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“Surviving is not the same as living”: Cancer and *Sobrevivencia* in Puerto Rico

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Abstract

“Cancer survivorship” is an evolving concept that has been elaborated to a large extent in the mainland U.S. through the work of national advocacy organizations, and it has served as a source of cohesion for many people who have experienced cancer. However, anthropologists and other social scientists have argued that dominant meanings of survivorship—such as the idea of “cancer as a gift” or the role of positive thinking in influencing the disease course—reflect distinctively American cultural values, and survivorship outside the U.S. has remained largely unexplored even while the concept has gained some traction globally. This paper explores how the concepts of “survivorship” and “survivor” are engaged in the setting of Puerto Rico, an unincorporated territory of the U.S., and how well they are seen to explain the nature of post-treatment life. Ethnographic fieldwork for this study was conducted over 12 months split between two field visits (2 months and 10 months) between June 2010 and March 2012 in San Juan, the capital city, and Ponce, a smaller city on the southern coast. This paper is based on interviews with 23 participants treated for cancer as young adults. Participants drew from many of the prevailing discourses of survivorship—such as transformation and the importance of optimism—as well as from what they understood to be distinctive aspects of Puerto Rican culture and identity, in the crafting of a local understanding of post-treatment life. Support organizations played a key role in shaping roles and expectations associated with having had cancer, and in solidifying particular views of survivorship more broadly.

Keywords

Cancer; Survivorship; Dominant discourses; Ethnography; Puerto Rico

1. Introduction

“Cancer survivorship” is an evolving concept that has been elaborated to a large extent in the mainland U.S. through the work of advocacy groups such as the National Coalition for Cancer Survivorship (NCCS) and the Lance Armstrong Foundation (now LIVESTRONG). Beginning in 1985 with Fitzhugh Mullan's influential thought-piece *Seasons of Survival*

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(1985), the period of time following cancer treatment, indexed by the new terms “survivorship” and “survivor,” has experienced increased scholarly, governmental, and activist attention.

While specific definitions and timepoints vary, in general “cancer survivorship” as outlined in the biomedical and advocacy literature refers to the long-term health and well-being of people with a history of cancer, and regards post-treatment quality-of-life and follow-up healthcare as essential components of the cancer care spectrum (NCCS, 2015). The shift in focus from physical survival alone to a more comprehensive assessment of long-term well-being is seen to be rooted in increasing survival rates over the past few decades (NCCS, 2015).

The concepts of survivorship and survivor identity have served as a source of cohesion for many people who have experienced cancer, but the particular terminology, discourses and images that are attached to them, such as the idea of “cancer as a gift” or the role of positive thinking in influence the disease course, have been critiqued both by “survivors” themselves as well as by academic writers and social critics (see, for example, Bell, 2012, 2014; Ehrenreich, 2001, 2009; Little et al., 2002; Segal, 2012; Sinding and Gray, 2005). Anthropologists¹ and other social scientists have argued that the dominant meanings of survivorship reflect distinctively American cultural values (Jain, 2013; Stoller, 2004, 2008). Others have argued that existing research on the meanings of life after cancer diagnosis and treatment, and on survivor identity, has been conducted almost primarily with one very particular group: white American women diagnosed with breast cancer (Bell, 2014; Khan et al., 2012a; Khan et al., 2012b). Thus, the meanings of survivorship outside the U.S. have remained largely unexplored, even while the concept has gained some traction globally. This raises the following questions: using the case setting of Puerto Rico, an unincorporated territory of the U.S., how are the concepts of “survivorship” and “survivor” taken up and engaged in different cultural contexts? What are the meanings of life following cancer diagnosis and treatment in Puerto Rico, and how might these be compared and contrasted with the understandings of survivorship/survivor documented in the literature? And more broadly, how is the emergence of cancer survivorship in Puerto Rico a case in point of broader issues of biocitizenship (Rose and Novas, 2005)? Signifying the new subjectivities and collectivities that are formed around “somatic” or bodily identities in this “contemporary age of biomedicine” with its attendant scientific and public health practices, biocitizenship is “manifested in a range of struggles over individual identities, forms of collectivization, demands for recognition, access to knowledge and claims to expertise” (Rose and Novas, 2005). The particularities of each are shaped by factors that vary by national histories and social contexts.

Accordingly, in this paper I seek to explore what it means to live after cancer diagnosis and treatment in Puerto Rico using in-depth interview data collected during a larger ethnographic study on cancer-related infertility. I will address the contested engagement

¹Although anthropologists have written much about cancer in terms of the lived experience of diagnosis and treatment (e.g., McMullin, 2008), cultural models of causation (e.g., Chavez et al., 1995; Hunt, 1998), metaphors (e.g., McMullin and Weiner, 2008), and structural aspects related to disparities (e.g., Balshem, 1993; Lee, 2008), they are just beginning to engage with the concept of “survivorship” to the same extent (e.g., Bell, 2012, 2014; DiGiacomo and Sumalla, 2012; Jain, 2013; Stoller, 2004, 2008).

with the terms survivor/survivorship as well as local meanings of “post-cancer” life, touching upon such topics as the transformational impact of cancer and three aspects that participants deemed highly important to their lives after cancer: specifically, family, faith and spirituality, and their role in helping others.

