

ORIGINAL ARTICLE

Self-identity After Cancer: “Survivor”, “Victim”, “Patient”, and “Person with Cancer”

Crystal L. Park, PhD¹, Ianita Zlateva, MPH², and Thomas O. Blank, PhD³¹Department of Psychology, University of Connecticut, Storrs, CT, USA; ²Department of Human Development and Family Studies, University of Connecticut, Storrs, CT, USA; ³ Connecticut Association of Directors of Health, Inc., Hartford, CT, USA.

BACKGROUND: Living through cancer often involves developing new identities which may strongly influence well-being and relationships with care providers, yet little is currently known about these post-cancer identities.

OBJECTIVES: To examine (1) the extent to which four post-cancer identities (patient, person who has had cancer, victim, and survivor) are adopted, (2) relations between each identity and involvement in cancer-related activities and mental and physical well-being, and (3) correlates of these identities.

DESIGN: Cross-sectional questionnaire-based study.

PARTICIPANTS: 168 young to middle-aged adults who had previously experienced cancer.

MEASUREMENTS: Cancer identifications, background variables, psychological functioning, cancer risk appraisals and coping, cancer-related activities, and mental and physical well-being.

RESULTS: At least somewhat, 83% endorsed survivor identity, 81% identity of “person who has had cancer”, 58% “patient”, and 18% “victim”. Identities were minimally correlated with one another and differentially associated with involvement in cancer-related activities. Survivor and person who has had cancer identities correlated with involvement in most cancer-related activities such as wearing cancer-related items and talking about prevention ($p < 0.5$). Survivor identity correlated with better psychological well-being and post-traumatic growth, victim identity with poorer well-being ($p < 0.5$); neither identifying as a patient nor a person with cancer was related to well-being. Through regression analyses, identities were shown to be explained by unique combination of background, functioning, appraisal and coping variables.

CONCLUSIONS: Survivor identity appears most common and most associated with active involvement and better psychological well-being, but other identifications are also common and simultaneously held. Adoption of specific cancer identities is likely to impact interactions with health care providers, including those in general internal medicine, and health behavior changes.

KEY WORDS: cancer; survivorship; identification; well-being; post-traumatic growth.

J Gen Intern Med 24(Suppl 2):430–5

DOI: 10.1007/s11606-009-0993-x

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As over ten million Americans who have been diagnosed with and treated for cancer have entered the ranks of survivors¹, many of whom have lived for many years as survivors, the medical community must be aware of not only the physical effects of cancer and its treatments but also its psychological and social impacts². The responsibility to treat the whole person of cancer survivors, especially after they have transitioned to longer term survivorship, often falls upon primary care general internists^{2–5}. Providing excellence in patient care to cancer survivors requires that clinicians understand crucial psychological and social elements of survivorship and meet patients where they are in terms of their post-cancer identities.

Living through cancer typically involves integration of the experience into one’s self-concept⁶, including developing new identities⁷. Further, identities adopted following cancer may strongly influence individuals’ well-being⁸. Therefore, the ways in which individuals understand and label or identify with their cancer experience may be important aspects of adjustment following cancer^{9,10}, with significance for their approach to their health and for interactions with primary care clinicians.

THE VARIETY OF CANCER-RELATED IDENTITIES

In recent years, one particular identity, “survivor”, has been actively promoted and widely and prominently used. The National Coalition for Cancer Survivorship, formed in 1986 as an advocacy group, chose the term *survivorship* to deliberately promote empowerment of those with cancer¹¹. The term *survivorship* represents living after a diagnosis of cancer, regardless of how long a person lives^{2,12}. This terminology is used by many health care professionals, researchers, and those recovering from cancer to refer not only to the physical but also the social, psychological, spiritual, and existential impact of cancer on one’s life for the remainder of one’s life¹¹. However, some may be reluctant to adopt the label *survivor* because, to them, it carries connotations of cure. In some contexts (e.g., natural disasters), *survivor* may imply that the danger has passed¹³. However, for those who have had cancer, long term adjuvant treatments and fear of recurrence often remain part of their lives^{8,14}. Thus, those with high fears of recurrence may be less likely to adopt the survivor label¹³.

Patient is another oft-used label. Patient identity may be common and appropriate during active treatment¹³, but continuing to identify as a patient beyond treatment may indicate passivity and adoption of the “sick role”¹⁰. Patient

identity may lead to reduced feelings of control and hope, and thus to relinquishing responsibility for one's health and welfare to the medical establishment^{15,16}. However, identifying as a patient beyond primary treatment may have some positive consequences, such as remaining vigilant for signs of recurrence¹⁰.

