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The salience of cancer and the "survivor" identity for people who have completed acute cancer treatment: a qualitative study

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Abstract

Purpose Globally, there are nearly 33 million persons who have survived 5 or more years after a diagnosis of cancer [1]. We explore the salience of cancer in such people's self-concept as an important element for creating patient-centered care for those living with a cancer history.

Methods Our data are responses to a free-listing exercise and subsequent qualitative interviews with 53 individuals aged between 45 and 74 who were diagnosed with non-Hodgkin's lymphoma or breast or prostate cancer at least 3 years prior and had completed acute treatment. Participants lived in the Baltimore-Washington region of the USA.

Results Cancer was not necessarily salient to participants' current self-concept, and espousal of a "survivor" identity is complex. We construct a typology of seven contrasting meanings of "survivor" based upon participants' narratives (factual, beaten, functional, temporary, adversity, passage of time, and lucky or blessed) and present interviewees' rationales as to why they did or did not adopt a survivorship identity.

Conclusions We examine the complexity of "survivorship" as an identity and people's affiliation with it, as well as how this relates to other salient and fluid elements of people's sense of self within a life course perspective.

Implications for cancer survivors Understanding how cancer factors into people's self-concept throughout the life course is important for designing effective, patient-centered programs that acknowledge diverse experiences and expectations and possible changes with the passage of time.

Keywords Cancer · Survivorship · Identity · Qualitative methods · Phenomenology

Introduction

A cancer diagnosis is a major life event for most people who experience it. Cancer has long been conceptualized as a highly feared [2–4] and stigmatizing disease [5, 6]. Public perceptions of cancer have, however, changed and developed with advances in detection, treatment, and the growing number of people living with a cancer history. Despite changes in both public perceptions and the reality of cancer prognoses, undergoing a cancer diagnosis and treatment still holds considerable potential to shift the way that people see themselves, and their relationship to the wider world.

The impact of a cancer diagnosis on one's sense of self is neither pre-determined nor universal, but rather individually and socially constructed. Individuals' sense of self and definition of the meaning of having cancer are constructed through the process of composing and sharing cancer experiences and expectations within a specific social context [7]. The experiences of diagnosis, treatment, and the long-lasting effects of cancer can shape people's sense of well-being and their ability to carry out previously held roles and responsibilities [8], which in turn can impact one's sense of self. Further, experiencing cancer has been found to significantly impact

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self-concept and create an impulse for identity reconfiguration [9]. In particular, stressors associated with a disease can alter the salience of existing identities that have been key to personal self-concept (e.g., career, professional, or family identities) such that these elements are replaced or reconstructed by illness-related identities [10].

Over the past 30 years, the concept of "survivor" has become one socially acceptable identity to adopt following a cancer diagnosis [10]. The term "cancer survivor" was initially coined by Fitzhugh Mullen and then later adopted by the National Coalition for Cancer Survivorship (NCCS) as part of an attempt to empower patients to engage in making decisions regarding cancer care and treatment and to push for improvements in research and treatment [11]. Adoption of a survivor identity is not, however, universal for those who have had a cancer diagnosis—although it has become a common cultural conceptualization for some cancers in some communities [12]. There is a growing body of work from many countries and populations examining whether or not people with a cancer history identify as a survivor [7, 9, 10, 13–17]. For example, Park et al. [9] found that four out of five people identify as survivor over "patient" or "victim" or "someone who has cancer." Moreover, "survivor" has been found to mean different things to different people. Khan et al. [14] presented a typology of six ways in which "survivorship" is understood and experienced among people with experiences of several types of cancer: (1) factual description of experience, (2) implied high risk of death, (3) choice, rather than luck or good care, (4) implication of cure, (5) changed identity or label that is not espoused, and (6) advocacy role.

Understanding how people conceive of themselves in relation to their cancer history, and how this may develop and change over time is important for creating patient-centered care for people living with a cancer history [7, 9]. The recent literature on survivorship identity has highlighted associations between embracing the survivor identity and positive health outcomes and well-being [9]. Those who identify as survivors have been found to take a more active approach to dealing with cancer and its aftermath, and to face reduced risks of anxiety and depression and improved self-esteem [18]. Highly salient identities (such as being a cancer survivor) may push people to engage in behavior change so that their actions match their sense of self [10]. For example, if one espouses a survivor identity that implies a focus on "living life to the fullest" and having "fought and won," this may push one to consider both major and minor life choices so as to be consistent with this self-concept. Deimling et al. [10] identified factors associated with espousal of a survivor identity including "feeling like a survivor," a positive personal orientation, religious faith, a sense of treatment success, and possibly a clinician's framing of one's condition.

