

“Basically, You Had Cancer and Now You Don’t”: Exploring the Meaning of Being a “Cancer Survivor” Among Adolescents and Young Adult Cancer Survivors

Katie Darabos, PhD,¹ and Jennifer S. Ford, PhD²

Purpose: Survivorship experiences among adolescent and young adults (AYA) with cancer are unique and may involve a process of identity construction. This qualitative study explored AYA survivors’ felt experience of being a cancer survivor focusing on the meaning of survivorship and whether identifying as a “cancer survivor” is consistent with their self-concept.

Methods: Twenty-six individual semistructured interviews were conducted with AYA ($M=19.6$ years; range: 16–24) with a history of cancer diagnosed between the ages of 14 and 18 ($M=15.6$ years). Relevant themes in the literature and through clinical practice guided the development and use of the semistructured interview guides.

Results: Thematic content analysis was used to identify cancer-related identities. Three identities emerged: *Embracing*: acceptance and identification with being a “cancer survivor,” cancer is a significant part of their life, *Part of the Past*: identifies as a “cancer survivor,” but does not let cancer define their life or see cancer as a nonissue, and *Not Part of my Identity*: does not identify with the term “cancer survivor,” cancer seemed like a small event.

Conclusion: AYA construct different meanings to the words “cancer survivor.” These different meanings might reflect a process of identity construction, for some, the characteristics of cancer seemed integrated into one’s self-concept, for others, the thought of being a “cancer survivor” rarely entered how they defined themselves. These findings shed light into how AYA reconcile integrating a cancer experience into their self-concept and emphasize the importance of not one-size-fits-all approach to understanding AYA internalization of being a cancer survivor.

Keywords: survivorship, quality of life, qualitative methods

Introduction

ADOLESCENTS AND YOUNG ADULTS (AYA) with cancer face many challenges across diagnosis and treatment and into survivorship. These challenges associated with a cancer diagnosis are characterized by disruptions and declines in health-related quality of life, impaired social relationships, fear of cancer recurrence, and ongoing uncertainty about late effects of cancer treatment.¹ However, as AYA move from diagnosis and treatment and into survivorship, an additional set of challenges arises as AYA must learn to manage complex emotions associated with re-entrance into their precancer worlds amidst the normal maturational and developmental changes occurring during this time period.^{2,3}

Given this period of significant psychosocial development, adopting the term cancer survivor into one’s self-concept

may involve a process of identity discovery and development. Therefore, this study aimed to qualitatively provide an analysis of how AYA identify and incorporate their cancer experience into their postcancer self-concept.

Identity theory suggests that identity formation is achieved through incorporating various roles into one’s self-concept that reflect meaning and expectations.⁴ Referred to as an identity paradox, AYA wishing to return to their precancer lives are challenged by reconciling and making sense of incorporating a cancer identity and a survivor identity into post-treatment life.^{2,5} Thus, postcancer identity formation involves a process of reflection on the meaning of their lived cancer experience and/or an element of will (i.e., personal choice).^{5,6} As such different conceptualizations of identification with being a cancer survivor might emerge.

¹Department of Behavioral Oncology, The Children’s Hospital of Philadelphia, Philadelphia, Pennsylvania.

²Hunter College and The Graduate Center, City University of New York, New York, New York.

Indeed, the broader adult cancer literature suggests that endorsement of the term cancer survivor ranges from 26% to 90% of diagnosed breast, prostate, and colorectal cancers.^{7–11} This wide range touches upon this notion that different cancer-related identities exist. On one hand, some older adults with cancer report that the term cancer survivor is unrealistically positive, reflects a connotation of cure, undermines the ongoing uncertainty that individuals might experience and creates an unwanted focus on their cancer experience.^{12–14} On the other hand, older adults who embrace the term cancer survivor are more likely to experience greater health-related quality of life, positive affect, and report more experiences of positive life changes (i.e., post-traumatic growth).^{8–11,15} However, these positive benefits are more likely to be reported among those who believe treatment is curative and for those who have a favorable cancer prognosis.^{10,11}

Only a few studies have focused on cancer-related identities among AYA. Cho and Park found that the most commonly reported cancer-related identity among AYA was a more neutral identity, *someone who has had cancer*, followed by *member of the cancer community*, *survivor* and *patient* with fewer AYA reporting an identity of *cancer conqueror* or *victim*.¹⁶ Similarly, Jones et al. found that AYA were qualitatively more embracing of a survivor identity, however noted that AYA did struggle to establish and accept a completely different identity.²

