

Fall 2016

Survivor, It's Not for Everyone: Perceptions of the Cancer Survivor Label by Individuals Diagnosed with Cancer as Emerging Adults

Rachel Murphy-Banks

Follow this and additional works at: <https://digitalcommons.lesley.edu/jppp>

Recommended Citation

Murphy-Banks, Rachel (2016) "Survivor, It's Not for Everyone: Perceptions of the Cancer Survivor Label by Individuals Diagnosed with Cancer as Emerging Adults," *Journal of Pedagogy, Pluralism and Practice*: Vol. 8 : Iss. 1 , Article 7.
Available at: <https://digitalcommons.lesley.edu/jppp/vol8/iss1/7>

This Article is brought to you for free and open access by DigitalCommons@Lesley. It has been accepted for inclusion in Journal of Pedagogy, Pluralism and Practice by an authorized editor of DigitalCommons@Lesley. For more information, please contact digitalcommons@lesley.edu, adhembe@lesley.edu.

Survivor, It's Not for Everyone: Perceptions of the Cancer Survivor Label by Individuals

Diagnosed with Cancer as Emerging Adults

Rachel Murphy-Banks, MA

Lesley University

Abstract

Seventy-thousand adolescents and young adults are diagnosed with cancer in the United States every year. The term *cancer survivor* is broadly used as a descriptor in mainstream society, and academic and oncology literature to reference individuals who have been diagnosed with cancer. It was originally used to provide a message of hope, not a label. This study provides an overview of the evolution of the term *survivor* and explores the often-overlooked perspectives of those who fall into this demographic, many of whom do not accept this identifier. Reasons for rejecting the survivor identity are shared with the intention of highlighting the importance of listening to emerging adults and to contribute to the discourse surrounding cancer survivor.

The label *cancer survivor* is applied to millions of people. But not everyone accepts this. While seeking to better understand the Emerging Adult Cancer Survivor (EACS) experience, the tendency to reject the *survivor* label came to the fore. Having personally experienced a cancer diagnosis in my twenties, I have a keen understanding of the impact it has on one's life and how a shift in identity can occur. It is not my story I am interested in telling. It is my intention to offer insights from the EACS community and to shine light on this demographic.

Emerging adulthood encompasses the period of the human lifespan that is perhaps the most volatile. It is “the age of *identity explorations*...the age of *instability*...the most *self-focused* age of life...the age of *feeling in-between*, in transition, neither adolescent nor adult...(and) the age of *possibilities*, when hopes flourish” (Arnett, 2004, p.8). The forward moving momentum and “asserting autonomy, developing a set of values, and establishing relationships with peers, as well as intimate relationships” (Williams, 2013, p. 293) so characteristic of the emerging adult time span is abruptly and unnaturally stymied by a cancer diagnosis. EACs form their own cultural group based on their shared schema, or in other words, understanding of what it means to have experienced a diagnosis and/or treatment of cancer between the ages of 18-29. The individually lived experience is shared in the public, social sphere with others who have similar experiences. The conceptualization of culture is thus based on a group of people having mutual understandings or meanings attached to certain stimuli, which influence how that group acts, reacts, and interacts both internally and interpersonally (Strauss & Quinn, 1997). Strauss and Quinn, along with Brumann (1999), emphasize that culture is heterogeneous, can be modified, allows for inconsistencies between group members, and requires people to make their own choices, as was exemplified by the participants in this study.

The literature review, interviews and observations included in this qualitative, grounded research study highlight the need for attention to be paid to the voices emanating from the EACS community. Examining the growth in cancer survivorship in the United States, along with the development of the term survivor and the array of meanings attached to it provided a platform to integrate perspectives provided by EACSSs. EACSSs defined what the term cancer survivor meant to them, expressed concern for the portrayal of the cancer experience in American society, landed on a continuum of accepting or rejecting the label, and offered alternative language to describe their experience.

Procedure & Participants

The research for this study commenced in the spring of 2014, under the purview of a thesis for an Intercultural Relations graduate degree at Lesley University. While this course project was exempt from the institutional review board, ethical considerations were taken, including gaining participant's informed consent. The completed paper, titled *The Oft Overlooked: Resiliency and Agentic Acts within the Emerging Adult Cancer Community*, highlighted the importance of establishing connections with cohort peers and examined how acts such as exercising, standing up to doctors or nurses, and using humor showcased the resiliency found in this demographic. Not blindly accepting the survivor label emerged as an agentic act employed by participants which has been extracted and explored further here.