1.1. “The seasons of survival” and survivorship discourses

The term “cancer survivor” was coined in 1985 by Fitzhugh Mullan, a physician treated for cancer who went on to co-found the NCCS. In his *New England Journal of Medicine* piece, Mullan (1985) delineated what he believed were the three seasons of survival through which an individual with cancer passes: acute survivorship, extended survivorship, and permanent survivorship. It was not until the late 1990s, however, that the cancer survivorship movement began to gain increased momentum (Park et al., 2009), perhaps because at the time of Mullan's writing, survival rates were lower and “the ‘ethos’ of cancer was that it [was] a ‘death sentence’” (Deimling et al., 2007, p. 758). Now, with increasing survival rates especially among children, scholars have argued that the paradigm of cancer treatment itself is evolving from a “seek-and-destroy mindset” (Aziz and Rowland, 2003, p. 250) into one that takes into account quality-of-life, the multiplicity of late effects of cancer treatment, and ongoing recurrence worries/risks.²

It has been argued in the biomedical and psychosocial literature that the process of adopting the cancer survivor identity can confer beneficial effects and positively impact a survivor's quality-of-life by, for example, reducing anxiety and depression, fostering healthy behaviors, increasing self-esteem, and encouraging the prioritization of valued social roles and activities (Deimling et al., 2007). At the same time, the endorsement and acceptance of the survivor terminology is not uniform, ranging from 26 to 90 percent in recent studies (Morris et al., 2014). Critiques of the terms and their associated expectations for identity and behavior have increasingly emerged from both academic circles as well as people experiencing cancer themselves.

Recognizing the value-laden nature of these terms, and how “words not only describe, but also construct, the phenomena under question” (Bell and Ristovski-Slijepcevic, 2013, p. 411), researchers have sought to shed light on the dominant discourses and images attached to cancer survivorship. Bell (2014) argues that discourses of breast cancer survivorship have come to frame public understandings of cancer more generally, employing themes of personal transformation, heroism and triumphalism, and a sisterhood of survivors (Coreil et al., 2012; Gray and Doan, 1990). Breast cancer survivors are depicted as empowered and advocacy-oriented, with optimistic views on life derived from their positive self-transformation following cancer (King, 2006). The image of the ultrafeminine woman, “immaculately groomed and seemingly at peace with the world” (King, 2006, p. 102), dominates public portrayals. Beyond breast cancer, the “warrior” discourse is evident in the National Cancer Institute's “War on Cancer” initiative as well as advocacy organizations that depict an encounter with cancer as a battle to be fought and conquered. Lance Armstrong,

²While biomedical survivorship literature constructs the narrative of a transformation from “seek-and-destroy” to a more comprehensive approach (as presented in Aziz and Rowland (2003), for example), it may instead be the case that the seek-and-destroy paradigm is alive and well with considerations of quality-of-life added to the mix, but I would argue still accorded lesser priority.

with his “LIVESTRONG” branding, provides a quintessential example of this framing (Jain, 2013; Stoller, 2008).

While undoubtedly these images of survivors have been valuable and empowering for some in making sense of their illness experience, as Ehrenreich (2001, 2009) has argued and researchers have shown (Bell, 2014; Segal, 2012; Sinding and Gray, 2005), they can result in a narrow range of acceptable expression and behavior for others. For example, the warrior discourse equates survival with personal victory, creating a potential “blame-the-victim” scenario if one experiences a recurrence or dies from the disease. The expectation to be a “fighter” and to “beat” cancer led those in Segal's (2012) study to feel less able to share the realities of their illness experience with loved ones. In Sinding and Gray's (2005) study with women following breast cancer, participants regarded cancer as ongoing and contested the expectation of cancer as definitively over. This latter expectation, along with what they regarded as the assignment of responsibility for cancer, created an inherent tension for them, an expectation to behave as if cancer is “over” while at the same time “taking responsibility” for staving off its return and maintaining their health.

Thus, despite their influence, dominant discourses do not uniformly dictate personal experiences of cancer; areas of critique and resistance are commonplace. For example, Kaiser (2008) found that breast cancer survivors drew selectively from the circulating survivorship discourse, using bits and pieces that might pertain more relevantly to their own lives in a “craftwork” (Frank, 2003) fashion. In a study by anthropologist Mathews (2000) on the formation of an African American breast cancer support group, some members conceptualized themselves as being “saved” from cancer in a religious sense, versus having overcome the cancer themselves. Thus, they rejected the survivor label with its attendant implication of individual accomplishment. Frank (2003) has similarly found a discomfort with the connotation of the word survivor that implies that cancer is definitively “over” or “accomplished.” Stoller's (2004) discussion of the inherent liminality of the cancer experience is relevant here; classically understood as a temporary state experienced by an individual as they are passing from one role to another (Turner, 1969), liminality references the disorienting and confusing experience of being “betwixt and between” states. An individual who has gone through cancer treatment lives always with the prospect of recurrence or the emergence of late effects, and is thus never fully “well.” However, when not in active treatment, life can go on somewhat normally; thus, the individual is neither fully sick. The idea of persistent liminality correlates with Frank's description of the “remission society” (Frank, 1997), in which sufferers of an illness (not just cancer) can get better but are never again considered fully healthy—just in remission.

1.2. Cancer survivorship in Puerto Rican context

What is missing from the above literature are analyses that reflect survivorship discourse in socio-cultural contexts outside of the U.S., which may delineate new ways of understanding survivorship that resist dominant images of survivors, or adopt and redefine them in new, locally appropriate ways. Anthropological research with Latino groups in the United States have focused on the moral overtones inherent to cultural meanings of cancer, especially cancers of the reproductive organs (Chavez et al., 1995; Martinez et al., 1997), the

conceptualization of cancer as a consequence of deviation from accepted cultural standards and the moral order, and the ways in which racialized and sexualized stereotypes have impacted access to appropriate cancer care (Chavez, 2008; McMullin, 2008). In another study (Dyer and Coreil, unpublished) some Latina women felt that they first had to deflect any question of moral culpability in order to establish a positive identity as a cancer survivor.

