they would tell them, "no, this is not so" (Latina support group leader, age 53).

## **Growth and Rebirth**

In general, participants in this study focused on the positive and transformative nature of their breast cancer experience. For both African American and Latina survivors, breast cancer was perceived as a catalyst for positive and beneficial change. For all women, but particularly the African American participants, this transformation was marked most strongly by a deepening faith in and reliance upon God. Positive individual transformation was seen to occur in tandem with the journey of faith. This finding cross-cut both the African American support groups, one of which was faith-based and the other secular. The following statements demonstrate the importance of participants' faith in God through the cancer experience:

It has helped me to mature actually as a woman of faith. It has helped me because I know I had to rely on my faith to get through it and when we talk in class and when we pray for one another it has really strengthened my faith even (African American, age 63).

I'm just a vessel. God pours into me and I just pour it back out to somebody else to help them to get through this. And it's nothing but a journey. You have to take this journey one step at a time. One day at a time. It's all you can do (African American, age 49).

Although the growth of faith was a theme expressed among Latina women, they more often drew a parallel between the transformative impact of cancer on their lives and the challenges overcome during migration to a new country. As stated above, all but one had immigrated to the United States at some point during their lives. The migration experience was seen as preparing these women for the challenges faced by undergoing cancer treatment and the long-term struggles of being a breast cancer survivor. Survivorship was likened to a "rebirth," conferring opportunities for a new life. One woman who came to the United States from Ecuador cited her migration experience as having prepared her for the "good fight" against breast cancer, by having "life challenges" to face, such as being alone in a new country and not knowing the language. "I am not a coward," she avowed, and "I don't give up." Set against the backdrop of migration, she attests that "it's not like cancer was the only thing" she had to deal with. Likewise, another woman explained:

No, it was not a difficult decision [to have surgery]. In my case it wasn't [difficult], because perhaps I am a woman that has had to make very tough decisions in my life, living in a country with my children, without my family, the language, alone. It was an immediate decision, I mean, I did not have much time to think and that's it. I think that in the moment the courage came to me, "no, take it out already" (Latina, age unknown).

## **Sisterhood and Bonding**

References to "sisterhood," "fellowship," and "bonding" were common among participants. As discussed earlier, it was extremely important for many participants to be around others who had "walked the same path," since other survivors are best able to understand the trials of surviving breast cancer. Participants in our study specifically sought out ethnically-identified support groups from which to receive support during their cancer treatment and beyond, and they also emphasized that non-survivors are unable to truly understand the trials of cancer. This conjunction of identities—gender, ethnicity, personal experience of cancer, and in the case of the Latina women, shared language—served to solidify the bonds between women in their respective groups. African American participants explained:

I feel real warm to African American ladies because they are of my color, they seem to sympathize more with you, and I feel more of a family around them (African American, age 73).

There is a difference between African American culture and white American culture . . . And we, as Latin and as African American people, we have more life in ourselves. We are more lively. We are more spontaneous. We are more, even more tactful, more caring. Not that white Americans are not. They are caring. But it's a different way of seeing life. They are more socialized in a different way. They are more rigid; they don't show emotions (African American, age 50).

[The support group] is just for us. And whether we realize it or not different cultures have different needs, different, just say different needs (African American, age 62).

In a related vein, several African American participants noted the need for cancer survivor role models of the same ethnicity. One woman explained:

Especially in the African American culture, we never had a lot of role models to relate to as survivors. Not so much role models but when you saw a lot of commercials about survivors, breast cancer survivors, you never saw a lot of African American females. You are starting to see it now but you didn't see that [before]. So when our community sees that we've got some women here surviving doing this thing and so if another woman is diagnosed she knows (African American, age 49).