An exploration of survivors' subjective experiences and beliefs about the impact of cancer on their lives (past, present, and future) is relevant to understanding the meaning of the concept of survivorship [8]. We note that previous research has focused on cancer identity in isolation, rather than considering how one's espousal (or not) of a survivor identity is contextualized by other aspects of one's self-concept. In this paper, we examine data from in-depth interviews with people who completed acute cancer treatment to address four related research questions:

- To what extent are cancer experiences salient in terms of identity presentation for people who have completed acute cancer treatment at least 3 years prior?
- To what extent do people who have completed acute cancer treatment identify with the idea of being a "cancer survivor"?
- How do people account for their adoption or rejection of a survivor identity?
- What does the term "survivor" convey to people who have experienced cancer diagnosis and treatment?

Methods

Sample

Data in this study are the result of a paper-and-pencil, free-listing exercise in which participants provided up to 10 responses to the question "Who am I?" followed by a qualitative interview focused on experiences with cancer and its impact. Participants were 53 individuals with a history of breast cancer, prostate cancer, or non-Hodgkin's lymphoma who were recruited as part of a study to explore dietary behavior after completion of acute cancer treatment. We included these three cancer types in order to facilitate comparisons of dietary behaviors across genders and between people with a history of various types of cancer. These cancers are all common cancers with high 5-year survival rates.

Participants were recruited in a variety of ways: during follow-up oncology visits (through chart reviews), through physician mailings, waiting room flyers, support groups, and cancer-related organizations. This study was approved by Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Data collection

Data included in this paper are the result of the first (of two) in-person qualitative interviews conducted with each participant. Authors 1 and 3 conducted all interviews; analysis was a collective effort between the authorship team, all of whom are social and behavioral scientists with extensive in qualitative methodology and cancer prevention and control. Before we began the interview, we asked participants to (1) complete a structured questionnaire on demographic characteristics, health status, and health behaviors, and (2) complete the Who am I? exercise. At the beginning of the qualitative interview, responses to the free-listing exercise were used as a prompt for discussion of the current salience of one's cancer experience, and discussion then followed regarding one's diagnosis and treatment experiences and the current relevance of cancer in interviewees' lives. The interview guide is included as Online Resource 1. Upon completion of the interview, participants completed a 24-h dietary recall exercise. The data in this paper are taken from the responses to the Who am I? exercise and the qualitative interview that followed directly afterward. The structured questionnaire and dietary data are not included in this analysis and are mentioned here only by way of context for the presented data.

Analysis

Each participant's responses to the Who am I? free-listing exercise were entered into an Excel spreadsheet in the order in which responses were provided. Two study authors conducted a hybrid thematic analysis/pile sort in which individual responses (such as "mother of 2 grown children," "wife," "nature enthusiast," "part-time teacher," "enthusiastic," and "cancer cheerleader") were grouped into categories. The emergent groupings included relational identities, occupations, hobbies and interests, personality, and cancer-related concepts. The construction of the categories was iterative and inductive and included input from the broad research team before finalization (see Online Resource 2 for our working codes).

The in-depth, semi-structured interviews were audio-recorded, transcribed verbatim by a professional transcription company, and analyzed using a constant comparison approach [19]. The coding process was largely inductive, beginning with one researcher reviewing each transcript for accuracy and all members of the research team reading the transcripts for familiarization. Two team members then drafted the coding scheme, which included both descriptive and conceptual codes (see Online Resource 2). The coding framework was revised to incorporate feedback from study team members. After the coding scheme was finalized, the full set of transcripts was coded using ATLAS.ti 7.

Results

Study sample

The study sample included individuals aged between 45 and 74 years recruited from multiple care settings in the Baltimore-Washington metropolitan region who had been diagnosed with cancer (stage I–III) at least 3 years earlier and had completed acute cancer treatment (see Table 1). The sample was purposively constructed to maximize variation in terms of treatment type, time since diagnosis, and self-reported race; all of these factors were thought to possibly influence one's experience of cancer treatment and survivorship. The majority of participants also reported having at least one comorbidity. The sample was unintentionally positively skewed in terms of education and income.