This study examines cancer survivorship in the context of Puerto Rico, an island characterized by a long history of Spanish and subsequent American colonization, development projects, and biomedical experimentation. Spain's occupation of Puerto Rico endured from 1508 to 1898, when, following defeat in the Spanish-American war, Spain ceded the island colony to the U.S. The long Spanish occupation resulted in a largely Spanish-speaking and Catholic society. The island has since remained an unincorporated territory under U.S. governance, and in 1952 was granted status as a Commonwealth (or associated free state) of the U.S. As members of the Commonwealth, Puerto Ricans maintain U.S. citizenship status but do not participate in American democratic proceedings, having neither the right to vote in federal elections nor voting representation in Congress. To this day, national controversy persists over the island's ambiguous legal status and relationship to the U.S. (Cabán, 1993; Grosfoguel, 2003).

American rule of Puerto Rico has been marked by very high levels of poverty and unemployment, and a continuing migration of Puerto Rican citizens, cultural resources, and goods to the mainland (Bourgois, 2002; Briggs, 2002). Puerto Rico's economy has been intimately tied to that of the U.S. in an extractive relationship since 1898, and it depends heavily upon both aid and imports from the mainland (Grosfoguel, 2003; Rivera Ramos, 2001). Despite (or arguably, as a result of) this relationship, there continue to be high rates of income disparities, unemployment, and poverty. To illustrate, in Mississippi, the poorest American state, 25 percent of residents live below the federal poverty line, while the Puerto Rican figure is nearly double, with 45 percent of islanders drawing below-poverty wages (U.S. Census Bureau, 2013).

Attempts to decrease poverty on the island via Operation Bootstrap, a mid-twentieth century industrialization program, largely failed. According to Briggs (2002), such failure was explained in terms of overpopulation, a rationalization which then justified a two-pronged campaign intended to solve the “under-development”/overpopulation problem: emigration and sterilization. Waves of migrants — many of them rural subsistence farmers displaced from their land — left the island, destined primarily for the booming factories of the Northeastern U.S. Thus, the Puerto Rican diaspora began, and continues today. At home, a sterilization program was instituted as the primary birth control option available to the population, while American researchers conducted now-infamous unethical contraceptive experimentation on Puerto Rican women (Lopez, 2008).

The ongoing diaspora, sterilization campaigns, and continued political hegemony of the U.S. have deeply shaped contemporary Puerto Rican society. Many scholars agree that Puerto Rico has developed a strong nationalist identity such that “Puerto Ricans today tend to view themselves as a distinct people” (Rivera Ramos, 2001, p. 69; see also Grosfoguel, 2003).

The symbolic significance of the Puerto Rican flag, the identification of Spanish as the first language, and other displays of *puertorriquenista* identity by Puerto Ricans both at home and abroad are all strong evidence of a national identity distinct from the U.S. (Rivera Ramos, 2001). This identity is often set in opposition to American culture; the historical and continuing emigration patterns and the incorporation of biomedicine as an instrument of the state in controlling Puerto Rican bodies historically were likely to shape different discourses of survivorship in Puerto Rico. This study sought to examine such local discourses and their relationship to dominant discourses of survivorship.

In this sense, the presence of American cancer advocacy organizations in Puerto Rico is an important consideration. At the time of the research, several mainstream North American nongovernmental organizations (NGOs) were operating chapters on the island—for example, the American Cancer Society and Susan G. Komen for the Cure, both prominent and influential American cancer advocacy organizations that utilize the survivorship concept. The term “survivor” has been directly translated by these organizations from English to Spanish as “*sobreviviente*,” which is derived from the verb *sobrevivir*, or “to survive.” “Survivorship” is translated directly to “*sobrevivencia*.”

2. Methods

Fieldwork for this study was conducted over 12 months split between two field visits (2 months and 10 months, respectively) between June 2010 and March 2012 in San Juan, the capital city, and Ponce, a smaller city on the southern coast. Methods included ethnographic interviews, an ethnographic content analysis of cancer depictions in the media, and participant observation in a public clinic and support group meetings. The interviews were comprised of unstructured interviews with 10 key informants who were all university-based researchers addressing socio-behavioral and medical aspects of cancer, and 50 in-depth, semi-structured interviews with four defined groups (23 individuals previously treated for cancer as young adults, 16 healthcare providers, 11 advocates, and 2 clergy). This paper draws principally from interviews with the 23 participants treated for cancer in order to describe the meanings of long-term survival.

These participants were recruited primarily through snowball sampling and presentations at cancer support group meetings, supplemented by clinic-based recruitment at a cancer hospital in San Juan. In general, however, contact was made with participants through word-of-mouth; the study was described as intended to examine quality-of-life issues for young people who had been diagnosed and treated for cancer before the age of 45. In this way, participants often introduced me to other people in their social circle who had also been diagnosed. Inclusion criteria consisted of a prior diagnosis of cancer (any type), reproductive-aged (diagnosed and treated before the age of 45), and off active treatment for cancer. Reproductive-aged individuals were selected for inclusion because one of the main study aims addressed cancer-related infertility among survivors (see Dyer, 2015). Inclusion criteria allowed for interviewing people diagnosed as children (although over the age of 21 at interview time) because the reproductive effects of cancer treatment can be life-long, thus potentially impacting childhood survivors' decision-making and options regarding parenting. In the end, however, only one participant was diagnosed under the age of 21. No limit was

set on the length of time elapsed between diagnosis/treatment and the interview, leading to a broad age range.