Among the Latina participants, a sharing of their native language became a unifying force—thus, both shared survivor status and a common language were crucial for these members in being able to obtain meaningful support during their cancer experience:

I became a volunteer for Reach to Recovery. I was the first Latina volunteer and I wanted them to give me the patients who speak Spanish. And right now I am full of patients. And I would go to see them in the hospital and I would knock on their door and say “Hola. Buenos Días.” And those eyes [would light up] to hear something in Spanish. “Oh you speak Spanish! Where are you from?” And the connection was done—I didn't have to say that I have gone through the same thing. We were united by language more than by the disease (Latina, age 53).

This is a very important union. Because we are all Latino and come from different countries. And we are in a country that is not our country. And being here—that unites us. You know, because our own language, but in different countries. Latinos, Americans (Latina, age 56).

Latina women placed the greatest emphasis on shared cultural features, such as music and making ethnic foods available at support group meetings. During the interviews, they frequently cited the importance of shared culture itself. One of the participants explained:

I think culture is obviously a huge thing . . . It's that personal thing. And I'm thinking it's stuff that you cannot list or check off that's hard to describe. Something about your interaction. The nuances. I think it's all about the nuances. When you greet somebody, how you stand. How you hug them, what you do (Latina, age 33).

## Optimism

An overarching theme in interviews was the importance of maintaining an optimistic and positive attitude in the face of cancer. Participants, especially African American women, repeatedly emphasized the role and potential power of positive thinking (or conversely, the detrimental effects of negative thinking), reflected by the following quotes:

When you are very negative, things happen, and if you stay positive and joyful it won't happen (African American, age 62).

I believe you can recover but it has to do with your attitude. If you go into it feeling defeated, if you see it as a death sentence, most likely you won't make it (African American, age 62).

I have always been like that; I didn't want to see myself sick. I wasn't sick; they had removed my cancer already so I had to recover and that was a process. So, positive, always positive and that's what I recommend to anyone. If not positive, the immune system will become weak. If you lower the immune system, the medication won't take effect, you'll get depressed, you'll have to take another medication, that medicine will counteract the previous one and by the time you realize it, you are not who you used to be (Latina, age unknown).

The importance of a positive outlook even extends to accepting defeat, exemplified by the statement of an African American woman, age 62, who believed that “death is not so bad if you can go through it and have a positive attitude.” Another woman elaborated on this theme through her explanation of “hope” and achieving a peaceful closure in life:

Hope to me would mean that either I'm going to make it or I'm not going to make it, but that's not a horrible thing. You make whatever length of time you have left be a good experience. If it's just closing up all of the loose ends that you need to close up, having some time that you have, the time you have left to say goodbye to friends and be with them in a positive way. If it means to say I'm sorry for some things I've done in the past or whatever, but to have a positive closure . . . Not an ending where I'm dragging my nails in the ground trying to hold on and it's time to go. To be able to release it and be happy about it, or at least at peace with it (African American, age 62).

On the part of all interviewees, but particularly the African American women, their adherence to the importance of optimism and thinking positively often sprung from religious roots and appeared to reflect a commitment to a divine plan. In these cases, faith in God's will was seen as the source of optimism; thus, allowing negative emotions to surface or take over represented a direct affront to their religious conviction. Conversely, the display of negative emotions was actively discouraged. Angry, resentful, or upset women were thought to invite further illness upon themselves, and their negative emotions could potentially interfere with the success of their treatments or remission status:

A positive attitude. You've got to have a positive attitude. And it's—I'm going to do this, I'm going to survive, I am a survivor. And one day at a time. But you have to have a positive attitude. Have the right spirit. And stay focused. Stay focused on getting better, on your healing. Know that you can be healed. One of the things that I don't do, I don't entertain negative people. I don't. It's like go away, I don't want to hear it (African American, age 49).

You have a home, you have a family. So I'm trying to teach young people, anybody, that everybody is going through something but do not focus on the negative because if you do, you are going to stay there for too long and there is no reason for that. Focus on the blessings that are around you. Once you see that, that what is going

on is not going to last long, then it's not going to be hard if you see what you are going through like that (Latina, age unknown).