Ethnographic qualitative research depends heavily on "learning to listen well to others' stories and to interpret and retell the accounts" (Glesne, 2011, p. 1). Interviewing EACSSs, as well as attending events where survivors congregate, was invaluable. It encouraged me to gain deeper insights, and provided me with the experience of hearing a variety of voices that comprise this cultural group. An in-depth, in-person interview occurred, lasting approximately one hour,

with each participant over the course of the study, with subsequent follow-up interviews and observations taking place through 2015. To encourage a sense of comfort, participants chose our meeting locations, which led to a variety of physical locations including coffee shops, outdoor benches, office conference rooms and either their home or mine. Ethically important, each participant was advised of their right to confidentiality, and reminded that they did not have to answer any questions they did not wish to and could stop participating at any time. Jomy and Sam gave their permission for their names to be used. The remaining participants have been given a pseudonym.

I recorded the majority of the interviews and then transcribed specific sections shortly after the interview. Recording established me as a researcher, helped separate me from my EACS status, and provided me with the ability to stay attuned to my participants, giving me the opportunity to explore the “meanings (I) infer(ed) from the bodily expression(s) accompanying words-gesture, movement, facial expression, tone of voice” (Emerson, et al., 2011, p. 65). It captured the word choice used to describe the EACSs experiences, which is especially salient in the Data Analysis.

Participant observation and direct observation have value in ethnographic research. Glesne (2011) noted the import of the researcher placing herself in the social arena of a culture to “learn firsthand how the actions of research participants correspond to their words; see patterns of behavior; experience the unexpected, as well as the expected; and develop a quality of trust, relationship, and obligation with others in the setting” (p. 63). Employing the notion that sampling in multiple locations is important in qualitative work I took part in a young adult support group and attended survivor conferences as well as cancer fundraisers.

Participants were diagnosed with and/or treated for cancer during the emerging

adult period of the life span, between the ages of 18 and 29. The 11 participants included five males and six females who were between the ages of 25 and 68 at the time of participation. All participants had no current evidence of cancer. Primary diagnoses included Acute Lymphocytic Leukemia (ALL), Colon cancer, Breast cancer, Brain tumor, cancer of the Middle Ear Drum, Ewing's Sarcoma, four diagnoses of Hodgkin Lymphoma and Testicular cancer. Two participants had been diagnosed twice, one with Ewing's Sarcoma followed by secondary Myelodysplastic Syndrome, and the other with Testicular cancer followed by ALL. Years from last treatment ranged from one to 38 years. Treatments included radiation, chemotherapy and/or surgery and were conducted at various hospitals in New York, Connecticut and Massachusetts. All participants had medical insurance while going through treatments, with the exception of Dave who did not have it during the first of his six years of treatment. Everyone spent their emerging adult years in the United States and speaks English.

Literature Review

An examination of peer reviewed journals, books, and multi-media resources provided information on the prevalence of emerging adults affected by cancer, how survivor became a broad-stroke categorization for describing anyone diagnosed with cancer and the finding that not all individuals who have a history of cancer derive the same meaning from the term. This search also displayed a clear need for more age-specific research. In the field of oncology, the 15 to 39-year age range is applied to a population referred to as Adolescents and Young Adults, or AYAs. Studies focusing on AYAs, of whom emerging adults fall between, have been limited. "There is a lack of descriptions from young adults with cancer about their personal experiences of treatment" (Snobohm, et al., 2010, p. 867), "research is still in its infancy" (Neinstein & Irwin, 2013, p. 560), and Keegan, et al. summarized this theme by noting this demographic

“encompass[es] a distinct, understudied, and underserved group in cancer care” (2012, p. 240).

The studies which have looked at AYAs report unmet information and service needs with concerns expressed regarding body image (Williams, 2013), self-esteem, fear of recurrence (Zebrack, 2009), fertility, long-term effects (Grinyer, 2009), and not being able to manage school or job responsibilities (Bleyer, 2002). Zebrack (2009) found that many needs were still not met years after diagnosis and treatment. Seeking to understand attitudes towards the survivor label contributes to the dearth of information regarding the emerging adult cancer experience.

