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Breast Cancer Survivors' Perception of Survivorship

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Abstract

Purpose/Objectives—To explore (a) how women who were diagnosed with breast cancer (BC) defined themselves as survivors and when this occurred, and (b) the types of benefits they derived from their experiences.

Research Approach—An exploratory, qualitative approach.

Participants—112 women who had BC (response rate = 70%).

Setting—Participants were recruited from two cancer survivor organizations in a northeastern U.S. city.

Methodologic Approach—Responses to open-ended questions in telephone interviews were examined by age at diagnosis using thematic analysis. Chi squares were used to conduct analyses by age (younger than 51 years; aged 51 years or older).

Main Research Variables—Meaning of survivorship, defining moment, benefits derived from surviving from breast cancer.

Findings—Participants' perceptions of survivorship included two main components, a defining moment and the meaning attached to being a survivor. Becoming a survivor is an active process, except in the case of those participants who realized they were survivors when informed by a third party. Meanings differed by age at diagnosis. Most participants listed at least one benefit from surviving cancer.

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Conclusions—The definitions of survivorship and benefits outlined here suggest that many positive aspects of the survivorship experience exist that may inform future interventions’ designs.

Implications for Practice—Providers should acknowledge the strength survivors show in the process of meaning-making and finding benefits in their adverse experiences. The use of expressive and supportive interventions may hold promise for women facing difficulties in coping with their diagnosis.

An estimated one in eight women will be diagnosed with breast cancer (BC) in their lifetimes and, of those, 94% live for at least five years after diagnosis (Centers for Disease Control and Prevention, 2010). Although much has been written about cancer survivorship, few qualitative studies have explored how BC survivors experience life after diagnosis (Montazeri, 2009). Most qualitative studies focus on the needs of BC survivors (Ashing-Giwa, Padilla, Bohórquez, Tejero, & Garcia, 2006; Beatty, Oxlad, Koczwara, & Wade, 2008; Buki et al., 2008; Thewes, Butow, Girgis, & Pendlebury, 2004). For instance, among BC survivors, those diagnosed before age 51 have more needs related to career and family (Thewes et al., 2004). Quantitative studies confirm findings regarding those diagnosed before age 51; they are more likely to experience psychological distress (Bloom, Stewart, D’Onofrio, Luce, & Banks, 2008; Wenzel et al., 2005) and a reduction in the number of social relationships (Ashida, Palmquist, Basen-Engquist, Singletary, & Koehly, 2009).

Few authors have focused on issues of BC survivor identity—that is, what it means to be a survivor. Two articles (Kaiser, 2008; Morris, Campbell, Dwyer, Dunn, & Chambers, 2011) explored the issue of survivor identity among women diagnosed with BC from a qualitative perspective. Kaiser (2008) explored what it means to be a BC survivor in terms of the “dominant” versus “alternative” cultural images of survivorship. She pointed out that although the BC survivor usually is described in terms of a “triumphant, happy, healthy and feminine” woman who has conquered BC through medical treatment (p. 80), this image is not embraced by all women with BC. Kaiser (2008) noted that a need exists for research on how the typical patient with BC views survivorship and that research in this area “would contribute to our understandings of the process of adjustment following cancer,” (p. 81). Morris et al. (2011) sought to understand the “lived experience” of BC survivors who participated in a challenge-based peer-support program (i.e., a 1,000-mile motorcycle ride). They found that when asked if they identified with the term *BC survivor* preride, women’s responses varied. Those who identified themselves as a BC survivor attributed positive meanings to the term. However, after completion of the event, some women reported a change in their perceptions of themselves as a cancer survivor. They were more likely to perceive themselves as survivors and connected being a survivor with a strong sense of belonging to the group of riders. The authors did not find any research that focused specifically on the point in time (i.e., the defining moment) when women considered themselves survivors. However, the research by Morris et al. (2011) appeared to touch on that issue.

Additional themes appear in the literature regarding how individuals respond to traumatic events such as a cancer diagnosis. One common theme is the personal search for meaning that occurs as people try to make sense of what happened to them (Dow, 1990). That readjustment process has been referred to as meaning-making (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Park & Folkman, 1997). Meaning-making does not occur simply with the passage of time; rather, it requires active engagement on the part of the individual (Dow, 1990; Lechner, Carver, Antoni, Weaver, & Phillips, 2006; Lechner et al., 2003). A certain amount of threat to one’s life and worldview prompts patients with BC to search for meaning (Lechner et al., 2003). In one study of BC survivors, those who felt no threat, as well as those who were overwhelmed by threat, found fewer benefits after the cancer experience than those who felt a moderate threat (Lechner et al., 2006).