## V. Discussion

An important study finding was the salience of the term survivor: over half of the participants used it unprompted when referring to either themselves or to someone else, and they pointed to the unique ability of other survivors to understand the experience they were going through. For this reason, support group leaders who were survivors themselves were particularly appreciated. However, a small minority did not identify with the term survivor, preferring to view cancer as a temporary state that ends and one then returns to normal life.

Themes from studies of survivor identity have highlighted why some people with cancer may reject the survivor label. In her study of African American women in North Carolina participating in a breast cancer support group, Mathews (2000, 2008) found that many of the women rejected the survivor label and preferred to think of themselves as being “saved” from cancer, invoking religious metaphors in the construction of their recovery. Sociologist Arthur Frank confronted the contested nature of the word survivor throughout his research on long-term survival from illness, having interviewed countless individuals who resisted its application to their situation (e.g., Frank, 2012a). Their discomfort often arose from the fact that the term conjures up images of heroism and superiority (Frank, 2012a), or of cancer as something that has been definitively overcome, while instead these individuals “realize how capricious the difference of physical survival is” (Frank, 2003, p. 251). The quotes from some participants in this study speak to Frank’s “limited liability narrative,” a metanarrative about cancer survivorship that he argues represents a “get-on-with-it” mentality—a conception of cancer as a bump in the road that can quickly be overcome. He observes that this narrative is “the restitution story of illness, in which the end of the story is that the ill person’s life before illness is restored and illness can be forgotten” (Frank, 2003, p. 250). Presumably, no work on self-identity need be done, as the illness is not seen to interfere with normal life trajectories, and the individual can return to her normal, pre-diagnosis life.

At the same time, one of the dominant discourses identified in the literature on breast cancer survivorship is the transformative power of the illness experience (King, 2006). Breast cancer is portrayed as an agent of change, with the power to catalyze positive and beneficial adaptations in one’s life. This transformative potential most often takes the form of individual growth and development, and is likened to a personal journey of discovery upon which the survivor embarks (Coreil et al., 2004) For participants in this study, however, the breast cancer experience was often conceptualized as a journey of spiritual renewal and affirmation, in contrast to the strong emphasis on individual growth and responsibility for personal change that characterizes the dominant transformation discourse. For African American women, individual agency for change was deemphasized in the context of a heightened role ascribed to God. For Latina women, nearly all of whom were first-generation immigrants, the migration experience served to create a template and preparation for overcoming the challenges of cancer treatment and survivorship.

Dominant discourses and metaphors of survivorship often draw heavily from religious belief and myth (Hydén & Brockmeier, 2008). Indeed, findings from this study point to the central role of spirituality and faith in the

cultural construction of the survivorship experience for all study participants, and particularly for African American women. This aspect is consistent with studies conducted among African American breast cancer survivors in North Carolina who, dissatisfied with a hospital-based support group that emphasized triumphal themes of empowerment and sports metaphors of victory, formed their own support group that highlighted the importance of religious and spiritual themes and allowed the expression of self-doubt (Mathews, 2000, 2008).

One explanation for the prominence of this theme lies in a deeply-rooted tradition of religiosity among African Americans. In a study of the popular media representations of cancer in African American popular magazines, Hoffman-Goetz (1999) found that the articles strongly emphasized the importance of religious faith and God's role in the cancer experience. "Mass media contributes to the discourse which shapes women's attitudes about survival from cancer" (Hoffman-Goetz, 1999, p. 36)—both molding it as well as reflecting social norms and beliefs regarding an illness such as cancer. Thus, it can be argued that the women in the current study were in some ways performing a socially accepted and distinct aspect of their ethnic identity by drawing upon an existing narrative that ascribes a heightened importance for African Americans on religious conviction and faith in God.