Cancer Survivors in the United States

The National Cancer Institute (2006) published a report stating there were “nearly 68,000 people aged 15 to 39- years diagnosed with cancer in 2002” (p. 6); that number is now calculated to be 70,000 newly diagnosed cases per year (2015). Thanks to a concerted effort to improve cancer outcomes through better detection and treatment, many more individuals are living beyond or with their disease. In 1970 there were 3 million survivors living in the United States (Parikh, et al., 2015, p. 423). As of January 1, 2016, “more than 15.5 million children and adults with a history of cancer were alive.” More than 630,000 are currently between the ages of 15 and 39. The number of survivors is projected to increase to 20.3 million by 2026. (American Cancer Society, 2016, p.1-2).

Two particular areas of concern regarding AYAs are the age-appropriate care gap within the health care system and progress in survival rates. First, the binary American health care system has resulted in survivors being treated as part of one of two groups, pediatrics or adults. Bleyer (2002) has called for this age demographic to be treated age specifically, “like pediatric, adult, and geriatric patients- (it) has unique medical and psychosocial needs” (p. 9). While cancer disproportionately affects older adults, the incidence rate of adolescents and young adults

is nearly six times that of children under the age of 15 (National Cancer Institute, 2015). Yet there is rarely a medical home dedicated to AYAs. The second area of concern regards survival rates that have not kept pace with other age groups. For example, “improvements in overall survival for AYAs with cancer has been lacking relative to pediatric and adult populations (Williams, 2013, p. 292). When analyzing the annual average percentage change in 5-year relative survival intervals this becomes apparent: 15-45-year-olds have seen a 0.39-0.76% increase compared to 1.07-1.18% in children (aged 0-14) and 1.06-1.23% in older adults (aged 46-85) (Bleyer, et al., 2012). Cancer is the “leading cause of nonaccidental death among adolescents and young adults” (Zebrack, et al., 2010, p. 4862). Bleyer, et al. state, “the number of deaths due to cancer declined in all age groups during the past decade except in individuals aged 15 years to 29 years and in those 25 years to 29 years it increased” (2012, p. 6018). Clearly, demographic-specific attention is required.

Evolution of Survivor

Morris, et al. have suggested that the change in public consciousness of seeing a person with cancer as a “survivor” instead of as a “victim” can be traced back to the declaration on “the war against cancer” (2014, p. 427), which coincided with the National Cancer Act of 1971. With presidential backing, scientists and the government sought to conquer cancer, a message which invaded homes through newspapers (Mukherjee, 2015). The term survivor was initially used in an article published in 1985 by Dr. F. Mullen, who was reflecting on his own cancer experience (Miedema, et al., 2007). Mullen called for a dedicated focus on survivorship, writing, “the simple concepts of sickness and cure were insufficient...I was, in fact, surviving, struggling physically and mentally with the cancer, the therapy, and the large-scale disruption of my life” (1985, p. 271).

In 1986, the National Coalition for Cancer Survivorship (NCCS) was created as an advocacy group. The NCCS wanted to empower individuals diagnosed with cancer and included in its definition of survivorship anyone “living after a diagnosis of cancer, regardless of how long a person lives” (Park, et al., 2009, p. S430). Prior to this, individuals who had been diagnosed were considered cancer victims and a survivor was “someone who had been free of any sign of the disease for five years” (NCCS, 2014). Khan, et al. (2012a) suggest meaning and discourse around the term survivor “remain(s) widely interpreted depending on the purpose of the research, or advocacy and policy motives of the different organisations applying the term” (p. 178). The socio-political changes, along with advances in cancer diagnoses, improvements in overall survival rates, and increased media attention has helped destigmatize cancer and has supported the evolution in the American mainstream in adopting the term cancer survivor (Deimling, et al., 2007).

Cancer Survivor: Accepted or Rejected

A range of meanings has emerged from listening to individuals who have been diagnosed with cancer. McGrath and Holewa noted there is “limited research exploring the meanings of the term to the very individuals to which the term is applied” (2012, p. 3288). In their Australian study, focusing on the perception of the survivor identity in individuals across the lifespan, McGrath and Holewa found the term was “meaningless” (p. 3289), implied an “unnecessary focus on their disease” (p. 3290), was deemed inappropriate for some as there is not a “cure but rather a pervasive angst over possible relapse” (p. 3290), was “valuable” (p. 3291), “assisted conversation as others would understand the term” (p. 3291), and “was associated with re-entering life and did not necessarily involve a heroic dimension” (p. 3294). Khan, et al. (2012a) conducted a similar study in the United Kingdom and reported cancer survivor was used “as a

factual description of an experience” (p. 179), implied “a high risk of death” (p. 180), “that survival was a choice” (p. 181), or that it involved an “advocacy role” (p. 183). The acceptance or refusal of the label varied. Two studies conducted by Kelly, et al. found “the cancer experience *was* enough to merit the term ‘survivor’ and identified factors such as completing treatment, cancer type, perceived risk and time since diagnosis as proponents for calling oneself a ‘survivor’” (2011, p. 164). Studies in which the survivor label or identity was rejected has led to new language to describe the cancer experience. Park, et al. (2009) reported concerns regarding recurrence or associating survivor with cure led some people to identify themselves as someone who has had cancer. McGrath and Holewa (2012) posited that survivor may be eclipsed with individuals identifying themselves as having lived through cancer.