To what extent is cancer part of how participants describe themselves?

None of the participants provided any cancer-related term as the initial or even second term to describe themselves in the Who am I? exercise. Rather, only 10 of the 53 respondents included any mention of cancer or survivorship as any of their 10 possible descriptors. Of the 20 men with a history of prostate cancer, only 1 mentioned cancer or survivorship (in this case, "survivor" came after "American male," "African American," "happily married," and "grandfather"). One woman with a history of non-Hodgkin's lymphoma described herself as a "cancer fighter" (after describing herself as a "mother" and a "grandmother"), and one woman with a history of breast cancer described herself as a cancer cheerleader (after mentioning being a "sister," "nurse," "friend," and "conscientious").

The pile sort process of the terms generated through the Who am I? exercise resulted in the identification of four concepts that were more prominent and typical than cancer-related terms: relational (e.g., mother, friend, and grandfather), occupational (e.g., teacher, pilot, and part-time), personality (e.g., funny, loving, and active), and likes/hobbies (e.g., nature lover and golfer). A few illustrative examples of the terms provided (in order that they were provided) are as follows:

(a) Wife, mother, co-worker, housewife, parental caregiver, survivor, type A personality, high morals, healthy, caring (non-Hodgkin's lymphoma, age 51, diagnosed approximately 3 years prior)
(b) Husband, dad, grandfather, brother, part-time employee, manager, golfer, someone who enjoys life, reader, gregarious (prostate cancer, age 67, diagnosed approximately 3 years prior)
(c) Good husband, good father, love to help others, politically aware, no is not an option, love music, love good food, passionate, philosophical, love travel (non-Hodgkin's lymphoma, age 70, diagnosed approximately 6 years prior)
(d) Rower, busybody, relaxed despite occasional craziness, friend and girlfriend, dog owner, middle aged woman, Asian born raised "stateside," IT professional, civic leader, wine and food buff (breast cancer, age 49, diagnosed approximately 16 years prior)

Table 1 Demographic characteristics of sample participants

Age (in years)	Mean (range)
	61 (47–74)
Race/ethnicity	*N* (%)
White	32 (60.4 %)
Black	19 (35.8 %)
Native Hawaiian/other Pacific Islander	1 (1.9 %)
Asian	1 (1.9 %)
Marital status	*N* (%)
Married/living as married	32 (60.4 %)
Divorced/widowed/separated	16 (30.2 %)
Single, never been married	5 (9.4 %)
Education	*N* (%)
12 years or completed high school	4 (7.6 %)
Post high school training other than college	1 (1.9 %)
Some college	5 (9.4 %)
College graduate	21 (39.6 %)
Postgraduate	22 (41.5 %)
Occupational status	*N* (%)
Employed	28 (52.8 %)
Unemployed	2 (3.8 %)
Homemaker	2 (3.8 %)
Retired	17 (32.1 %)
Disabled	4 (7.6 %)
Income	*N* (%)
\$0 to \$34,999	7 (13.2 %)
\$35,000 to \$49,999	4 (7.6 %)
\$50,000 to \$74,000	6 (11.3 %)
\$75,000 to \$99,999	7 (13.2 %)
\$100,000 to \$199,999	15 (28.3 %)
\$200,000 or more	10 (18.9 %)
Don't know/refused	4 (7.5 %)
Cancer type	*N* (%)
Breast	25 (47.2 %)
Prostate	20 (37.7 %)
Non-Hodgkin's lymphoma	8 (15.1 %)
Time since diagnosis (in years)	Mean (range)
	6 (2–24)
No. of co-morbidities (from list of 12 common chronic conditions)	*N* (%)
None	10 (18.9 %)
1	18 (34.0 %)
2	16 (30.2 %)
3 or more	9 (17.0 %)

This exercise illustrated that participants did not view themselves primarily through a health or cancer lens. Rarely was cancer mentioned at all, and when it was, it was not prioritized over roles and attributes that had little or nothing to do with cancer and that often existed before the cancer diagnosis. The concepts put forward provide illustrative context of the importance of relationships, life stages, and non-health facets of life in self-concept.