A third identity sometimes adopted by those with cancer, *victim*¹³, suggests passivity and lack of agency regarding one's cancer, and, perhaps, continued vulnerability. *Victim* suggests viewing the cancer as resulting from forces beyond the individual's control (cf.,¹⁷) connoting a sense of injury, injustice, and powerlessness¹⁸. A study of prostate cancer survivors found that, when given a choice, most eschewed any positively or negatively toned identity label, preferring a neutral label, "person who has had prostate cancer"⁹.

Thus, each identity clearly carries connotations that may affect personal health behaviors and interactions with one's health care team, most potentially in both positive and negative ways. It is also possible that individuals will endorse several identities, depending on the context of their particular concern or relationship with a clinician.

RESEARCH ON IDENTITY OF THOSE WHO HAVE HAD CANCER

Given the potential importance of identification following cancer, surprisingly little work has been conducted on the topic of post-cancer identities. One study examined identification in a sample of older persons who had experienced cancer many years prior¹³. Asked whether they identified themselves as survivors (yes or no), 90% answered affirmatively. Other labels included ex-patient (60%), victim (30%), and patient (20%). This study was conducted prior to the active promotion of the term "survivor"¹¹. In the late 1990s, the cancer survivorship movement gained momentum.

More recent studies have reported similarly high levels of survivor identity. In a study using the same measurement strategy as¹³, 86% of long-term survivors of colon, breast, or prostate cancer identified as "cancer survivor," 13% as "patient" and 13% as "victim"¹⁹. When able to select only one, over 50% of prostate cancer survivors chose the term "someone who has had cancer," a quarter chose "survivor" as the term that best described them; smaller numbers chose "patient" or "victim."⁹

VARIABLES ASSOCIATED WITH IDENTITY

There is currently little information regarding variables associated with post-cancer identities. One study of bone marrow transplant recipients (earlier diagnosed with leukemia or lymphoma) found that "patient" identity was unrelated to age or income, negatively related to education and time since transplant, and positively related to illness severity¹⁵. In the study of older individuals who had previously had breast, prostate, or colon cancer¹³, using more active and instrumental coping in dealing with cancer was related to increased identification as a survivor, while other types of coping were unrelated to self-identities.

The few studies examining post-cancer identities found little relation with psychological adjustment. For example, the study

of older individuals who had had cancer¹³ found that identification as a victim or a survivor was unrelated to mastery, self-esteem, anxiety, depression, or hostility, although a study of those who had prostate cancer found that identifying as a survivor related to having more positive affect, but was unrelated to negative affect⁹.

THE PRESENT STUDY

We examined four issues related to cancer identities in a sample of people earlier diagnosed with cancer. First, we examined the extent of adoption of four cancer-related identities: survivor, patient, victim, and "person who has had cancer". Second, we examined the extent to which each identity was associated with involvement in cancer-related activities, hypothesizing that those identifying as survivors would be most involved, while those identifying as victims would be least involved. Third, we examined the extent to which each identity was associated with mental and physical well-being. We anticipated that stronger survivor identity would be related to higher levels of well-being, victim identity to lower levels, and other labels somewhere in between. Finally, we examined the extent to which sociodemographic, psychological functioning, and cancer-related variables, such as worry and coping strategies, accounted for the degree of adoption of each identity. We expected that time since treatment end would be positively related to survivor identification and negatively to patient identification, while use of positive coping to deal with cancer (e.g., active and emotional approach-oriented strategies) was expected to be related to less identification as a victim and more as a survivor.

METHOD

The present analyses are part of a larger investigation of quality of life in young to middle-aged adults previously diagnosed with cancer. Potential participants (those aged 18 to 55, diagnosed 1-3 years prior) were identified through the Cancer Registry at Hartford (CT) Hospital. 600 questionnaires were mailed at Time 1; 250 completed questionnaires were returned. One year later (Time 2), follow-up packets were mailed to all Time 1 participants; 167 were returned. Only one attempt at contact was made at each time point. Because information on identity was only assessed at Time 2, the present analyses use only variables assessed at Time 2.

Measures

Background Variables. Participants reported current age, marital status, race, and length of time since diagnosis and since primary treatment ended.

Identity. Participants were asked, "When you think about yourself in relation to your cancer, how much does each of these phrases describe you?" (1) a victim of cancer, (2) a cancer patient, (3) a person who has had cancer, and (4) a survivor, each rated from 1 (not at all) to 5 (very much) (adapted from¹⁰ and¹³).