An acceptance of the survivor label by people diagnosed with cancer has been described as positive in the psychosocial literature. Grinyer (2009) found that the survivor identity persisted throughout the years following a cancer diagnosis and that for many the acceptance of the term “resulted in an enhanced sense of identity and self worth” (p. 124). While examining self-identifying labels, Park, et al. (2009) noted the potential correlation between the acceptance of the survivor label, or identity, with wellbeing and adjustment after cancer. This stance was also taken by Deimling, et al. (2007) who suggested the “adoption of the survivor identity may be an important step in the process of identity transformation or reconstruction” (p. 760). Morris, et al. (2014) referenced research that has shown the acceptance of the identity “may be empowering as it provides an alternative identity to those stereotypical of illness and a mechanism to replace those identities threatened or lost as a result of the cancer” (p. 428). It should be noted that participants in the Park, et al. (2009), Kelly, et al. (2011), and Morris, et al. (2014) studies had mean ages of 46, 47 or 58, and 70 or 52, respectively.

Cho and Park sought to measure acceptance of cancer related identities including “victim, patient, someone who has had cancer, survivor, cancer conqueror, and member of the cancer community” in 15 to 39- year olds (2015, p. 599). Respondents endorsed someone who has had cancer the most and cancer victim the least: “half of our participants endorsed identities such as member of the cancer community and survivor” (p. 607). Shown through Cho and Park’s expansion of identifiers, further examination of which terms individuals accept is needed.

The meanings attributed to the term survivor are as diverse as the population to which it has been applied. It is dangerous to assume that the survivor label is accepted by all; “the overemphasis of the positive aspects of survivorship has been shown to have latent problems such as alienating potential survivors” (McGrath & Holewa, 2012, p. 3293). Awareness and sensitivity must be incorporated in the discourse surrounding cancer survivor especially in reference to emerging adults.

Data Analysis

The evolution of the term cancer survivor, along with the differences in opinions regarding the term by individuals who have been diagnosed with cancer has been documented. Asking individuals diagnosed with cancer in emerging adulthood what survivor meant to them emphasized that the term must be further analyzed. The Merriam-Webster dictionary (2015) defines “survive” as “to remain alive, to continue to live, to continue to exist.” Allowing for the fact that they had survived cancer did not lead participants to say they were survivors. Various reasons were offered regarding why the term was not accepted. Those who do use the survivor label to identify themselves referred to the contextual situation of its applied usage and wished to make it clear it was only an aspect of their identity, not their entire persona. Determining what language to use requires further dialogue with individuals who have been diagnosed with cancer.

Defining Cancer Survivor

Participants referred to institutional definitions when answering who a cancer survivor was. These replies indicate the influence and integration of the survivor label, though slight variation was found. Jeff, who received two cancer diagnoses in his early-twenties, shared that his understanding of the survivor definition has changed over time, noting he did not like the word at first: “I misunderstood it as a label applied to those who had actually survived cancer, and it seemed to celebrate that, even though patients so often had so little control over whether they survived or not.” His attitude has shifted since learning the National Cancer Institute’s (NCI) definition, which includes “anyone diagnosed with cancer” (personal communication, September 20, 2015). While speaking at the Cancer Survivorship Intervention Research Symposium, Julia Rowland, Director of the Office of Cancer Survivorship at the NCI, noted survivor was never intended as a label. It was a message of hope. It got rid of the word victim (observation, April 2, 2015). Ivy, who was diagnosed with Hodgkin Lymphoma, defines the term based on what she read during an Internet search: “survivor was from the minute you were diagnosed, through your whole journey of cancer” (personal communication, November 11, 2014). Jena, who does not use the term often, said a cancer survivor could be applied to “somebody who hasn’t died from cancer, who had cancer and was treated for it” (personal communication, November 4, 2014). Ivy and Jena’s statements echo the American Cancer Society’s definition of cancer survivor, which is “any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life...in practice, however, the term 'survivor' is often used to mean someone who has finished active treatment” (2014, p. 1). To Jomy, who finished treatment seven years ago, a person becomes a survivor, “the minute they choose to fight. The minute they make that decision, like, ok, I’m going to go through with the

treatment” (J. Duran, personal communication, September 25, 2014). A general consensus that anyone diagnosed is a survivor appears to have occurred, though its acceptance is not as straightforward.