The meaning of "cancer survivor"

Shortly following the Who am I? exercise, we asked participants to articulate what they understood by the term cancer survivor. This question yielded a wide variety of responses, which we subsequently grouped into a broad typology of survivorship definitions: factual, defined by passage of time, cancer has been beaten, lucky or blessed, functional, dealt with adversity, or temporary state (see Table 2 below).

Some participants provided a seemingly simple "factual" definition as found by Khan et al. [14] (see Table 2, #1). These factual definitions tended to emphasize that one is no longer dealing with the disease or its manifestations without employing metaphors and without referencing the impact of cancer on one's life. Another relevant aspect of the retrospective constructions of survivor for some participants was the concept of the passage of a particular amount of time—in the examples provided by participants, the key number was 5 years (see Table 2, #2).

Somewhat different were responses that clearly linked "survivor" with notions of conquest and victory (see Table 2, #3). The "battle" with cancer was conceptualized and presented as having been won, such that cancer is not something that is necessarily being dealt with presently. Such definitions prioritized an internal locus of control calling upon the role the individual in creating or earning survivorship status. In contrast, some "it's over" notions of survivorship emphasized luck more than any element within one's control (see Table 2, #4). In such instances, the notion of who is a survivor emphasized having been either able to move beyond this event, or to restore life the way that it was before.

The concepts of luck and gratitude were not confined to those definitions in which cancer was presented as being in the past. Participants described survivorship in relation to their luck to live at the present time (when there are effective treatments) while others made comparisons between their own experiences and others who have died from cancer. The idea of "being blessed" was brought up by several interviewees, while being "blessed" seemed to convey some of the same sense as to be "lucky"; it also clearly integrates religious concepts (see Table 2, #4).

A more present-focused notion of survivorship was apparent for the participants whose definitions prioritized their ability to "carry on" and resume normal and desired activities and events (see Table 2, #5). For these interviewees, survivorship was about the quality of life now, and the fact that it was no longer defined and restricted by cancer experiences.

Some men with a history of prostate cancer in this sample conceptualized survivorship as an identity that is not automatically bestowed, but as only being appropriate following experiences that are sufficiently serious so as to warrant such a

Table 2 Contrasting definitions of "cancer survivor" and illustrative quotes

	Survivor definition	Illustrative quotes
1	Factual	"I take it down to the simplest level—somebody who has been diagnosed with the disease and has survived it." (Breast 137) "I no longer have knowledgeable cancer in my system. I am not being treated for it. I don't exhibit it—any symptoms of it….I don't have any residual effects of that" (Prostate 178)
2	Defined by the passage of time	"I've gone at least 5 years without a recurrence." (Breast, 159) "They say within that five year window that's really where survivorship takes effect. So, you are still in the back of your mind thinking, 'Ok, I have got to get to this milestone.'" (Prostate, 160)
3	Cancer has been beaten	"You made it. You survived that. The Big C." (Prostate 171) "It just means that I've conquered it." (Breast 157) "I beat it. It was hard. It was a tough ride, but I made it through." (Breast 125)
4	Lucky or blessed	"Lucky. Somebody who is lucky. I am a very fortunate person to be living in a time when cancer isn't the death sentence that it once was." (Breast 172) "Someone who's lucky. I have a—I had an older brother who died in his mid-50s from prostate cancer." (Prostate 43) "Its someone who's been blessed by being able to regain their health and overcome the obstacles that cancer has presented." (Breast 105)
5	Functional	"Cancer survivor to me is that I've been able to carry on my life normally. Its not really been a distraction. That would be it." (Prostate 48) "I don't need to define it as a time… that has definitely not worked for me. Its about having actively defeated it and moving on as you can with your life." (Breast 109) "To me it means I've been there, been through treatment, completed treatment and facing life now away from treatment and going forward with my life. And helping others." (Breast 147) "You are alive and well and can function normally." (Breast 158) "In the future they can do anything they want to do, can achieve anything that they want to achieve." (Breast 140)
6	Dealt with adversity	"Survivor to me is somebody that you really had to deal with a significant adversity within that context." (Prostate, 187) "My wife is a cancer survivor… She almost died." (Prostate,114) "Survivor to most people means that you had like lung cancer or something that was about to zero you out." (Prostate, 127)
7	Temporary state	"It means waiting for the other shoe to drop."(Breast, 145) "I don't think that we can use the word survivor because no cancer patient is free of it. … Cancer patients will always have cancer because we will always have that gene. They never take it all." (NHL, 163) "I know that cancer can kill at any time, but you are fine now and you are happy." (Prostate, 188)