More qualitative work is needed to understand the meaning of being a cancer survivor among AYA as defining AYA by predetermined cancer-related identities (i.e., survivor, warrior) might not reflect their felt cancer experience. Furthermore, it may not be the case that nonidentification with a survivor identity is inherently maladaptive. Therefore, understanding the reasons for and against identifying as a cancer survivor among this population might help to inform quantitative studies geared at understanding relationships between cancer-related identities and adjustment. Accordingly, the goal of this study was to identify and describe themes of AYA's felt experience and meaning of being a cancer survivor.

Method

Participants

Adolescent and young adults (AYA) with cancer who were seen at Memorial Sloan Kettering Cancer Center (MSKCC) and lived within ~1 hour of the cancer center were randomly

selected to participate in the study. Eligibility included 15–25 years old at participation, diagnosed with cancer between the ages of 14 and 21 years, completed cancer treatment at least 6 months prior, and the ability to participate in an in-person semistructured interview. Participants were 26 AYA between the ages of 16 and 24 ($M = 19.6$ years) with a history of cancer diagnosed between the ages of 14 and 18 years and were at least 6 months postdiagnosis ($M = 3.2$ years). All interviews were conducted in English. Consent and/or assent (for participants <18 years) was obtained and all procedures were approved by the MSKCC institutional review board.

Semistructured interviews

As part of a larger study, semistructured interviews (90 minutes in length) were conducted by a trained research assistant with 26 AYA. Semistructured interview guides were developed from relevant themes identified in the literature and through clinical practice (second author).^{17–21} Semistructured interview probes were pilot-tested and refined with five non-participant AYA survivors. Questions related to survivorship are included in Table 1. Participants were compensated \$40 for their participation in the semistructured interview.

Data analysis

Semistructured interviews were audio-recorded, transcribed, and imported into ATLAS.ti. Analyses of transcripts followed grounded theory and thematic content analysis with multiple rounds of iterative reading and interpretation to identify recurring themes and patterns across all transcripts.^{22–25} Full coding procedures are described elsewhere.²⁶ For the current analysis, codes were identified based on a broad range of available codes related to survivorship. These codes included response to survivorship, survivorship emotions and attitudes, survivorship changes in self-concept, and survivorship coping mechanisms. A thematic content analysis was then used to identify relevant major themes of survivorship. Identified cancer-related identities were compared by demographic and medical characteristics using chi-square analysis.

Results

Demographic and medical characteristics of the study sample are displayed in Table 1. AYA ranged in current age from 16 to 24 years ($M = 19.6$, $SD = 2.8$), with age at

TABLE 1. RELEVANT PORTIONS OF THE INTERVIEW GUIDE USED IN SEMISTRUCTURED INTERVIEWS

Interview topic	Interview questions/probes
Introduction	Do you consider yourself a cancer survivor? Do you ever use that term to describe yourself, or do you not think of yourself in this way?
Influence on cancer identity	Has being a cancer survivor impacted the way that you describe yourself?
Meaning of survivorship	When you hear the term cancer survivor, what goes through your head? What do you think of? <i>Probes:</i> Who do you think of when you think of cancer survivor? How would you define this term? Do you think “that’s me”? Is there a difference between the terms cancer survivor and cancer patient? What does being a cancer survivor mean to you? <i>Probes:</i> Do you think of yourself as a cancer survivor? Do you identify with this label? Does it make you feel proud? Embarrassed? Has being a “cancer survivor” changed your life? If so, how?

diagnosis between 14 and 18 years ($M=15.6, SD=1.3$). Participants were predominately female (61.5%), white (65.4%), currently in school (84.6%), and employed either part time or full time (61.5%). All participants identified as being single. Exactly half of the participants were between 2 and 5 years post-treatment ($M=3.2$) with most common cancer diagnoses, including lymphoma (30.8%), sarcoma (19.2%), and leukemia (11.5%). Majority of participants (65.4%) received treatment that was multimodal.