Survivor of What?

Attitudes of how cancer is discussed in the public domain were shared when investigating perceptions of what it means to be a cancer survivor. Examining the meaning of the term is a relatively recent development predicated on the notion that “society in general has shifted its view on cancer from that of a death sentence to a survivable, life-threatening illness” (Deimling, et al., 2007, p. 759). Dave, who was diagnosed in 1975 and endured surgery followed by six years of chemotherapy treatment, said, “I don’t like to hear it when you go to the doctor and they say something, but other than that, seeing commercials and all that other stuff doesn’t bother me” (personal communication, November 11, 2014). Others took issue with how cancer is portrayed. Tim, who experienced cancer himself in 1976 and then again as a caregiver to his wife, who was diagnosed with breast cancer at the age of 35, shared his belief that the perception within the public sphere is that cancer is a single disease. “[E]ven though everyone knows there is colon cancer and breast cancer, they think of it as, we’re going to find a cure for cancer. Like it’s a monolithic thing” (personal communication, October 6, 2014). Examples are readily found in print, multimedia and in-person at fund raising events. While attending a fundraiser for the Leukemia and Lymphoma Society, the message reiterated over the loud speaker was attendees were on a “walk to end cancer” (observation, October 9, 2014). Pointing to the discourse around celebrities who have been diagnosed with cancer, Jane – who was diagnosed in 2013 with a brain tumor – thinks an impression has been made where “people think it is easy...sort of glamorized (and) no, it’s not glamorous. Neither is an accurate portrayal” (personal communication,

October, 1, 2014). A reason for qualifying or outright refusing the cancer survivor title may be a reaction to the discourse national organizations and celebrity media coverage employ when talking about cancer.

Agentic Act: Rejection of the Label

It has been “recognized that not all people with a cancer diagnosis identify with the term ‘cancer survivor’” (American Cancer Society, 2014, p. 1). The act of choosing to reject or accept the label is not simple. When the control over one’s life is so drastically altered after being told *you have cancer*, a decision of how to identify one’s self becomes of great import. The survivor label rejection-acceptance continuum that came forth in McGrath and Holewa’s (2012) Australian study, and Kahn, et al.’s (2012a) United Kingdom study, was also found in this study of people diagnosed in emerging adulthood. Reasons to reject stemmed from a sense of not having earned the identifier, feeling one was not a survivor because having had cancer did not make them special, they perceived having little to do with the overall outcome, or not feeling they could put a time stamp on when they were in the clear. Application of the survivor identity to one’s self was predicated on context and was varied. Based on this small sampling and the two aforementioned studies, it is clear survivor is not a term fit for everyone.

Participants not inclined to use the label noted having survived cancer did not make you stand out. Told he had a 50/50 chance of surviving at the age of 29, Dave said being a cancer survivor, “just means you survived the disease. It doesn’t mean anything, you’re not extraordinary or anything. You don’t get the Oscars for it or whatever, but you survived” (personal communication, November 11, 2014). Leisel, diagnosed in 2011 at the age of 27 also noted that she had survived, and that fact did not make her any different. “I saw myself as a boring twenty-something year old, just working, doing what I thought was right by my family,

for myself, and that was it. I didn't think I was special before and I don't think I'm special after" (personal communication, March 13, 2014). Naming one's self a survivor for these participants was not deemed important in their daily lives.