Interviews lasted for one hour on average, and were conducted either at participants' homes or in public places, such as parks or cafés. All interviews were conducted in the language of participants' choice, either English (n = 5) or Spanish (n = 18), and interviewers were gender-matched. The author speaks Spanish as a second language; thus, in order to guard against potential missed meanings, two Puerto Rican anthropologists—one man and one woman and both native Spanish-speakers—assisted with the conduct of the interviews. With female participants, the female anthropologist served as primary interviewer with the author as note-taker, observer, and occasional question-asker. The male anthropologist conducted the Spanish-language interviews with male participants alone, a strategy advised by key informants in order to minimize men's discomfort sharing sensitive information. The author transcribed all English-language interviews, while a native Spanish-speaker transcribed all Spanish-language interviews. All transcripts were coded by the author with one of the assisting anthropologists serving as second-coder; differences were resolved through meetings and dialogue. Similarly, the author translated all quotes in this paper; translations were checked by the same anthropologist. Pseudonyms have been used to maintain confidentiality.

Interviews were audio-recorded and transcribed verbatim for entering into MaxQDA, a qualitative analysis software program. The author used a grounded theory approach to data analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1990), capturing initial open codes that were generated inductively through thorough readings of the transcripts, and then combining related codes into larger, more inclusive, categories or themes using the constant comparative method (Bernard and Ryan, 2006). The research question driving the inductive coding process for the data upon which this paper is drawn centered on how long-term survivorship is constructed and experienced in survivors' lives and the meanings they attach to the experience. Information about participant demographic characteristics is summarized in Table 1 below. The University of South Florida approved all aspects of the research, and all participants were asked to review and sign informed consent forms prior to the interviews.

3. Findings

Major themes emerging from the data revolve around participants' contested engagement with the survivorship/survivor concepts, their stories about the transformational impact of cancer, and three aspects that they deemed highly important to their lives after cancer: specifically, family, faith and spirituality, and their role in helping others. These themes will be discussed in turn.

3.1. Survivorship and survivor identity: framing the cancer experience

One way of beginning to understand what it means to have cancer in Puerto Rico is to look at the influence of the survivorship concept on the island. As noted earlier, the large advocacy organizations in Puerto Rico use the direct translation of the terms survivor and survivorship: “*sobreviviente*” and “*sobrevivencia*,” respectively. These terms are widely

used by individuals, healthcare providers, and advocates, although the participants interpreted them in a variety of ways. However, while the particularities of the actual words' meanings and application to participants' own lives varied, several consistent themes emerged. The majority of participants ($n = 16$) adopted the term survivor for themselves, and self-identified with it with varying levels of dedication; the rest either explicitly rejected the term or felt ambivalent. The specific time period in which participants reported adopting the term varied, ranging from immediately after diagnosis to several years later after subsequent tests were clear. It was evident that for some participants, "being cured" of cancer, or having scans and tests that came out clean, was a necessary prerequisite for identifying as a survivor.

For those with a self-identity as a *sobreviviente*, one theme became dominant: that of literally being alive. Many participants explicitly tied the identity of survivor to its literal interpretation—that of living in a physical sense, or not having succumbed to the disease, as in the following by Magdalena, diagnosed with breast cancer at age 45:

"[I consider myself a survivor] because I am here. Look at me. I survived the cancer. There are people that unfortunately do not have the same luck. I saw friends of mine [die] much younger than me."

Others layered additional meanings on this interpretation. For some, the survivor identity equated to normalcy and a return to their daily lives pre-cancer. For others, *sobreviviente* referenced a struggle, a battle to face head-on, and perseverance, as in the case of Veronica, diagnosed with breast cancer at age 36:

"The term cancer survivor for me, it has the meaning of a struggle, a battle. To accept it, to confront it, and to fight it. That is a survivor of cancer. And do not give up."

For participants who referred to themselves as survivors, this identity signified membership in a community of fellow survivors, and the bonding that occurred through shared experiences, understanding, and pride at having lived through a grueling event. This is evident in Pedro's comment, after he was diagnosed at age 35 with lymphoma:

"Here at [my workplace] we participated in the program Relay for Life. Although I worked there [before I was diagnosed], I never participated in the Relays for Life that they had. [Now] I have to go as a survivor, to put on the T-shirt that's different than what everyone else has. That first moment that I walked in, when we made the first round as a survivor, it made an impact. 'Wow, I am a survivor'; I am walking with all these people, I come here to help, to support all these people and now I am one of that group. [It was] shocking."

3.2. "Surviving is not the same as living": alternative terminology and meanings

On the other hand, the explicit rejection of the concept of *sobreviviente*, and the reasons given for this rejection, served to illuminate much about the meanings of life after diagnosis and treatment. Many participants noted the inadequacy of the term *sobreviviente* or its English equivalent. Three women noted that cancer was just "like a cold" or "like a flu," speaking to the idea that cancer was just a bump in the road to get over and move past. Two

others did not like the term because they thought that it kept reminding people of their experience with the disease. Daniela, age 33, diagnosed with recurrent breast cancer, stated:

“There are people for whom it is very significant for them to say it. Like saying that word makes them feel that they conquered the disease. For me, I don't like the term. I think it excludes you. The point about living after cancer is that you could return to normal life. That you would be normal. For me, always saying ‘I'm a cancer survivor; I'm a cancer survivor,’ is just reminding myself that I had it.”

A vocal contingent challenged what they saw as the dominant interpretation of the word *sobreviviente*—that it referenced mere survival, rather than a state of being more akin to thriving. At first, it seemed as if this critique referenced the literal meaning of the translated term—which is partially the case. However, these respondents were also critiquing what appears to be the general understanding of the “post-cancer state” in society, which is a social critique in addition to a linguistic critique. For example, Inez, diagnosed with breast cancer at age 36, explained her dislike of the term *sobreviviente*:

“Because it seems as if you were leaving a hole, struggling. We hate it. We do not like that they call us survivor, at least my group. We say ‘*viviente*’ or we say fighter, and we don't like fighter either. It is because [it means that] you are still there in that struggle. [We use ‘*viviente*’] because we do not like that we are *surviving*, we do not want to *survive*. We want to *live*. We do not want to survive.”

