Published in final edited form as:

J Cancer Surviv. 2012 December ; 6(4): 451–457. doi:10.1007/s11764-012-0240-z.

A Phoenix Rising: Who Considers Herself a “Survivor” after a Diagnosis of Breast Cancer?

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Abstract

Purpose—To investigate factors associated with patients’ identification of themselves as survivors after a diagnosis of breast cancer.

Methods—A self-administered survey was deployed through the non-profit organization Breastcancer.org. As part of a larger study, we collected data on treatment, mental health, perceived prognosis, concerns about recurrence and the question, “Do you consider yourself a survivor of breast cancer?”

Results—Of the 629 survey respondents, 492 (78%) considered themselves survivors of breast cancer. Factors independently associated with an affirmative response were (1) believing that one’s prognosis was “very good” compared to others ($p < 0.001$), (2) recalling being told that treatment was curative ($p = 0.04$), (3) having better mental health ($p = 0.002$), and (4) having received chemotherapy ($p = 0.01$).

Conclusions and Implications for Cancer Survivors—The disparate factors associated with the identification of oneself as a survivor—both the perception of having a very good prognosis and having received chemotherapy (reflecting high risk disease rather than a good prognosis)—are intriguing. Clinicians caring for women with breast cancer should be sensitive to the fact that not everyone considers herself a survivor. Addressing transitions at the end of treatment and during the follow up period may be challenging for clinicians and patients alike. Awareness of the complexities of the survivor identify may help clinicians in counseling their patients.

1. Introduction

Heightened awareness of the needs of cancer survivors, motivated by the reports of the President’s Commission on Cancer and the Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition* [1], and the efforts of advocacy and professional groups, have resulted in a surge of interest in improving the care and, even more important,

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A portion of this work was presented at the 2008 American Psychosocial Oncology Society Conference, Irvine, CA.

the lives of people who have been treated for and are surviving a cancer diagnosis [2–8]. Clinical programs designed to improve care and outcomes of cancer survivors have been developed at multiple sites in the United States and other countries.

The working definition of a cancer survivor has changed over time, and there has been inconsistency in the use of the term [9]. Before 1986, the term cancer “survivor” was generally restricted to someone living cancer free for five or more years [10]. Dr. Fitzhugh Mullan, a physician and cancer survivor, identified a need to broaden the term, recommending that one becomes a survivor at the time of the cancer diagnosis [11]. The National Coalition of Cancer Survivorship expanded the definition of “survivor” to include anyone with cancer “from the time of diagnosis, through the balance of his or her life” [12, 13]. Since then, many authors have offered additional definitions of survivors, some of which include family members, friends and caregivers [14, 10, 15, 16]. With the definition of “survivor” being so broad and inclusive, the question arises: What factors do patients themselves use to identify or not identify themselves as survivors?

The purpose of this study was to address the gaps in the literature regarding those factors associated with patient identification as survivors of breast cancer. Our aim was to investigate whether patients who were further out from the time of diagnosis would be more likely to consider themselves survivors than those more recently diagnosed. We expected that those who perceived themselves as having a favorable prognosis would be more likely to consider themselves survivors. Finally, because of confusion patients with non-invasive breast cancer (ductal carcinoma in situ, DCIS) have regarding their diagnosis and prognosis [17–19] and the ongoing debate amongst medical experts about terminology and the natural history of DCIS, in addition to the lingering uncertainty about whether or not DCIS should even be called cancer [20–22], we expected that respondents with DCIS would be less likely to consider themselves survivors related to contradictory messages they receive from health care providers and others about their diagnosis and prognosis compared with those who had invasive breast cancer.