Psychological functioning was assessed with the Psychological Well-Being Scale (PWB,²⁰) and the FACIT-sp²¹. The PWB includes six scales of psychological functioning: Self-Acceptance, Environmental Mastery, Positive Relations with Others, Personal Growth, Purpose in Life, and Autonomy. Participants rate how well each item describes them from 1 (disagree strongly) to 6 (agree strongly). Internal consistency reliabilities for the subscales were acceptable (α s = 0.68–0.93). The FACIT-sp asks participants to rate the extent to which they experienced aspects of spirituality from 0 (not at all) to 4 (very much) and has two subscales, meaning/peace (α = 0.86) and faith (α = 0.87).

Cancer-Related Risk Appraisals and Coping. Two appraisals were included: how worried they were about their cancer returning, rated from 1 (not at all worried) to 6 (extremely worried), and appraised likelihood of getting cancer again rated from 1 (extremely low) to 6 (extremely high)²². Coping with cancer was assessed with subscales of the Brief COPE²³ representing major types of coping, including problem-focused coping (active coping), emotion-focused coping (emotional processing), avoidant coping (alcohol and drug use), and meaning-focused coping (positive reinterpretation and growth) (adapted from^{24,25}).

Cancer-Related Activities. Presented with a list of activities commonly reported by people who had had cancer (see Table 1 for items), participants were asked, “Following your cancer experience, do you do any of the following that you didn’t do before (or increased significantly) (circle all that apply)”. Items were coded 0 if not endorsed, 1 if endorsed.

Well-being included measures of health-related quality of life (HRQOL), positive and negative affect, intrusive thoughts, life satisfaction, and post-traumatic growth. The SF-12²⁶ assessed mental and physical HRQOL. Participants rated perceptions of their physical and mental health status on yes/no and numeric scales. The Positive and Negative Affect Schedule²⁷ produces scores for positive and negative affect. Participants indicated the extent to which each of 40 adjectives (e.g., inspired, scared) described how they generally feel (α s = 0.82 and 0.89, respectively). Intrusive thoughts were assessed with the eight-item subscale of the Impact of Event Scale (IES;²⁸), assessing frequency of distressing cancer-specific intrusive thoughts over the past week from 0 (not at all) to 4 (often). Internal consistency reliability was very good (α = 0.86). The Satisfaction with Life Scale²⁹ summarizes five items regarding life satisfaction rated from 1 (strongly disagree) to 7 (strongly

agree). Internal consistency reliability in the present sample was excellent (α = 0.94). Post-traumatic growth was assessed with the Perceived Benefits Scale³⁰, 15 items (e.g., “My relationships with family”) rated in terms of change since having cancer from 1 (much worse now) to 7 (much better now). Scores for perceived *positive* change were calculated from recoded items (i.e., 0 “no change” to 3 “much better now”)³¹, then summed for a total growth score (α = 0.88).

Statistical Analysis

We first examined the extent to which each identity was endorsed. We then conducted point-biserial and Pearson correlations between identities and background variables, cancer activities (dummy coded), and dimensions of well-being.

Then, separate regression models were estimated for each identity based on the hypothesized explanatory variables of psychological functioning, appraisals, and coping. In addition, background variables statistically significantly correlated at the bivariate level with any dependent variable (i.e., education, time since primary treatment end) were entered into each linear multiple regression model. Because the explanatory variables were of equal potential interest and there was no specific desired order of entry attached, forward stepwise variable selection was used with a threshold of probability-of-F-to-enter ≤ 0.05 .

RESULTS

Participants

The Time 2 sample comprised 108 women and 59 men. Mean age was 46.34 (SD=6.29), with a mean of 3.5 (SD=1.7) years since cancer diagnosis and 2.6 (SD=1.6) years since completing primary treatment. The sample was largely White (89%), married or cohabiting (73%), college educated or higher (71%), and had a household income of at least \$50,000 (83%). The most common cancer sites were breast (47%), prostate (12%), colorectal (6%), lymph nodes (5%) and cervix/uterus (4%). Primary treatment included surgery only (49%), chemotherapy only (5%), combination of surgery and radiation (15%), combination of chemotherapy, surgery and radiation (22%), and other treatments (9%).