Emerging adults tended to reject the term with regard to themselves if they attributed being a survivor to playing a particular role in their treatment plan, having a certain type of treatment, or if they had uncertainty regarding when they would have less of a chance of a cancer reoccurrence. Currently in his late-thirties, Nick said, "I think that's what a survivor is, it's being a hero. A hero is somebody that goes above and beyond." He does not name himself a survivor due to his attitude, which he described as "not the best," and lack of involvement in ridding himself of the disease. "I felt, I'm showing up and I'm there, but the chemo and the medicine is doing everything" (personal communication, November 20, 2014). Like Nick, Jane was diagnosed in her early twenties and rejected the label because "I didn't do anything to survive. I took the drugs my doctor gave me, I took the course of treatment he prescribed for me, I had zero say in it so I don't feel I deserve the badge of honor of survivorship" (personal communication, October 1, 2014). Jena, diagnosed with breast cancer at the age of 29 shared that she is not inclined to use the term in regards to herself. She referred to her surgery and radiation treatments as having less of an impact than if she had been treated with chemotherapy; "I don't feel like what I went through is as severe as what other people went through...I don't know if that (chemotherapy) would have killed me, I don't know if I would be a survivor if I had to go through that" (personal communication, November 4, 2014). A link between treatment type and identity was reported by Cho and Park (2015) who found individuals who had been treated with chemotherapy were more likely to identify themselves as survivors which "might imply that chemotherapy potentially affects LAYA (late adolescents and young adults) participants' sense of

self” (p.608). John was diagnosed with colon cancer and received an initial prognosis of a 32% chance of survival at the age of 26. He said, “I don’t consider myself a survivor, because survivor seems like it’s behind you, like you’re done. I do consider myself surviving” (personal communication, November 8, 2014). John’s comment builds off of Deimling, et al.’s work: “most of those who have had cancer also are aware that long-term survival of one type of cancer does not ensure a future free from cancer. They recognize that after one cancer has been 'survived' or 'cured' there is the possibility of another type of cancer” (2009, p. 759). Jeff, who was diagnosed in 2007 while studying abroad in Italy, then again, two years later during a routine follow-up, echoed this finding as well: “I suppose I accept it (label of survivor), though not with conviction. What I think is important about the context is whether others around me know what that means—do they know that it means that I’ve fought cancer, and not necessarily conquered it?” (personal communication, September 23, 2015). Tim, diagnosed at the age of 29, referenced his acceptance of the survivor label, yet shared that it has receded in relevance due to his heart disease, a likely result of his cancer mantle radiation treatments: “for many years that’s how I defined myself, I’m a cancer survivor. Now I’m a heart disease survivor” (personal communication, October 6, 2014). As a long-term survivor, of nearly 40 years, Tim exemplifies how the acceptability of the label can change over time.

Sam identified situational context – of accepting and using the term – in a different manner. Diagnosed in 2001 during her senior year of college, at 21, and then again at 23, the founder of the AYA financial support non-profit, the SAMFund, uses “survivor because it validates me in my role working with young adult survivors,” but also pointed out that others care more that she has a master’s in Business Administration, ensuring she knows how to run a non-profit (S. Eisenstein Watson, personal communication, September 11, 2014). At an annual

Young Adult Cancer Conference, a room of survivors discussed the term. The consensus of the speakers in the group was acceptance of using and labeling the individuals within the room as survivors. One young woman questioned who had come up with survivor and suggested it was “non-cancer people” who had labeled “us” survivors (observation, March 28, 2015). Sam’s response and the comments made at the conference support Morris, et al.’s theory that for the “cancer survivor, identity may be the product of an interaction between perception of self and interactions with other individuals and their social environment” (2014, p. 434). The participant who was the most enthusiastic about embracing the survivor label was Jomy, who was on active chemotherapy treatment for ALL from age 16 through 19. Wearing a yellow t-shirt with survivor emblazoned over her chest during our first interview, when asked to define the term she replied “It’s me.” However, she made it clear this was only one aspect of her identity: “It’s a part of me. It’s not completely me.” She warned against broad assumptions of the label noting, “you’re not just that label. There’s so much more to someone and I think that’s also important.” Her acceptance may be linked to her transforming the negative discourse used when discussing cancer into a positive, “there is something that’s good attached to it (cancer); cancer survivor, cancerversary” (personal communication, September 25, 2014). If the emphasis is placed on survivor rather than cancer, perhaps more individuals would accept the term.

Replacing Survivor

In a study asking people who had been diagnosed with cancer to identify themselves as a victim, survivor, someone with cancer or as a patient, Park, et al. found “the most frequently endorsed identity was survivor (83% endorsed this identity at least ‘somewhat’), followed closely by someone with cancer (81% at least ‘somewhat’)” (2009, p. S433). Cho and Park (2015) included “member of the community” and “cancer conqueror” in their self-identification

study. Giving participants structured options limits one's agency in being able to describe their preference in describing their experience. Multiple individuals who had been diagnosed with cancer as emerging adults explained they preferred to say they *had cancer* versus they were a *cancer survivor*. Nick said, "I like to say 'I'm living proof,' more so than 'hey look I'm a survivor.'" Mentioning he rarely talks about his cancer experience unless he meets someone who has been diagnosed, he says "I've lived through it" or "I've gone through it" (personal communication, November 10, 2014). John, diagnosed ten years after Nick, in 2011, echoed a similar sentiment when describing how he identifies himself: "I usually say I had cancer. And so far, so good" (personal communication, May 7, 2014).