Like Inez, some of the participants, who were all members of the same support group, preferred the term *viviente*, translated literally as “one who lives.” *Viviente*, for these individuals, spoke to the ability to thrive and their desire to squeeze every last drop out of life, taking advantage of opportunities, and valuing life and loved ones more than before. Francisco, a student diagnosed at age 23 with oral cancer, spoke about this:

“The term ‘cancer survivor’ really isn't the most appropriate but it is the only one that exists, and I will explain. Surviving is not the same as living; surviving implies that one goes beyond the situation but not fully. To live, when we talk about living, the joy of being human beings is living fully. To survive does not imply an abundance, it implies a limitation, because if you say to a person ‘you are a survivor’—survivor of what? Now automatically you are reaching the conclusion that there is a limitation. [...] Cancer isn't an absolute limitation; it is a wall, but like all walls it can be knocked down. [I do not consider myself a survivor]. I consider myself a ‘*viviente* in abundance.’”

Camila, diagnosed at age 22 with breast cancer, referenced ideas similar to Francisco's:

“[The word] ‘*sobreviviente*’ actually gets me kinda angry because I'm not surviving, I am living. If you're living, you say ‘I'm living; *soy viva*.’ You use the same term ‘*sobreviviente*’; you just add the front part. To me, surviving is that you're just dragging your life, and you're just surviving it because there's no option. But when you live, you say ‘*yo soy una viviente de cancer*.’ I'm not a survivor—I say ‘*viviente*’ because I live every day. I get up, I have my children with me, I have work, I have my family, I have a house, I have a home, and I live every day. I don't survive. Because when you're on a survival mode, you're trying to make it. And I

don't try to make it, I already am. I'm just making things work for me. So I get a little bit angry hearing someone say, 'Oh, you're a cancer survivor!' In English, it sounds better. It doesn't make me as upset as when I say it in Spanish [...] I don't survive. I am living life. I don't drag my life with me. I enjoy it."

Of note is Camila's distinction between the less-problematic English version of the term and its Spanish counterpart; she believed that the English version was closer to the idea of "thriving" than *sobrevivencia*, a thin state of being. The use of the survivorship framework in Puerto Rico, and its relationship to what participants' voiced as cancer's meaning in their lives, is complex. Paralleling Camilla's comment regarding the Spanish-English differences in the word survivor, participants commonly made distinctions between what were referred to as "American" versus "Puerto Rican" visions of post-treatment life and values.

3.3. Conflicting emotions and personal change

Overwhelmingly, participants spoke positively about the impact of cancer on their lives; the experience was credited with multiple benefits. At the very least, the personal change wrought from a confrontation with cancer was seen as something good in the midst of evil. Thus, cancer was often located by participants within an overarching framework of "*conflicting emotions*," as articulated by Maria, who had been treated for cancer three times: that is, it brings positive changes as well as difficult situations and pain.

Participants' accounts of their pre-cancer lives were often presented as being incomplete or even misguided in some way, with the end result being that they had worked through the psychological and physical difficulties that cancer presented, and come out on the other side as enlightened and improved. Several participants credited cancer with providing the motivation to change their career path or refocus on a position that allowed them to help others, often other people with cancer.

In general, most participants believed that cancer fundamentally changed their "outlook on life." They spoke about learning to appreciate life more, to value "the little things," and to "discover who one truly is." Cancer was seen in some sense to open them up to this secret, and to allow them to be able to better recognize and appreciate the truly important matters. Camila, a 34-year old treated for breast cancer, noted that, for her, cancer had been a blessing:

"I've met some spectacular women in my life because of breast cancer, so to me it's kind of like a blessing. And people say, 'what, are you freaking crazy?' After 12 years I can say that it's a blessing; I didn't say that before. It took about 6 years before I could actually see why it was a blessing. And it's made me love the little details in life that we take for granted every day, a flower popping up, a little crab walking on the beach. Any little details that people go 'aw, yeah, whatever,' I see it as a blessing. Every time I see a rainbow, it's amazing to me. Every time I see a butterfly, it's amazing, because I have a chance to see it [...] It's made me become a better person and love life more."

A prominent theme was cancer's impact on clarifying relationships. Many participants spoke about experiencing improved relationships, and felt that they were now better able to

recognize people who brought positive qualities and experiences into their lives, to verbalize their love and appreciation, and to pay those relationships the attention they deserve. Thus, for them cancer seemed to bring a clarity or distillation of what and, more significantly, *who* was most important in participants' lives—most often children and extended families. Conversely, they felt better able to identify those who brought negativity, and to be able to let those relationships go. For some, these realizations resulted in the end of romantic relationships and frequently in divorce—this was often phrased as wanting to remove a negative influence from one's life. Daniela, a 33-year old artist treated for recurrent breast cancer, stated:

“[Cancer] puts your life and priorities in some perspective. I think the more that I have changed is that I don't have time now to lose life with people, with situations, with money. It's not that I have become somebody that uses people either; it's not that, but if you're not going to bring something positive for me than you are discarded from my life. Get out of the way! Time is ticking! I am not going to lose time with you.”

3.4. “Everyone in the family gets cancer”

In general the extended family was discussed as part of the community of survivors, and participants specifically pointed out that this was a very “Puerto Rican” cultural value—actively distinguishing it from “American” perspectives and juxtaposing the two sets of values. Several advocates emphasized the idea that family members were “co-survivors,” and that the cancer experience was as difficult for them as for the survivor him/herself. Lucia, a long-term advocate who had been treated for breast cancer, articulated this perspective in a letter describing her organization:

“Cancer survivors have a large and extended family environment the majority of times. The concept of extended family is used as a framework [in this support group], and friends and co-workers are added that want to help in the patient's recovery. We must provide knowledge and strategies to that support group of how they can really be of great help to their family member or friend.”