Participants' narratives reflected the importance of bonding and sisterhood among women, while emphasizing the value of shared culture and language. Likewise, a distinct characteristic of the breast cancer movement is its emphasis on the "sisterhood" of survivors and the bond that breast cancer creates between them (Delinsky, 2001). This common experience of breast cancer survivorship has been seen by some authors to transcend other differences between women (Wescott, 2005). However, based on our data we argue instead that although the shared survivor status and experience did indeed form a crucial bond between women and was very important to them, it also interfaced with other important identities, including shared ethnicity and language. Indeed, for many women, being around other survivors who were ethnically or culturally similar was an essential component of their survivorship experience. This is also reflected in Chavez and colleagues' (2014) study on post-mastectomy experiences among women involved in ethnically-identified support groups. A "common intersection of identities" (p. 249) increased their comfort level and encouraged them to share their stories.

For African American women in particular, it was extremely important to have visible, ethnically-similar role models of breast cancer survivorship. This finding supports earlier work conducted by Moore (2001), who found that the African American breast cancer patients that she interviewed believed that breast cancer was a "white woman's disease," due in large part to the lack of African American role models in media and medical representations of breast cancer. Nelson and Machias' (2008) study on representation in breast cancer information is also instructive on this point. The authors studied women of color's engagement with breast cancer information, finding that dominant discourses of breast cancer—as portrayed through educational material—excludes representations of women of color and lower-income communities. Because women are forced to engage with this information on some level, this exclusion has consequences: "the racialized Other, immigrant, or outsider is rendered deviant from the norm and is forced to adapt, revise, resist, or reject the discourse" (p. 20).

An unwavering display of optimism was held to be paramount for all participants, critical because of optimism's power to heal, but also conversely, because of negativity's power to sabotage one's treatment, recovery, or peaceful transition to the afterlife. Thus, many participants frowned upon displays of what might be perceived as

negative emotions. According to a number of authors (Ehrenreich, 2001, 2009; King, 2006; Segal, 2012), a display of unrelenting optimism and an emphasis on maintaining a positive attitude in the face of potentially long-term and mortal illness is one of the overarching discourses surrounding breast cancer survivorship. In their now-classic writing on the role of hope in American oncologic practice, Good and colleagues (1990) note that the maintenance of optimism—for both patient and provider—is a fundamental goal for cancer care.

The absence of resistance to the dominant narrative of positive thinking is a noteworthy finding, and contrasts with recent studies in which some survivors challenge what they perceive as an expectation to be optimistic or positively-transformed individuals (see, for example, Sinding & Gray, 2005). Indeed, much has been made of the optimism discourse in relation to cancer in both popular literature (expounding its potential health benefits) and scholarly literature (often critiquing its frequency as well as the unintended side effects). Aligning with the increasingly common phrase “the tyranny of positive thinking,” some studies on cancer survivorship have found that survivors resist the emphasis on optimism and positive thinking on the grounds that it can inhibit the expression of a full range of emotional reaction (Segal, 2012; Sinding & Gray, 2005).

An alternative way of viewing optimistic speech is proffered by Wilkinson and Kitzinger (2000), who contend that it is an idiom that serves several purposes in conversation: for example, more gently allowing the speaker to share concerns and express negative emotions, to signal the end of a speaker’s contribution, or to create a sense of cultural inclusiveness between the speaker and audience. The authors note that “ ‘thinking positive’ functions not as an accurate report of an internal cognitive state, but rather as a conversational idiom, characterized by vagueness and generality, and summarizing a socially normative moral requirement . . . even those breast cancer patients who report ‘thinking positive’ can also actively resist its moral prescriptions” (p. 797). In their view, optimistic speech does not necessarily represent an unwavering subscription to the tenets of optimism and a positive attitude, as is frequently assumed in much of the psychosocial and popular literature, and the strong subscription to optimistic thinking on the part of participants in this study should be interpreted with this explanation in mind.