label. The men who described survivorship in such a way distanced themselves from this identity on the basis of their relatively "mild" experience of diagnosis and treatment (see Table 2, #6). The linkages between cancer and one's past, present, or future varied. In some cases, survivorship was understood through reference to events in people's past (specifically completion of treatment); in others, survivorship was linked to current capacity or circumstances or even the possibility of future states (see Table 2, #7).

Espousal of the survivor identity

In addition to asking participants how they understood the concept of cancer survivorship, we also explored whether this was a term or concept that they used in relation to themselves or with which they felt comfortable. Not all interviewees espoused the survivor identity. Some explicitly rejected survivorship in terms of how they either thought of themselves or presented themselves to others. Others presented a complex, multi-faceted view which showed that the concept served some limited utility, often only at certain times or in certain situations.

I am a survivor

Consistent with the factual responses to the meaning of cancer survivorship, some participants' espousal of the survivor identity appeared relatively straightforward. Several interviewees articulated how the very fact that they had had cancer made them a survivor, whereas others referred simply to having had cancer in the past versus no longer having it presently (see Table 3, #1). Factual presentations of the survivor identity also drew upon a normalization of this concept such that people seemed less to be actively choosing this identity for themselves, but not explicitly rejecting it if others defined them this way (see Table III, #2). One interviewee framed her factual approach to the idea of survivorship in relation to her oncologist's perspective (see Table 3, #2).

In contrast, others framed their decision to adopt a survivor identity not as a "given" but as resulting from a defining cancer experience. For such individuals, life was no longer the same after cancer, and the survivor identity resulted from some meaningful change (see Table 3, #3). The idea of life having changed was not something abstract, but rather related to ongoing experiences and events, and the concept of oneself as a survivor was related to current activities and events (see Table 3, #3)

One theme to emerge among some women with a history of breast cancer was that the "action" of cancer survivorship is sometimes related to new connections and roles pertaining to being a part of a broader survivor "community" (see Table 3, #4). For these women, survivorship had clear positive connotations both for themselves, personally, and in relation to a sense of community membership. The concept of community connection was not, however, always a positive rationale for people to adopt a survivor identity. Survivorship was sometimes presented as a default, given the loss of others to cancer (see Table 3, #4).

I am not a survivor

In contrast with the examples above, many interviewees did not associate with the idea of being a cancer survivor. Some explicitly rejected the idea of any kind of label (see Table 3, #5), whereas other respondents expressed specific reluctance to identify with cancer as a disease (see Table 3, #6). There were also people who were resistant to adopting a survivor identity because this was seen as shaping people's perceptions and expectations of them in ways that were not desirable (see Table 3, #7). For some interviewees, their cancer experience was described as being highly personal, with only close friends knowing about what they had gone through. In such instances, the espousal of a survivor identity generally seemed to be taken as invasive rather than liberating or empowering (see Table 3, #8).

Two interviewees who had a history of non-Hodgkin's lymphoma distanced themselves from the survivor identity on the basis that they defined "survivor" in relation to cancer as being in the past (see previous section). They described how the nature of their illness was such that they did not identify with this term because their cancer was not in the past but was either an ongoing struggle or a looming threat (see Table 3, #9).

Survivor identity is complicated

Not all interviewees were so easy to categorize in relation to their survivorship identity. Some distanced themselves from the survivor identity not because they rejected the notion outright but, rather, on the basis of the time that had passed since their cancer experience. As cancer became less salient, so the idea of the survivor identity also faded (see Table 3, #10). For such individuals, accepting a survivor identity for themselves personally was more acceptable than wearing such a label in public in terms of what this was seen to entail by way of expectations toward a survivorship collective (see Table 3, #11).

Several men with a history of prostate cancer gave accounts in which they both accepted the idea that on some level they are cancer survivors, and also provided an explanation of why the survivorship concept was not applicable to them (linked to the "arduous" definition outlined in Table 2, #7). These men's explanations included the idea that their cancer experience was not sufficiently onerous compared to people who had had different kinds of cancer, as well as not wanting to engage in or be seen to engage in advocacy efforts (see Table 3, # 12).