To evaluate whether our sample was representative of the population from which it was drawn, we compared demographic and cancer characteristics of our sample to all persons of the same age range in the Cancer Registry during the period

Table 1. Bivariate Correlations of Cancer Identities with Cancer Activities

	Survivor	Patient	Victim	Someone with cancer
Belong to cancer-related organizations	0.10	0.00	0.19*	0.085
Contribute money to cancer-related causes	0.20**	-0.05	0.07	0.04
Participate in cancer-related events (e.g., walk for research)	0.21**	-0.08	0.14	0.13
Participate in cancer-related advocacy to public officials	0.01	0.08	0.26**	0.17*
Follow media stories related to cancer treatment or survivorship	0.16*	0.10	-0.08	0.22**
Wear cancer-related items (e.g., bracelets, t-shirts)	0.25**	0.02	0.02	0.19*
Talk about your own experience (e.g., with family, friends, coworkers, etc.)	0.32**	0.02	0.06	0.25**
Talk about prevention or screening value (e.g., with family, friends, coworkers, etc.)	0.31**	0.00	0.09	0.18*

** Correlation is significant at the 0.01 level (two-tailed)

* Correlation is significant at the 0.05 level (two-tailed)

Table 2. Bivariate Correlations of Cancer Identities with Mental and Physical Well-Being

	Survivor	Patient	Victim	Someone with cancer
Mental HRQOL	0.03	0.05	-0.41**	-0.07
Physical HRQOL	0.12	-0.02	-0.12	0.11
Positive Affect	0.22**	-0.02	-0.22**	0.10
Negative Affect	-0.22**	-0.05	0.36**	0.01
Intrusive Thoughts	-0.09	-0.05	0.44**	0.07
Life Satisfaction	0.09	0.05	-0.30**	-0.07
Post-Traumatic Growth	0.28**	0.11	-0.08	0.03

** Correlation is significant at the 0.01 level (2-tailed)

in which the sample was drawn. The sample appeared very similar to the population on all characteristics except for somewhat lower minority percentage. For example, the total population gender ratio was identical, and the percentages receiving specific treatments or combinations of treatments were virtually identical. In the population, 85% was white/non-Hispanic, 6.5% Hispanic, 6% African-American, and 2.5% mixed/other.

Cancer Identities

The most frequently endorsed identity was survivor (83% endorsed this identity at least “somewhat”), followed closely by someone with cancer (81% at least “somewhat”); then patient (58% at least “somewhat”) and victim (18% at least “somewhat”).

Bivariate correlation analysis indicated significant relationships only between survivor and someone who has had cancer ($r=0.35, p< 0.01$) and victim and patient ($r= 0.15, p< 0.05$).

Relations of Identities with Background Factors. Bivariate correlations were conducted for each identity with gender, race (both dummy-coded), age, income, marital status, education, time since diagnosis and time since end of primary treatment. No identity related to any background

variable ($rs< 0.12, ps> 0.14$), except for survivor identity and education ($r=-0.19, p< 0.5$) and victim identity and months since end of primary treatment ($r=-0.22, p< 0.5$).

Relations of Identities with Cancer Activities and Well-being.

Table 1 shows relations of extent of each identity and cancer activity involvement. Extent of identifying as a survivor and as someone with cancer both positively related to many cancer-related activities, such as talking about their cancer experiences and prevention. However, only survivor identification was associated with contributing money to cancer causes and participating in cancer-related events. Victim was the only identification associated with belonging to cancer organizations; both victim and someone with cancer identities were positively related to involvement in advocacy. Patient identity was unrelated to any cancer-related activity.

Table 2 shows relations between extent of each identity and adjustment. No identity was related to physical HRQOL, and only victim identity was related (negatively) to mental HRQOL. Higher victim identification was also related to more negative affect and intrusive thoughts and less positive affect and life satisfaction. Identifying as a person who has had cancer or as a patient were unrelated to any aspect of well-being, while identifying as a survivor related to higher levels of positive affect and post-traumatic growth and lower levels of negative affect.

Multivariate Models of Cancer Identities

The final multivariate analysis results are shown in Table 3.

DISCUSSION

These results suggest that various identities adopted by adults who had experienced cancer are related to a constellation of background and psychological factors. The frequent use of survivor as an identity and less frequent use of patient and victim were similar to previous research (e.g.,^{9,19}). Although these identities were minimally related to one another, people who have had cancer appear to identify fairly strongly with

Table 3. Results of Separate Linear Regression Analyses Modeling Each Identity

Model	Independent Variable	Coefficient	Probability >t	VIF*	Model probability >F	Model adjusted R2
Victim	Worry about recurrence	0.390	<0.001	1.089	0.035	0.324
	Substance use coping	0.277	0.003	1.067		
	Time since treatment end	-0.187	0.035	1.024		
Survivor	Emotional processing	0.368	<0.001	1.304	0.044	0.209
	Education level	-0.168	0.029	1.011		
	FACIT faith	0.181	0.029	1.186		
	Autonomy	-0.163	0.044	1.132		
Someone with cancer	Worry about recurrence	0.250	0.004	1.067	0.031	0.060
	Purpose in life	0.185	0.031	1.067		
Patient	Perceived risk of recurrence	0.172	0.037	1.000	0.037	0.023

*The variance inflation factor (VIF) is a method of detecting the severity of multicollinearity. Multicollinearity is the extent to which the independent variables are related to each other. A VIF close to one suggests there is no multicollinearity, whereas a VIF near 5 might cause concern

multiple labels relative to their experience. Most cancer survivors recognize different identities as parts of their experience, and those different identities trigger or support different aspects of their experience.