It is also important to note the role of the support group in the interpretation of our findings. The fact that participants were drawn from support groups structured specifically along ethnic lines is an important feature of the research context. Previous research has investigated the cultural models created by support groups, arguing that, through group processes, cancer support groups create their own shared models of appropriate support, meaningful recoveries and “survivorship experiences” (Coreil et al., 2012; Coreil et al., 2004; Corvin et al., 2013; Mathews, 2000, 2008). In her study of the formation of a breast cancer support group, Mathews (2000) found that the cultural model of breast cancer created by the group “transcend[ed] some of the boundaries of ethnicity, class, and age by articulating a view that all group members can share and by aiding them in arriving at a meaningful understanding of their illness experiences” (p. 409). It is important, therefore, to recognize the interplay of the cultural models of breast cancer, the survivorship experience, and ethnic identity created by the support groups studied here, and the interpretations espoused by individual members.

## VI. Conclusion

Our study of the local meanings underpinning the survivorship experience for women participating in ethnically-identified support groups revealed distinctive themes related to religious faith, ethnic identity, migration history and shared culture and language. Analysis of these themes in relation to dominant discourses of survivorship in the West – transformation, growth and rebirth, sisterhood and bonding, optimism – shows the interplay between societal level assumptions about illness and local constructions of the experience. These results illustrate the powerful ways in which dominant discourses are drawn upon to express individual stories, while at the same time being shaped and molded by survivors' firsthand experiences, relationships, cultural background, and support group experience.

We do not argue that these findings serve as representative of the beliefs and experiences of all African American or Latina breast cancer survivors. Rather, we present the data as descriptive of how participants who sought out a support group composed of women from a similar sociocultural background articulated their own views on breast cancer survivorship—views that, because they were in meaningful ways distinct from the mainstream discourse, may help to explain how illness experience is shaped through interactions with women who share important social identities.

These findings and their implications must be interpreted in light of the study's limitations. First, our sample was limited to women who chose to participate in a support group, which may not be representative of all women. The inclusion of a faith-based African American support group may have influenced the members' emphasis of spiritual themes, and especially the role of faith and God in survival. However, we found similar themes and emphases expressed within the non-faith based African American group that met in an institutional-style hospital classroom. Furthermore, both groups followed similar religious practices of opening and closing meetings with a prayer circle, and invoked the idea of divine will in similarly-themed testimonials. Secondly, Frank (2012b) has cautioned about the negative effects of support groups that put pressure on members to conform to the "cheerful warrior" model. While the emphasis placed on optimism by participants was quite strong in our study, we acknowledge the potential bias that may stem from recruiting solely from support group members.

These findings have several clinical implications. At a general level, the findings underscore the importance for health care providers to be cognizant and respectful of alternative perspectives on illness. Particularly in the cancer field, where certain discourses dominate the terrain with tenacity, it is important that clinicians do not assume unquestioningly that all patients share the normative views about survival following breast cancer that have been so widely disseminated in North America. Our findings highlight the importance of multiple social identities in shaping one's expectations about post-treatment life, including characteristics such as religious faith, immigration history, language use and other cultural practices. As one African American woman stated, "cultures have needs," a theme echoed by a Latina participant who stressed that "it's all about the nuances." Providers need to be sensitive to the nuances of cultural background and be knowledgeable about culturally appropriate support and educational resources in the community, but at the same time should not assume that all members of a particular ethnic group share the same set of beliefs. While our findings provide further support for the importance of cultural context in community resources for breast cancer survivorship, further research is needed on clinical outcomes, including quality-of-life, response to treatment, and long-term survival, for women who participate in ethnically-identified support groups.



## Acknowledgements

We thank both the members and leaders of the breast cancer support groups who participated in this study.

The study was supported by Susan G. Komen for the Cure Foundation (*Grant No. DISP0706938, 2007-10, PI: J. Coreil*). A draft of this paper was prepared for a workshop funded by the Canadian Institutes of Health Research (*Grant No. FRN90903, "Critically Interrogating Cancer Survivorship: Social Science and Humanities Perspectives," PIs: K. Bell & S. Ristovski-Slijepcevic*), held in Vancouver, British Columbia in July 2011. Feedback from the organizers and participants of this workshop was instrumental in the development of this manuscript.

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