Table 3 Rationales for espousing or rejecting a survivor identity

Espousal of survivor identity		Rationale for espousal, rejection, or complication	Illustrative quotes
I am a survivor	1	I had cancer	Interviewer: "Do you consider yourself to be a cancer survivor?" Breast 172: "Absolutely. I had breast cancer." "I guess by definition I had it and it's gone. So, I guess I am." (Prostate 47)
	2	Defined by self or other	Interviewer: "Do you consider yourself a cancer survivor?" NHL 111 (female): "I do. My oncologist always tells me, you're never cured. You're treated." "I consider myself a survivor because that's how we as a volunteer team talk about it—as being a team of cancer survivors." (Breast 138)
	3	Life changing events	"There was life before cancer and life after cancer" (Breast 132) "It defines you because you are now viewing another dimension of your humanity." (NHL 165) "With being a survivor and all that I've been through with it, I still have a lot going on from having cancer." (Breast 107)
	4	Connections to others and sense of community	"I'll say four time cancer survivor… I will engage with other people that are just discovering their own cancers and be a mentor to them." (Breast, 109) "It means that I've been able to talk to other people about the experience—to be more of an advocate for others. It means that I have an understanding that I didn't have before I was diagnosed of what it means and what it feels like to have gone through that process" (Breast 139) "As I said to my son when I was going through chemo, I've got too many things in my life to do. I'm going to beat this…I will tell you when I do think about it. When I meet people who are newly diagnosed with cancer, or who are also cancer survivors. That is when I think, "oh yeah", I am a survivor also. I think that is kind of cool." (Breast 145) "Yeah. Since I lost my two friends, yes. I consider myself a survivor." (Prostate 177)
I am not a survivor	5	Reject any labeling	"I wouldn't say survivor because I never liked that term because it puts you in a box. I don't like labels. When you label people you limit them." (Breast 136) "I just would not define myself. I don't think twice about it." (Breast 158)
	6	Reject being labeled with or by cancer	"I feel very healthy and like that was just another health event…I'm more of an in the moment kind of person… It's just the disease is not very important…. I didn't want to be defined by that. I'm still who I am." (Breast 122) "I don't let cancer come into the picture. It doesn't define me."(Prostate 52) "I don't look at myself like a cancer survivor. Maybe that is because when it was detected it was like—it had no effect on me. I just view it as things happen in life. You deal with it, you move on, and you keep doing things you like to do." (Prostate 187)
	7	Survivor identity shapes how others see you	"I don't want to fit into their definition like a cliché. They'll think that I am an advocate or that I am an angry person for being sick—and I am not." (Breast 137) "I didn't want to be that, to be part of my identity. I didn't want people to feel sorry for me." (NHL, 119)
	8	Cancer experience is personal	"Generally, I have never used the term cancer survivor… its not like I tell everyone that I had cancer… I think it's very personal to me, so I generally don't use that. My very close friends know that I had cancer." (Breast 140)
	9	Cancer is not over	Interviewer: "Do you consider yourself to be a survivor, a cancer survivor?" NHL 163: "No. I am a cancer fighter … because I still have cancer. I'm not free of it, and he [doctor] made that clear." "I think I'm more in remission rather than a survivor even though it has been three years." (NHL, 113)
Its complicated	10	Passage of time	"I do sometimes say that I'm a cancer survivor but it does not sit in my brain everyday. I do not spend time worrying about whether cancer will come back." (Breast 109) "For me, it has been about 33 or 34 years so, right now, I don't even think about it as the word cancer anymore. I keep on going with my daily routine…. I'm using it [survivor] because I don't know what other word to use…. We caught it so early. I didn't know if that made it different. He [doctor] said, 'You call yourself whatever makes you feel good'" (Breast 151) "It doesn't really define me, I really don't think about it much anymore. I mean it's always kind of in the back of your mind. That you can think about you could have a relapse" (NHL 117)
	11	Internal and external identity can differ	Interviewer: "Do you consider yourself a cancer survivor?" NHL 117: "Definitely. Cause I've had two cancers … I mean I don't wear it like a badge, I don't get involved in a lot of activities and stuff. Sometimes I feel like I should be out there advocating with people, but part of me, I don't want to be defined by that. When I used to