2. Methods

2.1 Development of the questionnaire and measures

To confirm our clinical impressions that patients with early stage breast cancer hear inconsistent messages about their prognosis, two focus groups, led by two trained facilitators, were conducted with a total of 15 breast cancer survivors. Thematic saturation was reached after the two focus groups were complete. We then created and pilot tested a novel, web-based, self-administered questionnaire. The questionnaire took approximately 10 minutes for respondents to complete. The questionnaire was posted on the website of the organization Breastcancer.org. Breastcancer.org, a 501c(3) organization, is a leading online resource for breast health and breast cancer information and support. An invitation was placed on the homepage of Breastcancer.org that read “Take a survey about your breast cancer experience.” Additional links to the survey were placed on the pages for “Treatment Options” and “Ductal Carcinoma in Situ.” Data were collected over a 6-month period. No personal identifiers were collected, including site of residence, date of diagnosis, name or location of medical site, and email addresses. All study procedures were approved by the Institutional Review Boards at the University of Michigan and Purdue University. The entire instrument is available from the authors.

We collected participant-reported demographic information, information about the cancer and treatments they received, month and year of diagnosis, their preferences for aggressive versus less aggressive treatment, the Medical Outcomes Study SF-36 (MOS SF-36), perceived prognosis, concerns about recurrence, as well as the question, “Do you consider

yourself a survivor of breast cancer?” Each of these measures is described in more detail as follows:

The demographic information we collected included age (as a categorical variable), race, ethnicity, and number of years of education completed (as a categorical variable). Diagnosis and treatment history included the number of months or years from their cancer diagnosis and the types of treatments they had received (type of surgery, receipt of chemotherapy, radiation therapy and endocrine therapy; the questionnaire included a complete list of adjuvant endocrine therapies currently in use). Patient self-report of receipt of cancer treatment has been shown to be accurate when compared to medical records [23–25]. The SF-36 is a 36-item health survey that contains 8 subscales, including physical functioning, bodily pain, general health, vitality, social functioning, emotional role functioning, and mental health. The nine items from the mental health subscale were used to assess mental health, particularly symptoms of depression [26, 27]. In analyses, the responses were handled as a continuous variable.

Respondents were asked how they felt their prognosis compared with the prognosis of other people with breast cancer. Response options were “It is very good,” “It is about the same as others,” “It is poor,” “It is very poor,” and “I don’t know.” In analyses, we dichotomized the responses to “It is very good” vs. other. Finally, they were asked, “Has anyone ever told you that you are “cured” of breast cancer? In analyses, responses were handled as “yes” vs. “no”/ “I don’t know.”

2.2 Participant Eligibility

Eligible participants were those who identified themselves as having breast cancer and as being over 18 years of age. While people who did not have breast cancer or were being evaluated for possible breast cancer could access the survey, the survey ended if they indicated that did not have breast cancer or if they were under the age of eighteen. Patients with metastatic breast cancer were excluded from this study. No other exclusion criteria were applied.

2.3 Analyses

The dependent variable was an affirmative answer to the question, “Do you consider yourself a survivor of breast cancer?” Descriptive statistics were generated and correlations between the independent variables were examined. Bivariate analyses were conducted to identify unadjusted differences between those who answered “yes” and those who did not. We investigated correlations between the independent variables.

Multivariable analyses controlled for factors that we hypothesized would be associated with the dependent variable, including time since diagnosis, DCIS vs. invasive disease, perceived prognosis, and recollections of being told that treatment had cured the disease. Other covariates included age, race, ethnicity, educational attainment, SF-36 measures of mental health, and diagnostic and treatment variables that might serve as proxies for disease severity, specifically, type of surgery (mastectomy vs. breast conservation), chemotherapy vs. no chemotherapy, and endocrine therapy vs. no endocrine therapy.

3. Results

3.1 Subject Characteristics

The original respondent sample included 801 participants who completed the majority of the questions on the survey. A total of 629 (79%) answered the question, “Do you consider

yourself a survivor of breast cancer?" The respondents who did not answer this question ($n = 172$) were excluded from this analysis.