Likewise, Angela, a long-term advocate who had also had gone through cancer treatment, stated:

“[Puerto Ricans] are quite family-oriented, so to us the family is important and when somebody gets cancer everybody in the family gets cancer too. The mother, the father, the daughter, even the neighbor (laughter) [...] The neighbor [says]: ‘Oh you have cancer, do you want something? I can get you soup, I can hug you, you can go with me—anything.’ Because we are like this when someone in the family has cancer.”

3.5. Cancer as a faith-deepening experience

Because of its long history of Spanish colonization, Puerto Rico is a deeply Catholic society, and this was evident in narratives of survivorship. Cancer was described as an experience that deepened and strengthened participants' faith in God. Participants pointed to how their confidence in God was enhanced and given a new dimension, and they reported a distinct

“before-and-after” effect. At the same time, their participation in church activities and frequency of attendance remained unchanged after the illness. Church participation was a different matter than one's personal relationship with God, and it was the latter bond that was seen to be strengthened:

“I'm not saying that I am going to go to church now every day, so if I say I talk to God every day, and I give thanks, it's because he let me start this day and continue living, and I give thanks because, in spite of everything, this was in the hands of my doctor, and my doctor helped me get through this but I know that over those hands there were others” (José, 27-year old treated for lymphoma).

José linked his successful treatment to God's guidance of the doctors, which was an oft-cited comment by participants. For these participants, their deepened faith in God left them less fearful about the future, and helped some to realize that physical survival is not the most important thing. For example:

“My faith in God helps a lot to not be so afraid of whatever is going to come. It helps you in the sense of vision in life, because knowing that [life] is not permanent helps you to have better relationships now” (Magdalena, 52-year old treated for breast cancer).

3.6. Helping others

One of the strongest themes to emerge in discussions about the meaning of cancer in individuals' lives was the desire to help others. Participants often phrased this as an “ability” that developed after cancer, an aptitude for speaking and reaching out to other people that may not have existed in them prior to their diagnosis. Many spoke about helping others cope with diagnosis and treatment, a form of peer counseling from one survivor to another. Their experience was seen to prepare them especially well for this role, as was the case for Marisol:

“When I know a person that had cancer or had a problem or is dealing with someone that had cancer, I try at least to speak with the person and give the person my perspective and my experience and try to give the person something” (Marisol, 46-year old treated for breast cancer).

Surviving cancer was thus framed as providing an opportunity for participants to better themselves and help others at the same time. Without exception, they discussed these new abilities and tendencies as positive traits. Soledad, a 34-year old who was deeply involved in a local breast cancer support group, viewed her struggle with cancer as surmountable and worthwhile because it had allowed her the ongoing opportunity to help others:

“I have had the opportunity to reach out to many people, in order to demonstrate that cancer is not everything and it doesn't destroy everything – it can take away your breast, you can lose your breast – but you are a stronger person and you discover abilities that you didn't know that you had. If I hadn't gone through this experience then probably I wouldn't have had [this opportunity]; it is something I thank God for every day [...] Getting a patient through the disease and knowing that it isn't the end, and they can see the positive side, for me that justifies my

disease. I got [cancer] because I had to help others, not because I had to suffer with my diagnosis.”

Support groups were subtly framed as a tool through which members learned to live their lives post-treatment, to the fullest extent possible. Indeed, one commonality between those identifying as *sobreviviente* versus *viviente* was the importance placed on helping others and being involved in a community of survivors. While this was not necessarily vocalized as an explicit component of these identities per se, they were pointed to as important aspects of what participants believed their role after cancer entailed more broadly. Some participants directly expressed the idea that helping others was an *obligation* for people who survived cancer, rather than just common practice.

4. Discussion

The above findings are important to connect to the existing literature on dominant discourses (specifically transformation), survivor identity and the role of group culture, and to consider how these participants have both embraced and challenged hegemonic ideologies of survivorship within the neocolonial context of Puerto Rico.

4.1. The transformation discourse: cancer as a catalyst for change

The transformational power of the cancer experience was an overarching theme for many of these participants, who imbued their experience of cancer with catalytic qualities, generating positive and beneficial changes in one's post-treatment life. Life after cancer treatment—what has been termed survivorship or recovery—involved living in accordance with these transformations. When speaking of future plans, participants often wanted to continue the growth and realization process—for example, continuing to appreciate loved ones, the “little things in life,” and their relationship with God—as much as they had learned to during cancer. Participants framed their transformation in a social or relational way; in almost every case, a participant's transformation involved managing their relationship to others or to the wider world, including God. While they grew *personally*—their realization of the value of loved ones was an *individual* change—this transformation is fundamentally social because it affects the energy and time they could invest in others. It was most often linked to a participant's greater clarity regarding healthy versus unhealthy relationships, and whether or not their partners valued them to the extent they felt they should.

This response to cancer is increasingly being documented in the literature; indeed, one of the dominant discourses relating to breast cancer survivorship in particular is the transformation and rebirth discourse (King, 2006). This arises in a study by Coreil et al. (2012) on African American and Latina narratives of breast cancer recovery; for the Latina women in the study, most of whom were first-generation immigrants to the U.S., their recovery narratives included frequent reference to transformation/rebirth, and they drew parallels between their migration experience and confrontation with cancer. Survivorship was likened to a “rebirth,” giving women the opportunity to start a new life. Jones et al. (2010) identified a similar theme in their study with adolescent/young adult Latino survivors, many of whom believed that cancer had happened to them for a reason and had improved their perspective and behavior. These findings parallel a robust body of literature in psychology on “benefit-

finding”; the construct refers to the positive psychological shift that takes place after experiencing a negative or traumatic life event, a shift that creates a deeply meaningful transformation in an individual's life (e.g., Tomich and Helgeson, 2004).