Table 3 (continued)

Espousal of survivor identity		Rationale for espousal, rejection, or complication	Illustrative quotes
			go back to the clinic, get my checkups, it was just kind of overwhelming seeing people, how sick they were and remembering being that sick….”
	12	My cancer wasn’t serious enough to be a “survivor”	“Obviously so far I’m a cancer survivor. I guess I find the whole cancer experience mysterious because basically I thought I was pulling through because I exercised a lot because nobody in my family had cancer… Prostate cancer is so common, that is why I wouldn’t consider myself a cancer survivor.” (Prostate 127) “I’m a prostate cancer survivor… trying to go out in the community and help other people so that they do not develop the terminal phase of this illness of prostate cancer and they can also be survivors… I go on living my life. I don’t wear it on my forehead and I don’t go out and badger people” (Prostate 41) “I would say yes, but I put a little footnote next to it. Because it was the type that men survive if its detected early I guess I see myself in a category of, with early detection and great medical care that’s the expected outcome.” (Prostate 51)
	13	Don’t talk it up again	Prostate 160: “I don’t speak about it often because somewhere back in the recesses of my mind, I’m like I don’t want to talk this thing back up again” Interviewer: Do you consider yourself a cancer survivor? Prostate, 160: “Cancer Survivor, yeah.”

Finally, one man with a history of prostate cancer framed his acceptance of the survivor identity with the caution that he wanted to not think about cancer so as to protect himself from its possible return (see Table 3, #13).

Discussion

Our analysis builds on numerous prior studies that have considered why some people adopt a survivor identity following a cancer diagnosis while others do not [7, 10, 12, 17]. As in previous studies, our work illustrates that “cancer survivor” is a social construction for which there is no monolithic understanding or definition [11]. The methodology used in this analysis to explore espousal of cancer identity was distinct from that employed in previous research. Our qualitative approach to exploring identity and the meaning of “survivor” did not employ any forced choice between various cancer-related terms (such as patient, victim, or survivor) and did not require participants to either explicitly adopt or reject the idea of being a survivor. This revealed considerable nuance and complexity not previously explored in work on survivorship identity.

The data presented illustrate that how people think about themselves in terms of their cancer is only one important piece of their self-concept. In the qualitative interviews, we were able to explore the rationales that people provided for any position that they adopted. We found that it is not necessarily easy to dichotomize those who espouse a survivor identity from those who do not. Rather, our explorations of self-concept in the free-listing exercise and in the qualitative interviews both suggested that cancer experiences were often not highly salient to how interviewees saw themselves—at least at this time. When participants elucidated terms or descriptions of who they are without having to choose between various cancer-related lenses, cancer was only sometimes referenced. This finding adds an important dimension or consideration to prior research. It is not only important to consider survivorship as a complex construct, but also as only one piece of a multifaceted, somewhat fluid construction of self that is highly likely to change over time.

Whereas prior studies have largely treated “cancer survivor” as a stand-alone identity to be adopted or rejected, we illustrate how one’s cancer experiences are appropriately considered in the context of numerous possible elements of one’s identity. The experience of being stigmatized or championed for one’s cancer experience sits within an ongoing context of identity as a mother, wife, bird-watcher, and part-time accountant (for example). Our work resonates with Kaiser’s [12] analysis that outlined the variability and complexity of one’s cancer identity, arguing that people continue to experience stigma (at least for some people in some situations) while also being championed, such that one could be “simultaneously encouraged to proclaim their status via pink t-shirts and ribbons and disguise the true nature of their bodies following treatment via clothing, reconstruction, and prostheses.” (p. 81) [12].

One emergent finding was that, for some people in our sample, rejecting a survivor identity was not so much about the specific concept but, rather, the very idea of any label for them as a person. We also note that participants often provided distinct descriptions of what (or who) prompted them to adopt or reject a survivor identity. Whereas some people described being told by a clinician or a community member that they were a survivor, others recalled the process of identity reconfiguration as being personal, and often entirely internalized. Not all interviewees who could conceive of themselves as survivors necessarily wanted others to view them through this lens, which may be a challenge in terms of application of findings to appropriate clinical intervention approaches. In the future, more structured research is also necessary to consider possible associations between socio-demographic characteristics and likelihood for cancer and survivor identity to play as central role in one's self-concept.