Characteristics of the study sample are provided in Table 1. Most (79%) of the participants were under 60 years of age, white (91%) and reported having completed some college or a higher degree (61%). Participants who had only a high school education comprised 37% of the sample. The majority of the participants (84%) were less than five years from their time of diagnosis. The majority of the participants (81.7%) were from the United States. The other participants were from the United Kingdom ($n = 40$, 6%), Canada ($n = 27$, 4%), and Australia ($n = 12$, 2%). The Bahamas, India, Israel, and United Arab Emirates each had two participants, and Germany, the Netherlands, Norway, the Philippines, Poland, Singapore, and the U.S. Virgin Islands, USA each had one respondent. Over 62% believed they had a very good prognosis compared to other women with breast cancer. Of the 629 participants included in this study, 492 (78%) answered affirmatively to the question, "Do you consider yourself to be a survivor of breast cancer?"

In bivariate analyses (Table 1), women who were further from the time of diagnosis were more likely to consider themselves survivors ($p = 0.01$). Contrary to our hypothesis, more women with DCIS (82%) answered affirmatively compared to those with invasive disease (75%, $p = 0.04$). Positive associations were also found amongst women who received a mastectomy compared to those who received a lumpectomy ($p = 0.034$), those who recalled being told they were cured ($p = 0.004$), those who believed they had a "very good prognosis" compared to other women with breast cancer ($p < 0.001$) and those with higher mental health scores on the SF-36 Mental Health subscale ($p < 0.001$). Age, race, ethnicity, and educational attainment were not associated with participants' identity as a survivor. Several of the variables were significantly correlated with one another (Table 2).

3.2 Multivariable Analysis

In multivariable analysis (Table 3), factors independently associated with considering oneself a survivor of breast cancer were believing they had a "very good" prognosis compared to other women with breast cancer ($p < 0.001$), recalling being told that treatment had cured the cancer ($p = 0.04$), having higher scores on the SF-36 mental health subscale ($p = 0.002$), and receiving chemotherapy ($p = 0.01$). Time since diagnosis, a diagnosis of DCIS, and type of surgical treatment were no longer significantly associated with considering oneself a survivor of breast cancer in the multivariable analysis.

4. Discussion and Conclusion

In summary, in this sample of 629 women diagnosed with breast cancer, 78% of patients considered themselves survivors of breast cancer. Patient perception of a "very good" prognosis, recollections of being told that they were cured, better mental health, and the receipt of chemotherapy were all associated with a higher likelihood of considering oneself a survivor. Contrary to our hypotheses, increasing time since diagnosis and having DCIS rather than invasive disease were not associated with considering oneself a survivor. Type of surgery, age, level of education, and race were also not associated with identification of oneself as a survivor although the number of non-white respondents was small.

That 78% of our sample considered themselves survivors is consistent with previous qualitative research with smaller samples. In a study of 50 patients who had different types of cancer, 90% considered themselves survivors [28]. This finding was replicated in a larger sample (in the same study), in which 86% of the 321 participants also identified with the term [28]. In another study that included patients with various types of cancer, 83% identified themselves as survivors [29].

Respondent perceptions of prognosis (reflected by two items, perceived prognosis compared with others and a recollection of being told they were cured) were important in respondents' perceptions of themselves as survivors. That is, the likelihood of future survival played a role in whether or not they perceived themselves as survivors. This finding is also consistent with previous qualitative research with small samples. In a study of 39 patients with breast cancer, some of the participants reported struggling with the concept of being survivors due to uncertainty about their prognosis; others accepted the term with confidence as they felt they had already "won the battle" [30]. Another qualitative study of 18 patients with a history of breast cancer reported that some patients needed to be told they had been "cured" or were "free of disease" by a physician in order to consider themselves survivors [31].

We had hypothesized that participants with DCIS would be less likely to consider themselves survivors as described above; this hypothesis was supported in bivariate analysis. In multivariable analysis, however, DCIS no longer was associated with considering oneself a survivor. DCIS was, however, positively and significantly correlated with the perception that the prognosis was "very good" (correlation coefficient of 0.33) and recalling being told that treatment had cured the disease (correlation coefficient of 0.17). In multivariable analysis, these two factors may have obscured the relationship between DCIS and findings seen in the bivariate analysis.