Finally, benefit-finding is another theme frequently found in the literature. Studies have shown that individuals diagnosed with BC often grow as a result of the experience (Dow et al., 1996), particularly regarding an appreciation of life, spirituality, and personal relationships (Ashing-Giwa et al., 2006; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Morris et al., 2011; Stanton et al., 2002).

Although finding benefits after BC is not a new phenomenon (Dow, 1990; Park & Folkman, 1997), an Institute of Medicine report discussed the adverse psychological effects of cancer and the need for survivors to avoid or ameliorate those effects (Hewitt, Greenfield, & Stovall, 2006; Howlander et al., 2011). Given that many individuals find benefits in cancer, a focus on this issue may present an opportunity to empower survivors.

This study adds to the literature by focusing on survivorship from the point of view of the survivors themselves—contrasting those diagnosed before age 51 versus 51 and older. Specifically, the authors explored the following questions: (a) How do women who were diagnosed with BC define themselves as survivors and when did this occur, and (b) what are the benefits women derive from the BC experience?

Methods

Participants and Recruitment

An invitation to participate in the study was sent to BC survivors who previously had participated in the events organized by the Pittsburgh chapter of Susan G. Komen for the Cure® or the University of Pittsburgh Cancer Institute's Celebration of Life annual luncheon. Women who replied and returned a completed consent form were contacted by telephone to schedule an interview. Trained female project staff conducted the telephone interviews from July to August 2003. Interviews were tape-recorded and later transcribed. Women who completed the interviews received \$20. The study was approved by the University of Pittsburgh's institutional review board.

Instrument

The instrument was comprised of a combination of 83 open- and closed-ended questions, including information on diagnosis and treatment, participant perspectives on survivorship, and demographics. The open-ended questions were derived from focus groups conducted by the research team with Caucasian and African American women to investigate their concerns. The demographic questions were similar to those used in national surveys. The instrument was pilot-tested with cancer survivors who were not part of the study. The main data reported in this article were derived from the open-ended questions regarding the definition and meaning of survivorship and the benefits experienced from having BC: Do you consider yourself a survivor? If so, when did you consider yourself a survivor? Why did you consider yourself a survivor then (i.e., at that point in time)? What is the meaning of being a survivor? If the participant did not consider herself a survivor, the investigator asked, "Why do you not consider yourself a survivor?" Next, women were asked about any perceived benefits of having BC: Has anything positive come from you having had BC? Has having BC changed how you view what is important in life?

Data Analysis

Qualitative and quantitative methods were used to analyze the data. Data were entered into the statistical program PASW® to describe participant characteristics. Age at diagnosis was dichotomized as younger than 51 years, because the median age at menopause in the United States is 51 years (Ashida et al., 2009), versus 51 years or older. Frequencies by age at diagnosis were computed for demographic, health and care access, and tumor variables. A t

test was used to determine whether the mean time elapsed since diagnosis was different by age at diagnosis.

The purpose of the current study was to describe how women think of themselves as BC survivors and when in the process this occurred. The authors used thematic analysis (Tashakkori & Teddlie, 2003). In addition, the authors looked at each participant's response on a single topic in its entirety; that is, the answers to all questions that comprised a topic were considered to develop the codes and definitions. Three coders participated. First, they developed a list of salient words after a first reading of the data. Second, they discussed the salient words to develop the codes and code definitions. Third, each coder individually coded the participants' answers to each open-ended question, writing analytic memos as needed. Fourth, they compared codes, discussed the memos, and amended the definitions, if necessary; no inter-reliability was calculated, as all disagreements were resolved during this process. Finally, the number of codes was reduced by grouping them into broader themes. To avoid biasing the process, coders had no knowledge of the participants' ages at diagnosis.

The final themes from the qualitative analysis were turned into dichotomous variables ("yes" and "no") for each respondent. The chi-square test of independence was used for each variable to observe differences in the definition of survivorship and the types of benefits found by age group (younger than 51 years and 51 years or older). When the frequency of one or more cells of the 2-by-2 table was less than five, Fisher's exact test was used (Milton, 1992). The authors wanted to identify all possible associations to raise new hypotheses for future research. Because the consequences of detecting a possible association that later proves nonexistent is not serious, a liberal p value (0.1) was chosen (Milton, 1992).

Results

Participant Characteristics

A total of 163 potential participants were identified, two of whom were ineligible. A total of 113 women agreed to participate, for a response rate of 70%. In one case, age was not available; therefore, 112 participants were included in the analysis. The majority of participants were diagnosed before age 51 ($n = 78$). The participants were primarily Caucasian ($n = 96$), their ages ranged from 34–81 years, and all had health insurance (see Table 1). In addition, 81 (72%) reported having a partner. The time elapsed since diagnosis varied from 1.53–29.36 years and was significantly longer for women diagnosed before age 51 (t test = 3.6, $p < 0.001$). Tumor and treatment information are outlined in Table 2.