The transformation discourse focuses on cancer as an agent of change, a catalyst that spurs positive growth and self-discovery, and generally has a beneficial impact on one's life. This explains the frequently-noted comment of “cancer is a blessing in disguise” in this study and others (see, for example, Coreil, et al., 2012). Some authors have argued that, because of the widespread circulation of this discourse, positive transformation has become an expectation for survivors. For example, DiGiacomo and Sumalla (2012) argue that the victim-blaming discourse still lingers within the survivorship concept, noting that “victim” and “survivor” are two sides of the same coin. As they point out, the key to the survivor identity is active engagement with the disease, treatment, and the outside world—versus the more passive identities of patient or victim. But, the ways in which the survivor discourse has been invoked in psycho-oncology has created the dominant expectation that survivors will undergo a positive identity transformation in the process of confronting cancer—an idea that Bell (2012) also points out is predicated upon the assumption that cancer is a traumatic event, which is not necessarily always the case. As DiGiacomo and Sumalla (2012, p. 47) argue, “an undeniable air of moral superiority attaches to the image of the person capable of positive self-transformation in traumatic circumstances.” While at the same time being held responsible for his/her illness, a “real survivor” must respond to the experience in very particular ways. Critiques of the survivorship discourse point to a tyranny of optimism that pervades the social expectations of a survivor and challenges the validity of negative emotions. Taken to the extreme, these negative emotions are made dangerous because they are seen to invite recurrence and ultimately death.

While I do not aim to negate the personal and life-changing transformations that participants in this study spoke about, it is important to consider the role of the above critique. Perhaps, as DiGiacomo and Sumalla (2012) suggest, the change that survivors speak of occurs as an intense, embodied learning experience in which “new truths—positive or negative—are drawn out of an encounter with one's own mortality” (p. 47), versus the identity change conceived by the psycho-oncology literature. This learning experience prompts survivors to share what they have learned with others who are going through the process, explaining one of the ubiquitous themes in the literature that also appeared in this study—an overriding need to give back and help others. This is a strong theme even in the small body of research with Latina cancer survivors (e.g., Buki, et al., 2008). The authors note that this learning and knowledge about “‘how to live’ ... is not ‘coping’ (a thin description) or illness management; it is existential” (DiGiacomo and Sumalla, 2012, p. 51).

4.2. **Sobrevivencia and Vivencia: experiencing post-treatment life**

Participants in this study displayed varied reactions to the *sobrevivencia/sobreviviente* concepts and terminology, with many embracing the terms (while offering different interpretations), and others actively resisting and rejecting both the vocabulary and what participants viewed as their associated meanings. A few participants preferred to conceive of cancer as being “over,” reflecting Frank's (2003) limited liability narrative in which cancer

is something to be quickly overcome—a bump in the road. As he writes, the impact of cancer on one's self-identity and life trajectories is minimal; thus, the individual is not forced to grapple with existential quandaries and can return quickly to his or her pre-cancer life.

However, many of those who resisted the term, and specifically those who used *vivencia/viviente* rather than *sobrevivencia/sobreviviente*, were members of one grassroots breast cancer organization: while survivorship was regarded by them as merely living in a physical sense, a “*viviente*” meant that one is squeezing every last drop out of life, living to the fullest degree possible, and leaving no opportunity behind.

In this way, support groups and organizations helped shape people's terminology and thinking about what it means to have cancer and served several functions. First, individuals learned how to identify themselves to others and how to situate themselves in the larger world vis-à-vis cancer. Second, they learned what obligations, responsibilities, expectations and meanings come with different identities—and more broadly, how to live one's life post-cancer. Previous research has investigated the cultural models created by support groups, arguing that these groups develop templates of survivorship experiences and recovery that—through time and group processes—become shared and embraced among their members (Coreil et al., 2012, 2004; Corvin et al., 2013; Mathews, 2000, 2008). For example, Mathews (2000) studied the creation of a breast cancer support group for African American women in which the resulting cultural model of breast cancer “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” (2000, p. 409). While the survivor identity piece is one example, another concerns the theme of helping others. Support groups provided the space in which people helped *themselves* psychologically and emotionally, but almost more importantly, they provided the venue through which to help *others*. This was encouraged both explicitly and implicitly as a responsibility of being a survivor, and the cause was actively taken up by support group members.

These critiques of the survivorship concept and attendant meanings of post-treatment life must be viewed within the context of the Puerto Rican history and political relationship to the U.S. Many participants explicitly juxtaposed “Puerto Rican” values with what they understood to be “American” values, referencing Puerto Ricans' religiosity, and the importance of kin networks and sociality, when discussing the impact of cancer in their lives. Many of these issues have arisen in the sociocultural literature on cancer; for example, numerous anthropologists have cited the prominent role of religious beliefs in negotiating an illness experience such as cancer (e.g. Erwin, 2008; Mathews, 2008). However, some of these participants understood their cancer experience as different because of what they perceived as *distinctive* cultural values. As noted above, Puerto Rico has been an unincorporated territory of the United States since 1898 following the Spanish-American War, with a long history of colonial economic exploitation. It was also the site of decades-long experimentation in birth control and a notorious sterilization campaign to reduce the island's population and ostensibly to improve its economic condition (Briggs, 2002). Accordingly, the role of large American cancer advocacy organizations is not benign and can carry powerful cultural meanings arising from a century of economic and political

domination. These findings warrant a further investigation of the relationship between neo-colonial resistance in the context of biomedical meanings of illness categories.