These identities are complex and appear related to individuals' psychological functioning as well as the ways they appraised and coped with their cancer. In particular having a sense of religious well-being and autonomy along with emotional processing of the experience was associated with stronger identification as a cancer survivor, similar to previous findings^{19,32}. Curiously, survivor identity was negatively related to education (cf.,¹⁹). Worrying about recurrence and stronger sense of life purpose were related to the relatively neutral label of someone with cancer. Victim identification was explained by worries of recurrence, as hypothesized, as well as use of alcohol or drugs to cope with the stress of cancer. In addition, victim was the only identification that changed (diminished) over time since treatment, contrary to our expectation that survivor identification would increase and that patient identification would decrease with time since treatment. The amounts of variance accounted for in the models for victim and survivor were reasonable, but those for patient and person with cancer were disappointingly small. In addition, many of the psychological functioning variables we would expect to be linked with self-identity after cancer, such as mastery, personal growth orientation, or social relationships, were unrelated to the adoption of any identity.

Each identity had unique patterns of relationships with cancer-related activities and well-being. While identifying as a victim was related to lower well-being, contrary to expectation, it was related to *greater* involvement in several cancer-related activities, including advocacy efforts and belonging to cancer organizations, than other identities. On the other end of the spectrum, identifying as a survivor had a range of apparent advantages in terms of psychological well-being and active involvement. Both of those aspects confirmed our expectations but were different from previous research that indicated minimal relationships with well-being^{13,19}. Identifying as a person with cancer was similar to survivors in cancer-related activities, yet unrelated to well-being. Patient identity was neutral vis-à-vis well-being.

It is important to note the limitations of the present study. We examined only a single time-point in a trajectory of post-cancer living. Our response rate was limited, introducing potential biases into our results. Our sample had experienced various types of cancer, limiting generalization of these findings to any particular cancer type. In addition, like much of the research on cancer, our sample was predominantly White, female, and skewed towards higher socioeconomic status. Finally, as with any cross-sectional study, causal relationships remain speculative.

In spite of these limitations, these results add important knowledge regarding the complex ways that individuals think about themselves vis-à-vis their experiences with cancer and the potential differences in the meanings of these identities. Our findings suggest that these identities are critical aspects of those who have experienced cancer. Further research is needed to understand the interplay of these simultaneously held identities, the meanings they hold for individuals, and the impact that they have on health and well-being.

Cancer survivorship care is a central role of primary practice internists now and even more in the future^{2,4,5,33}. To provide

such care, general practice clinicians will be asked to address cancer as a chronic illness alongside other chronic conditions and acute illnesses they address on a regular basis. As they do so, issues of psychosocial support and health promotion are key, as indicated in a recent study of what breast cancer survivors said they needed their primary care physicians to help them address³³. Identity and its attendant psychological and behavioral sequelae are important aspects of survivorship concerns. Thus, this added understanding of the roles that each identity plays in the lives of survivors can enhance the interactions of general practice internists with the long term cancer survivors that make up a sizable portion of their patients. Finding out which label(s) or identity(ies) are most comfortable or useful for a particular patient can help in tailoring practice in a patient-centered way and can provide the context for enabling these patients to incorporate their cancer experience into the broader context of their health most effectively. Discussion of the identity process for survivors can be part of the initial transition to a care plan and can be a touchstone for integrating the highest quality holistic care with full recognition of the activities and sense of well-being that appear related in complex ways with those identities.

Acknowledgements: This study was supported by a Scientific Research Grant from the Lance Armstrong Foundation to the first author. We are indebted to Dr. Andrew Salner and the Helen and Harry Gray Cancer Center at Hartford Hospital for their help in conducting the study, and to the survivors who were willing to share their experiences with us.

Conflict of Interest: None disclosed.

Corresponding Author: Crystal L. Park, PhD; Department of Psychology, University of Connecticut, Storrs, CT 06269, USA (e-mail: crystal.park@uconn.edu).

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