When discussing the difference between saying he is disease-free versus cancer-free, John prefers the latter, underscoring the situational relativity of language choice. Saying he is cancer-free represents the "battle wound that I'm kind of proud of, sometimes really proud of" (personal communication, November 8, 2014). The war metaphor touched on by John was also mentioned by Ivy, who calls herself a survivor: "Sometimes (I) question cancer warrior, or cancer fighter. I'm no longer fighting. Terms tend to lean towards war terms...It's a battle, it's a war, but it's not, in that political sense" (personal communication, November 11, 2014). Sam finds the "cancer fighter" and "losing a battle with cancer" terminology used in obituaries problematic: "It implies they did not fight hard enough. And it implies that I did something differently and better than they did because I'm here" (personal communication, September 11, 2014). These comments highlight that the terminology surrounding the cancer experience is still evolving and is troubling to individuals who have been diagnosed with cancer in emerging adulthood.

In the absence of an alternative option, survivor has been used to describe, lump and categorize people diagnosed with cancer, whether they feel the word applies to them or not. The refusal-acceptance continuum on which EACSs fell exemplify that differences exist. This is indicative of the ongoing processing of one's cancer experience and advocates for the necessity of gathering diverse individual voices in lieu of one, all-encompassing voice or worse, a dominant non-EACS voice.

Conclusion

Inquiring about how Emerging Adult Cancer Survivors viewed the term cancer survivor led to finding a cautious acceptance at minimum and outright rejection at most. This was a surprising outcome given the widespread usage of survivor in topical literature, mainstream society and by cancer organizations. Cancer survivor has effectively replaced cancer victim, and now we must seek to understand if survivor should or could be replaced. Saying one has had cancer was offered an alternative. EACSs' negative reaction to the portrayal of cancer, including use of war terminology in mainstream media suggests current language is not sufficient. Special attention must be paid to terminology surrounding the cancer experience, as well as the meanings it may evoke to decrease the potential of causing "harm, upset or alienation" (Khan, et al., 2012b, p. 35). The work of scientists, medical professionals and advocates has created more survivors; those individuals must be listened to.

"I think that a lot of trouble comes when we try to figure out what word to use for somebody else. I think that everybody has the right to choose the label that fits them and that they feel comfortable with. All of these things are so loaded because there are people that will never be in remission, but consider themselves survivors and there are people who feel like, patients and victims, and whatever words, but who are no longer going

SURVIVOR: IT'S NOT FOR EVERYONE

20

through treatment. It's just such a complicated thing for any group of people to try and assign a label to somebody else" (S. Eisenstein Watson, personal communication, September 11, 2014).

While it is problematic to attach a label to a diverse group of people, I wonder if there really is an alternative. Even I categorized and labeled my participants as survivors. Further insights from individuals diagnosed with cancer as emerging adults are needed to understand the preferred language to describe one's self as well as this cancer cohort. When speaking to individuals with a history of cancer I strive to remain cognizant that the label of survivor is not for everyone and therefore should be used with careful consideration. I urge others to do so as well.

References

American Cancer Society. (2014). *Cancer Treatment and Survivorship Facts & Figures 2014-2015*. Atlanta: American Cancer Society.

American Cancer Society. (2016). *Cancer Treatment and Survivorship Facts & Figures 2016-2017*. Atlanta: American Cancer Society.

Arnett, J.J. (2004). *Emerging adulthood: The winding road from the late teens through the twenties*. New York, NY: Oxford University Press.

Bleyer, A. (2002). Overview cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Medical and Pediatric Oncology*, 38, 1-10.

Bleyer, A., Ulrich, C., & Martin, S. (2012). Young adults, cancer, health insurance, socioeconomic status, and the patient protection and affordable care act. *Cancer*, 6018-6021.

Brumann, C. (1999). Writing for culture: Why a successful concept should not be discarded. *Current Anthropology*, 40(S1), S1-S27.

Cho, D., & Park, C. (2015). Cancer-related identities in people diagnosed during late

adolescence and young adulthood. *British Journal of Health Psychology*, 20, 594-612.