Overall, 153 quotes related to cancer survivorship and perceptions of being a cancer survivor were identified based on codes related to survivorship (Table 2, top). There was at least one instance of identification or nonidentification with being a cancer survivor mentioned in each transcript. Three main cancer-related identities emerged (Table 2, bottom): “Embracing,” “Part of the Past,” and “Not Part of my Identity.” Representative quotes from each theme are provided in Table 3.

TABLE 2. SURVIVORSHIP CODES AND REPRESENTATIVE PARTICIPANT QUOTATIONS ($N=26$)

<i>Survivorship code</i>	<i>Relevant codes</i>
Response to survivorship	Become a cancer advocate Carpe diem/making up for lost time Dynamic shift/adaptation over time Change in drive/motivation Gain positive life outlook Attitudes about being considered a “hero” or inspiration Cancer card
Survivorship emotions and attitudes	Evoked when discussing or thinking about cancer Evoked when transition to life postcancer
Survivorship changes in self-concept	Self-confidence Cancer survivor identification
Survivorship coping mechanisms	Moving beyond the cancer experience Acceptance of cancer-related outcomes
<i>Theme</i>	<div style="display: flex; justify-content: space-between;"> <div style="text-align: center;"> <p><i>Endorsement</i></p> <p><u>Total n (%)</u></p> <p><u>Female n (%)</u></p> <p><u>Male n (%)</u></p> </div> <div style="text-align: center;"> <p><i>Exemplar quotes</i></p> </div> </div>
Embracing	<div style="display: flex; justify-content: space-between;"> <div style="text-align: center;"> <p>6 (23.1%)</p> <p>3 (50.0%)</p> <p>3 (50.0%)</p> </div> <div style="text-align: center;"> <p>Every time I see commercials and stuff, I think “<i>Ya, I’m one of them.</i>” I know what people feel like ... so ya, I would consider myself a cancer survivor. I’m not ashamed to admit it at all. I’m a cancer survivor, I will admit it, I don’t care. (17-year-old male diagnosed with Hodgkin’s lymphoma at age 14)</p> <p>I think there’s never a day that I don’t think about it, and also, like I’m surrounded by it every day ... So, it’s like it’s just following me everywhere kind of. So, I just, yeah, I think I just think about it every day and – It’s part of me, yeah. (17-year-old female diagnosed with Hodgkin’s lymphoma at age 14)</p> </div> </div>
Part of the past	<div style="display: flex; justify-content: space-between;"> <div style="text-align: center;"> <p>15 (57.7%)</p> <p>10 (66.7%)</p> <p>5 (33.3%)</p> </div> <div style="text-align: center;"> <p>I don’t really think about it on a day to day basis. It’s definitely a part of my life. But it’s not something I go around telling everybody on a day to day basis, or event really think about. Because it’s – to me it’s in the past, you know. (19-year-old male diagnosed with acute myeloid leukemia at age 15)</p> <p>I mean when I see the commercials for the kids who are still bald and have leukemia, and they’re asking for donations, I don’t immediately go, “<i>Oh, that was me.</i>” But then I do like a second later and I go, “<i>Oh that was me.</i>” So, I guess I still identify with them somewhat, but not immediately or it’s not sort of like the first thing I think of about myself. (16-year-old female diagnosed with lymphoma at age 14)</p> </div> </div>
Not part of my identity	<div style="display: flex; justify-content: space-between;"> <div style="text-align: center;"> <p>5 (19.2%)</p> <p>3 (60.0%)</p> <p>2 (40.0%)</p> </div> <div style="text-align: center;"> <p>People will say that, like, “<i>Oh, you’re a survivor,</i>” and I’m like, “<i>No,</i>” like it just happened, and like I had to deal with it. That’s like how I want to think about it. (19-year-old female diagnosed with pancreatic cancer at age 17)</p> <p>Well like the thing about cancer survivor is that is conjures up the image of somebody who like really, really struggled with trying to fight cancer for a long time and they might have had relapses or something like that and none of that happened to me. I had two surgeries. I didn’t have to go through chemo, I didn’t have to have any radiation treatment, I didn’t have any bone marrow transplants. Nothing of that happened to me. So, the only thing—I don’t feel like I survived it because I hardly feel like I was hurt by it. (19-year-old male diagnosed with a germ cell tumor at age 17)</p> </div> </div>

Underline values represent the total N and percentage for that theme.