Similarly, contrary to our hypothesis, time since diagnosis did not play a role in participants identifying themselves as survivors. In the study cited above [28], 60% of the 50 participants and 50% of the 321 participants adopted the term "survivor" by the time treatment had ended. Still, many of the remaining participants adopted the term shortly after their treatment had ended with only 14% adopting the term around the 5-year anniversary mark [28].

The independent association between receipt of chemotherapy and perceptions of being a survivor was unexpected. Given the negative correlation between receipt of chemotherapy and perceived prognosis (correlation coefficient -0.275), our findings suggest that the concept of "survivor" is not entirely straightforward. Women who received chemotherapy were most likely at higher risk of recurrence, i.e. a poorer prognosis at the time of diagnosis than those who did not receive chemotherapy and, as one might expect, were less likely to perceive their prognosis as "very good." Yet despite understanding that their prognosis was not very good, chemotherapy was independently associated with patient identification as a "survivor." We speculate that undergoing the travails of chemotherapy leads to a sense that one has earned the badge of "survivor," paid one's dues, or come through the fire, like a phoenix rising from the ashes. The metaphorical nobility of chemotherapy for the treatment of cancer is not a new concept. As reflected by a patient in Aleksandr Solzhenitsyn's 1968 novel *Cancer Ward*, "There is something noble in curing with strong poison. Poison doesn't pretend to be innocent medicine. It says plainly: I am poison. Watch out! Or else. And we know what risk we're taking" [32].

The finding that receipt of chemotherapy played a role in which participants considered themselves survivors may be particularly important when the marginal benefit of chemotherapy is low. Several qualitative studies have included feedback from patients who felt going through chemotherapy meant they had done all that they could, or that they had "survived" something [30]. (Whether they believed they had survived cancer or the chemotherapy itself is not entirely clear.) Others said that going through surgery or radiation might not be enough, but that by going through chemotherapy they would have earned the title of "survivor" [31]. Finally, others stated that they would not consider themselves a survivor until after primary treatment and "definitely after chemo" [31]. Social comparison

to other patients also appears to play a role in that other women who went through more strenuous treatment were considered more deserving of the title [31].

This study has several limitations. We are not able to determine the response rate as one would with other study designs. Response bias is a likely bias of this type of study. In addition, this was a cross-sectional study; it is thus not possible to assess causality in our study between the identification with the term “survivor” and the factors described above. For example, we do not know whether women who had better mental health were more likely to consider themselves survivors or if women who considered themselves survivors were more likely to have better mental health. Optimistic personal orientation has been linked with identification of oneself as a survivor [28]. As this was a web-based survey, generalizability may be limited, but research conducted by other investigators has demonstrated that Internet-based surveys provide similar responses to studies using those paper surveys [33–36]. The small numbers of women of non-white race/ethnicity limits our ability to draw conclusions amongst non-white patients. Nonetheless, 37% of our sample had only a high school education or less, suggesting that this sample was not comprised merely of highly-educated patients, and the age distribution resembles fairly well the distribution of breast cancer among different age groups.

The term “survivor” may have been problematic for some of the study participants [9]. We intentionally did not offer alternative terms such as “victim,” “thrivor,” or “warrior” because we specifically wanted to know how many specifically identified themselves as survivors and did not want to dilute the responses with alternatives. Many people who have had cancer reject the term “survivor” because they harbor ongoing concerns about recurrence and persistent uncertainty about the likelihood of actually surviving [30]. Others reject the term because they do not perceive their lives to have been threatened in the first place [30]. Some report the term brings a sense of pressure to “act like a hero” even though they may not feel like one [37]. In addition, while the term “survivor” is commonly used in the United States, it is less frequently used by patients in other countries [9].