Deimling, G., Bowman, K., & Wagner, L. (2007). Cancer survivorship and identity among long-term survivors. *Cancer Investigation*, 25(8), 758-765.

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). *Writing ethnographic fieldnotes* (2nd ed.). Chicago, IL: The University of Chicago Press.

Glesne, C. (2011). *Becoming qualitative researchers* (4th ed.). Boston, MA: Pearson Education, Inc.

Grinyer, A. (2009). *Life after cancer in adolescence and young adulthood. The experience of survivorship*. Oxon, UK: Routledge.

Keegan, T., Lichtensztajn, D., Kato, I., Kent, E., Wu, X., West, M., AYA HOPE Study Collaborative Group. (2012). Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *Journal of Cancer Survivorship*, 6, 239-250.

Kelly, K., Shah, N., Shedlosky-Shoemaker, R., Porter, K., & Agnese, D. (2011). Living post treatment: definitions of those with history and no history of cancer. *Journal of Cancer Survivorship*, 5(2), 158-166.

Khan, N., Harrison, S., Rose, P., Ward, A., & Evans, J. (2012a). Interpretation and acceptance of the term 'cancer survivor': a United Kingdom-based qualitative study. *European Journal of Cancer Care*, 21, 177-186.

Khan, N., Rose, P., & Evans, J. (2012b). Defining cancer survivorship: a more transparent approach is needed. *Journal of Cancer Survivorship*, 6, 33-36.

McGrath, P., & Holewa, H. (2012). What does the term 'survivor' mean to individuals diagnosed with a haematological malignancy? Findings from Australia. *Supportive Care in Cancer*, 20, 3287-3295.

Miedema, B., Hamilton, R., & Easley, J. (2007). From "invincibility" to "normalcy": Coping strategies of young adults during the cancer journey. *Palliative and Supportive Care*, 5, 41-49. doi: 10.1017/S147895150707006X

Morris, B., Lepore, S., Wilson, B., Lieberman, M., Dunn, J., & Chambers, S. (2014). Adopting a survivor identity after cancer in a peer support context. *Journal of Cancer Survivorship*, 8, 427-436.

Mukherjee, S. (Writer), & Goodman, B. (Director). (2015). Cancer: The emperor of all maladies [Television documentary]. Public Broadcasting Service (PBS).

Mullen, F. (1985). Seasons of survival: Reflections of a physician with cancer. *The New*

England Journal of Medicine, 313, 270-273.

National Cancer Institute. (2006). *Closing the gap: research and care imperatives for adolescents and young adults with cancer. Report of the adolescent and young adult oncology progress review group*. Bethesda, MD: NCI.

National Cancer Institute. (2015). *Adolescents and young adults with cancer*. Retrieved from www.cancer.gov/types/aya

National Coalition for Cancer Survivorship. (2014). *Defining Cancer Survivorship*. Retrieved from <http://www.canceradvocacy.org/news/defining-cancer-survivorship/>

Neinstein, M. D., & Irwin Jr, C. E. (2013). Young adults remain worse off than adolescents. *Journal of Adolescent Health*, 53, 559-561.

Parikh, R., Kirch, R., & Brawley, O. (2015). Advancing a quality-of-life agenda in cancer advocacy. *Journal of the American Medical Association Oncology*, 1(4), 423-424.

Park, C., Zlateva, I., & Blank, T. (2009). Self-identity after cancer: "survivor," "victim," "patient," and "person with cancer." *Journal of General Internal Medicine*, 24(Suppl 2), S430-S435.

Snobohm, C., Friedrichsen, M., & Heiwe, S. (2010). Experiencing one's body after a diagnosis

of cancer-a phenomenological study of young adults. *Psycho-Oncology*, 19, 863-869.

Strauss, C., & Quinn, N. (1997). *A cognitive theory of cultural meaning*. Cambridge, UK: Cambridge University Press.

Survive. In *Merriam-Webster's dictionary*. (2015). Retrieved from <http://www.merriam-webster.com/dictionary/survive>

Williams, K. (2013). Adolescent and young adult oncology: an emerging subspecialty. *Clinical Journal of Oncology Nursing*, 17(3), 292-296.

Zebrack, B. (2009). Information and service needs for young adult cancer survivors. *Support Care Cancer*, 17, 349-357.

Zebrack, B., Matthews-Bradshaw, B., & Siegel, S. (2010). Quality cancer care for adolescents and young adults: A position statement. *Journal of Clinical Oncology*, 28(32), 4862-4867.