TABLE 3. DEMOGRAPHIC AND MEDICAL CHARACTERISTICS (N=26)

Variable	n	%	M	SD	Range
Gender					
Female	16	61.5			
Male	10	38.5			
Age at diagnosis (years)			15.6	1.3	14–18
Age at study (years)			19.6	2.8	16–24
15–19	15	57.7			
20–24	11	42.3			
Ethnicity					
White	17	65.4			
African American	5	19.2			
Hispanic	2	7.7			
Asian/Pacific Islander	2	7.7			
Marital status					
Single	26	100			
Married	0	0			
Education					
Partial high school	7	26.9			
Partial college	12	46.2			
Completed college	1	3.8			
Not indicated	6	23.1			
Currently a student	22	84.6			
Currently employed	16	61.5			
Time since treatment ended (years)					
<2 years	8	30.8			
2–5 years	13	50.0			
>5 years	5	19.2			
Cancer diagnosis (grouped)					
Lymphoma	8	30.8			
Leukemia	3	11.5			
Sarcoma	5	19.2			
Neuroblastoma	2	7.7			
Thyroid	2	7.7			
Other ^a	6	23.1			
Type of treatment					
Chemotherapy	18	68.2			
Radiation	11	42.3			
Surgery	17	65.4			
Multimodal treatment	17	65.4			

^a“Other” includes malignant diagnoses of craniopharyngioma, germ cell cancer, gestational trophoblastic disease, melanoma, pancreatic cancer, and teratoma tumor; SD, standard deviation.

Chi-square analyses found no difference in cancer-related identities by gender or current age groups (15–19, 20–24). Given the small sample size and wide range of cancer diagnoses statistical differences between cancer-related identities and cancer diagnoses were not analyzed. There was a significant difference in cancer-related identities by multimodal treatment [$X^2(2, N=26)=9.69, p<0.01$]. AYA identifying with cancer as being *part of the past* were more likely to have received multimodal treatment than those identifying with *embracing* or *not part of my identity*.

Embracing

Almost a quarter of participants (23.1%) viewed having cancer as being a significant part of their present lives and

identified and *embraced* their cancer experience. These participants actively identified as cancer survivors and were proud of being survivors. AYA reported participating in cancer walks, openly talked about cancer and their experience, and felt a sense of connection with other cancer survivors. One participant when asked how she would describe herself stated, “*Definitely I would say cancer survivor, that’s a big part of it.*”

Part of the past

This cancer-related identity comprises those AYA who may or may not identify as a “cancer survivor.” These participants acknowledge that cancer was something that they went through but they did not report spending too much time thinking about it and/or did not let it define their present life. One participant stated when asked if cancer survivor is a term that she relates to, “*It’s very odd. Occasionally, I do but, obviously as the years go by it sort of lessens in severity. And so I – I hear that word and I know it’s me but I don’t immediately think, ‘Oh, that word means me.’*” This was the most commonly cited theme, described by 57.7% of participants.

Not part of my identity

Almost 20% of participants (19.2%) stated that they do not identify as a cancer survivor and do not view cancer as a significant life event. These participants mentioned not thinking about cancer (“*I don’t think it’s like that big of a deal*”), that they knew they were “*gonna be fine,*” and that cancer felt like a “*small thing.*” One participant when asked if he thinks of himself as a cancer survivor stated, “*I don’t see myself as that. I’m just a regular guy. I feel like nothing happened to me ... It seemed like a small thing. It didn’t feel like anything big happened.*”

Discussion

AYA cancer survivors construct different personal meanings of being a “cancer survivor.” These differences might reflect a process of identity construction. For some AYA, the cancer experience seemed integrated into their self-concept, either by actively identifying as a cancer survivor or by recognizing that cancer was something that they experienced, but did not feel the need to be defined by it. However, for others, the thought of being a cancer survivor rarely entered conversations of how they defined themselves. The most endorsed cancer-related identity, *part of the past*, in which AYA saw cancer as something that happened to them but did not let cancer define their present life, might reflect a struggle, an identity paradox, between forming a present identity that includes reflecting and honoring their cancer experience while also separating from their cancer experience and navigating life postcancer.