We would also highlight our finding that a subset of the men with prostate cancer described rejecting the survivor identity on the basis of a comparison of their experience with those of people with other cancers, and other possible harrowing life events. These men articulated a clear sense of what or who "deserved" to be called a survivor, and distanced themselves from this moniker. One possibility is that for some, the battle that is survived with a cancer experience is getting through arduous chemotherapy, which these men with prostate cancer had not faced. Another interesting consideration is the extent to which survivorship may be a gendered concept in relation to its historical connections to war and battle, and it is not as readily assumed for men as it is for women in the context of disease experiences. These questions could be addressed in future research studies.

Our data suggest that both the physical conceptualization of the cancer itself, and time since treatment appear to have different meanings to different people. While we do not want to go beyond the capacity of this single exploratory study, we suggest that perhaps for non-Hodgkin's lymphoma patients, and those prostate patients who perhaps had a period of watchful waiting prior to intensive treatment, or did not have a surgical event, or continued to receive maintenance or other therapies, their conceptualization of the transition dates between treatment and post-treatment survivorship may be less clearly defined. This may be particularly apparent when their accounts are compared to those, such as some breast cancer patients, who had a single significant treatment event, and may consider themselves survivors who are "cured" at the time of that event.

It is worth noting that our study participants were all at least 3 years post-diagnosis. Although our data are cross-sectional, they suggest that one's relationship to the cancer experience is unlikely to remain static throughout one's life course journey. We heard how, over time, salience of cancer may fade in the context of more recent events and circumstances. The time frame of "5 years" was salient for some interviewees in whether and how they saw themselves as survivors. Thus, not only is saliency of cancer distinct for each individual, it is also possible for people's relationship to cancer to develop or change over time.

Effective health promotion throughout the survivorship trajectory is predicated on connecting with people, and prior research has found identifying as a cancer survivor to be protective [17]. Efforts to categorize people as either espousing a survivor identity or not may therefore have limited utility without explicit consideration of how and when one's self-concept in relation to cancer might shift. The saliency of other aspects of self (specifically important relationships, personality features, occupation, and likes and hobbies) should be considered both in terms of appeal and the possible influence that these will have on engagement with any health promotion messaging or other interventions.

It is important to note that these data were collected in the context of a cancer-related study. Interviewees were primed to think about their health and cancer experiences. The Who am I? exercise was a novel and easy way to generate data regarding participants' self-concept, and the role of cancer in it. We acknowledge that this was a somewhat artificial exercise, conducted at one point of time, in a research context. Interviewees completed this task soon after completing consent to take part in the research study that they knew related to cancer. It seems likely that they would have been primed to consider cancer, given these circumstances. In contrast, we also recognize that the low levels of identification with "survivor" in our study may be impacted by the skewed nature of our sample with regards to high education. Previous research [17] has found people with more formal education to be less likely to identify as a survivor.

Our analysis leads to more questions about exactly how the survivor identity serves to protect (as prior research has found). We suggest that it may be because this identity is appealing for a subset of people with a cancer history who are already in an advantageous position—possibly in terms of positive attitude, or something like an internal locus of control. Alternatively, it may be that there is something protective in the act of identifying as a survivor in terms of the behaviors that are associated with such an identity and possibly the sense of community that it implies. We suggest that there is a need for more research that can disentangle whether a survivor identity is a marker for existing protective factors or a possible intervention goal.

In any case, our data provide further evidence that among this small sample of long-term cancer survivors living in one region of the USA, there was considerable heterogeneity regarding the salience of cancer and adoption of a survivor identity. It is critical to understand this heterogeneity if we are seeking to develop patient-centered clinical care and health promotion for the growing number of people living for years and decades with a cancer history. This will be increasingly important in the global context of cancer control, as cancer incidence, and slowly cancer survivorship as well, become common health care priorities in all societies. To the extent that interventions and care initiatives can be framed in ways that are congruent with an individual's self-concept (whether or not this is centered around survivorship), so this may allow people to take agency and more actively engage in their own care and health promotion.

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Compliance with ethics guidelines

Ethical standards All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Conflicts of interest The authors declare that they have no conflicts of interest.

Informed consent Informed consent was obtained from all individual participants included in this study.

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