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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.

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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* (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

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¹ Although 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., Balslem, 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).

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 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, 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

² While 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.

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