Indeed, similar studies have reported that AYA living with chronic health conditions struggle to find meaning when faced with a life-threatening illness.^{27,28} Identity formation and shift from cancer patient to transitioning into cancer survivorship is a difficult process that AYA face and one in which the cancer-related identity will most likely remain throughout adulthood. In fact, Cho and Park found that the only cancer-related identities that decreased in membership

over 1 year time were found were for *patient* and *victim*, there were no differences over time among those that identified as *someone who has had cancer*, *survivor*, and *cancer conqueror*.¹⁶

Identification with not being a cancer survivor in the broader literature is often influenced by the course of treatment (i.e., not requiring chemotherapy, radiation), favorable prognosis and trust in oncology providers. In this study, AYA who did not align with the term cancer survivorship spoke about cancer being a small event, feeling that they had a good relationship with their oncology providers and felt protected by that relationship.^{9,10,12–14} Given this finding, it may be that identification with being a cancer survivor is rooted in the felt experience of cancer and that felt experience defines the structure of one's self-concept, that just being diagnosed with cancer might not be enough to warrant a cancer survivor identity for some AYA, whereas for others it is enough.²⁹

This is particularly important to consider given definitions of the term survivor. Once reserved for individuals who have survived at least 5 years without recurrence, several cancer-related organizations (i.e., American Cancer Society, National Cancer Institute) define a *survivor* as anyone who has been diagnosed with cancer from the time of diagnosis until the end of life.^{30,31} However, identification with a survivor identity is multifaceted and may not be immediately endorsed. Furthermore, the term "cancer survivor" often connotes feelings of happiness and success, terms that are often not synonymous with those undergoing cancer-related treatment. Therefore, researchers, health care providers, and social support networks should be mindful about how their use of cancer-related identity terms (e.g., patient, survivor, warrior) might affect AYA especially given that constructing a cancer-related identity is a person experience.¹⁶

These findings shed light on the intricacy of identifying as a cancer survivor among AYA and draws attention to the need for future studies, health care professionals, and the media to be sensitive to these multiple identifications. These findings also suggest that, for AYA, the term cancer survivor has multiple meanings and even among those who embrace some aspect of being a cancer survivor there are variants of that experience, whereas some AYA might embrace survivorship and other AYA are able to reflect on and honor their cancer experience but do not let it define their present postcancer life. These distinct variants are missed in the quantitative literature.

As AYA transition into survivorship, manage their risks for late effects, relapse, and surveillance, it will be important for future studies to explore and understand the potential role that multiple identifications if being a cancer survivor might have with engagement in follow-up care and health-related quality of life. A recent qualitative study focusing on preferences for cancer survivorship care among AYA found that some AYA survivors report a desire to feel "normal" and wish to focus their survivorship care on wellness and not on future risks due to their past cancer treatment.³² This finding reiterates the need to explore ongoing survivorship care (i.e., well-being, surveillance, adherence) in the context of postcancer-related identities.

This study has its strengths, which include the qualitative design that consisted of a robust sample size, comprehensive in-depth semistructured interviews, the use of multiple coders, a rigorous coding process, and an age range that spans both adolescence and young adulthood. In addition, this is

one of the few AYA-focused studies that specifically focus on the felt experience of being a cancer survivor. This study is not without limitations, including the sample of AYA cancer survivors, which represents only a small portion of AYA recruited from one large urban cancer center thus limiting generalizability to a broader AYA population. However, study findings do tend to align with other AYA-related studies on cancer survivorship identification.^{2,16} Finally, it is possible that in a more heterogeneous AYA population differences in demographic and medical characteristics might have emerged.

These findings shed light into how AYA reconcile integrating a cancer experience into their self-concept and emphasize the importance of a not one-size-fits-all approach to understanding AYA internalization of being a cancer survivor. Although the preponderance of AYA embrace some aspects of cancer survivorship and align with being a cancer survivor, researchers and health care providers should be sensitive to the consideration that different conceptualizations of being a cancer survivor exist. The results of this study has potential implications for better supporting AYA across their varying survivorship identities by informing the cancer community to be abreast and sensitive to the various ways in which AYA who may identify with a survivor identity.

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Address correspondence to:

Katie Darabos, PhD

*Department of Behavioral Oncology
The Children’s Hospital of Philadelphia
Colket Translational Research Building
3501 Civic Center Boulevard, 10300-03
Philadelphia, PA 19104*

E-mail: darabosk@email.chop.edu