The concept of being a “survivor” is complicated. The disparate findings—that both the perception of having a very good prognosis and having received chemotherapy (reflecting high risk disease rather than a good prognosis) were associated with considering oneself a survivor—are intriguing. These two distinct factors may make addressing transitions at the end of treatment and during the follow up period challenging for clinicians and patients alike. Moreover, people with cancer who do not consider themselves survivors may experience confusion, resentment, or feel excluded from programs directed at survivors. Although we are unable to determine the direction of association between all of the factors associated with considering oneself a survivor, it appears the concept of identifying with the term “survivor” is multi-faceted and not uniformly endorsed by patients who have had cancer.

As clinicians and health care systems move forward with the development of survivorship research, programs and resources, it is important to be aware that not everyone who has been diagnosed with cancer considers themselves survivors. Those who do not may not avail themselves of programs and resources directed at survivors. Keeping these factors in mind may be useful when thinking of how and to whom survivorship efforts are offered so that both clinicians and patients alike will be clear on the intended recipients of these services [9].

Acknowledgments

The SF-36 was used under license from Qualitymetric (license number QM013008).

Funding

A portion of this work was supported by a grant from the National Cancer Institute at the National Institutes of Health (R01 CA922444-01A1).

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Chemotherapy					
Yes	300	48%	237	79%	0.750
No	329	52%	256	78%	
Time since diagnosis (missing, n = 7)					
Less than 5 years	528	84%	401	76%	0.010
5 years or more	94	15%	83	88%	
Perceived prognosis (missing, n = 3)					
Very good	391	62%	304	78%	< 0.001
Poor/same as others/not sure	235	37%	159	68%	
Recalled being told cured (missing, n = 5)					
Yes	118	19%	104	88%	0.004
No	506	80%	384	76%	
SF-36 mental health (mean, SD)					
Among those answering "yes"	5.7	(2.1)			
Among those answering "no" or "don't know"	5.1	(2.2)			<0.001

[†] p values obtained from two-sided Chi-square test comparing those who answered "yes" to those who answered otherwise.
SD = standard deviation

Table 2

Correlation matrix

	Age	Education	Time since diagnosis	DCIS	Mastectomy	Chemo-therapy	“Very good” prognosis	Recalled being told cured	Mental health
Age	1.00	0.046	0.091	0.015	-0.031	-0.136	0.056	-.0003	0.161
Education		1.00	0.059	-0.009	-0.057	-0.079	0.117	0.062	0.013
Time since diagnosis			1.00	-0.053	0.195	0.042	0.044	0.059	0.087
DCIS				1.00	-0.048	-0.542	0.332	0.165	0.078
Mastectomy					1.00	0.366	-0.016	0.184	0.040
Chemotherapy						1.00	-0.275	0.034	-0.043
“Very good” prognosis							1.00	0.132	0.099
Recalled being told cured								1.00	0.071
Mental health (SF-36)									1.00

Table 3

Identification of oneself as a survivors, multivariate model, N = 629.

	OR	95% CI	p value
Time since diagnosis	1.65	(0.72 to 3.40)	0.18
Age			
Under 50	Referent		
50 – 59	1.24	(0.77 to 2.01)	0.38
60 and older	1.63	(0.86 to 3.09)	0.14
Education			
High school or less	Referent		
Some college or college degree	1.00	(0.54 to 1.83)	0.99
Graduate school	1.22	(0.68 to 2.20)	0.51
Race/ethnicity			
Non-white, non-Hispanic	0.69	(0.25 to 1.96)	0.49
Diagnosis and treatment			
Ductal carcinoma in situ	1.43	(0.81 to 2.50)	0.22
Mastectomy	1.21	(0.77 to 1.92)	0.41
Chemotherapy	2.02	(1.13 to 3.58)	0.02
Mental health and perceptions of prognosis			
Perceived prognosis "very good"	2.91	(1.80 to 4.73)	< 0.001
Recalled being told she was cured	2.05	(1.02 to 4.12)	0.04
SF-36 mental health subscale	2.17	(1.34 to 3.53)	0.002

Controlling for age, education, race, ethnicity, none of which were significant
OR = odds ratio; SE = standard error; CI = confidence intervals