The above findings are relevant to Rose and Novas' (2005) elaboration of biocitizenship as being both individualizing and collectivizing. In the sense that individuals actively engage in “biomedical self-shaping”—shaping their relationship with themselves using the knowledge of their somatic or biological/bodily individuality—they also engage in the production of a moral economy of hope, in which “ignorance, resignation and hopelessness in the face of the future is deprecated” (Rose and Novas, 2005). In this way, the transformation discourse that emerges in this study might be seen as a manifestation of a moral economy of hope, through which a confrontation with cancer has provided a window of “opportunity” to transform the self and enact a hopeful, more promising future. Biocitizenship can be read as a collectivizing enterprise too, reflecting the increasing formation of and importance of social groupings based on shared biological identities. This can be seen in two ways in this study: the role of advocacy organizations in Puerto Rico in shaping a national discourse of survivorship (in the case of the larger U.S. organizations, by “importing” and “translating” the North American meanings of survivorship directly into the Puerto Rican context) and the role of smaller grassroots organizations in shaping the terminology and expectations attached to the cancer experience, and presenting, at least in the case of one support group, an alternative understanding of what survivorship does and does not mean. These expectations include both the terminology attached to oneself (for example, *sobreviviente* versus *viviente*), or the associated behavioral expectations, such as helping others and being active in influencing other peoples' experiences with cancer.

Future research should examine how these discourses of survivorship, and the associated post-treatment expectations of individuals with cancer, intersect with a growing focus on survivor healthcare in the United States and elsewhere. Increasingly, discussions about cancer survivorship in the West have referenced a distinctive set of health concerns and healthcare needs faced by people post-treatment. Issues of care-planning around survivors' health and psychosocial outcomes have come to the fore; embedded is the implicit need for survivor “self-management practices” related to potential late effects, adherence to continued screening, and utilization of follow-up care. The National Cancer Institute (NCI)—the largest single source of cancer research funds in the U.S.—has explicitly called for research into survivorship care planning (NCI, 2015), and professional guidelines have delineated the state of the science on appropriate follow-up care and screening (NCCN, 2014). Survivorship care is thus coming to reference a continued surveillance of survivors' bodies that suggests the formation of an ongoing “patient-ness,” bringing with it a different set of expectations, roles and status. Research should examine how these discourses of follow-up care—which are becoming ever-more-urgent in the U.S. as the sheer number of survivors increase—circulate to Puerto Rico and intersect with already-existing survivorship discourses to shape novel forms of biocitizenship.

4.3. Limitations

Study limitations must be taken into account in the interpretation of these findings, particularly with regards to sample bias. As in much cancer survivorship research, there is

an overrepresentation of women with breast cancer in the sample, and men were very difficult to recruit. This is not a problem unique to this study, as noted by Bell (2014), who argues that much of what we know about cancer survivorship is, in fact, specific to the unique case of breast cancer and specific to women. She argues that because “a desire to participate in research is partially determined by the extent to which the target population have taken on a politicized, biosocial identity in relation to (breast) cancer, it is inevitable that the resultant research will primarily attract people who conceptualize their experience in such terms” (p. 62). The composition of this sample, unfortunately, with its high proportion of breast cancer diagnoses and the male-female ratio, reflects the same bias.

5. Conclusion

Coreil et al. (2012) argue that dominant discourses often frame people's engagement with a disease such as cancer, providing a lens through which people can understand or talk about their own experience with others. However, while these dominant discourses provide the initial structure, they are imbued with local meanings that are relevant to a group's experience, leading to particular and varied cultural constructions of survivorship. Applying this concept to the current study highlights both the dominant discourses and the cultural construction of survivorship in the Puerto Rican context. Participants drew from many of the overarching discourses of survivorship—such as transformation and the importance of optimism and positive thinking—as well as from what was understood by participants to be distinctive aspects of Puerto Rican culture, in the crafting (Frank, 2003) of a local understanding of life after cancer diagnosis and treatment. These distinctive elements, which include the high value placed on extended family, social relationships, and faith, were often noted by participants as cultural values that lie in contrast to those held by Americans and which differentiate the context of Puerto Rico from the U.S. Future research should take into account the potential performance aspect of these espoused values and the importance of maintaining a distinctive set of Puerto Rican values in the face of a continuing American colonial presence.

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Table 1

Demographic characteristics of survivor sample.

Demographic variables		Survivor group N = 23
Sex	Female	20 (87%)
	Male	3 (13%)
Age at interview	Mean	43.43 years
	Range	27–73 years
Age at diagnosis	Mean	33.61 years
	Range	13–45 years
Years since first diagnosis (<i>primary cancer</i>)	Mean	9.6 years
Years since most recent diagnosis (<i>primary, recurrence and/or secondary cancer</i>)	Mean	7.2 years
Marital status	Single (no partner)	2 (9%)
	Living with partner	1 (4%)
	Married	9 (39%)
	Separated	3 (13%)
	Divorced	8 (35%)
	Widowed	0 (0%)
Religious affiliation	Catholic	8 (35%)
	Christian (non-specified denomination)	5 (22%)
	Baptist	3 (13%)
	Espiritista	1 (4%)
	Pentecostal	1 (4%)
	Evangelical	1 (4%)
	None or non-practicing	2 (9%)
	Unknown	2 (9%)
Annual household income	Under \$14,999	5 (22%)
	\$15,000–39,999	12 (52%)
	\$40,000–69,999	2 (9%)
	Over \$70,000	4 (17%)
Years of education	High school/GED	1 (4%)
	Some college or technical school	3 (13%)
	College degree	16 (70%)
	Advanced degree	3 (13%)
Type of cancer (<i>includes primary and secondary, n > 23</i>)	Breast cancer	16
	Lymphoma	3
	Uterine cancer	2
	Thyroid cancer	2
	Colorectal cancer	1
	Angiosarcoma	1
	Melanoma	1
	Oral cancer	1