Survivorship as Seen by Participants

Participants' perceptions of survivorship had two main components. The first was the defining moment when a participant identified as being a survivor. The second was the meaning they attached to being a survivor.

The Defining Moment

The vast majority of participants ($n = 107$) considered themselves survivors. Six defining moments were identified (see Table 3). The three most common defining moments were feeling that life was back to normal, "completion of a process," and confirmation from someone else that one was a survivor. "Back to normal" ($n = 35$) was defined as a return to prediagnosis conditions, including feeling physically healthy, free of cancer, and/or back home and into day-to-day activities. One participant said, "Everything was fine and I just moved on with my life." The phrase "completion of a process" ($n = 34$) often referred to the

completion of cancer treatment and surgeries. As one participant put it, "... because I lived through the process ... and came out on the other side."

Twenty-five women reported that they were informed by a third party that they were a survivor (outside confirmation). The third party could have been a person (e.g., doctor, family member), something read or heard from the broadcast media, or just "everyone." Thus, the defining moment was related primarily to what others told them. For example, one woman stated, "[The] surgeon implanted the seed that I was a survivor." The defining moment often coincided with a woman reaching the five-year mark postdiagnosis, although other time points (e.g., 1 year, 10 years) also were reported. To further illustrate, one participant explained, "Those were the guidelines that [were] reiterated to me by all of the doctors and everything I read or heard, and that was the guideline I used also." Three less-frequently mentioned themes involved feelings of "strength," "group of survivors," and "removal of cancer." Strength (n = 13) was described as spiritual or moral strength that took women through a "fight" or "battle," rather than physical strength, as exemplified by one woman who said, "Because I knew I had to fight and I wasn't going to let it get me down and beat me."

Eleven participants described how joining a group of women that labeled themselves as survivors often influenced their own perceptions and feelings. For example, one participant felt she was a survivor the first time she went to the Komen Race for the Cure® "because it made me feel real, being around a bunch of women, of great women."

Finally, 11 individuals stated that the removal of the cancer from their bodies was their defining moment. One participant said that she was a survivor right after surgery because "[they] took out my tumor and it wasn't in my lymph nodes so it wasn't in my body."

The Meaning of Survivorship

Six key themes emerged regarding the meaning of survivorship. Participants often articulated more than one meaning of survivorship. Twenty-five participants assigned at least two meanings to survivorship and eight did not report any meaning.

"Conquering" was the most frequently mentioned meaning of survivorship (n = 36). Participants who defined survivorship as conquering spoke of displaying a particular strength and being victorious against an enemy, almost in military terms. One participant, for example, said that "[A] positive attitude has [helped me] overcome an invasion in my body."

"A new outlook" (n = 30) was defined as an increased awareness of one's mortality and appreciation of the value of time as well as newly discovered values and activities. One participant said, "I had to take a better look at what life is about. It also taught me that you can't really know what's going to happen from day to day."

Twenty women defined survivorship as "helping others," which included an interest in and behaviors directed toward assisting others, particularly other cancer survivors, in their journey. As one participant put it, "I need to be available to whoever would need me." The theme "free of cancer" (n = 24) was defined as feeling disease-free and alive. One participant said, "It means that I had cancer, that I'm rid of it, and I no longer have cancer in my system."

For 21 participants, being a survivor meant that life was "beyond one's control." They often described their survivorship as being in the hands of God or a result of luck. For instance, one participant described it as "not my time to leave this earth," and another felt as if she

had won a prize. For seven participants, survivorship meant being part of a larger group that had a similar experience, or a “sisterhood.” Two participants said of surviving, “It’s a mark of distinction. You’re one of a very exclusive club.”

Four participants did not consider themselves survivors. Three of them did not see themselves as survivors because they thought they had not yet completed a process, underscoring the defining moment. A third participant said “it was only luck,” underscoring the “beyond one’s control” meaning.

Age at diagnosis was related to some meanings of survivorship. “A new outlook” was mentioned significantly more frequently among women who were diagnosed before age 51 (chi square [degree of freedom = 1] = 3.633, $p = 0.057$).

Benefits of the Cancer Survivorship Experience

A total of 109 participants (97%) listed at least one benefit of having had BC. No statistical differences existed in benefits found by age at diagnosis.

The “new appreciation of life” ($n = 95$) involved being aware of one’s own mortality and that time is a precious commodity. As a result, many participants said they would spend time more carefully with their loved ones and do the activities that they enjoyed most. Twelve participants said they now knew that “little things” were unimportant or that “little things” were actually the most important. However, in both cases, the meaning was the same. One participant said, “The little things aren’t as important as I once thought they were. When I get upset over things, I stop and tell myself, ‘Hey, I’m alive.’” Another participant described it a different way. “Everything is important in my life; every little thing. Breast cancer makes you more aware of what life is about.”

Improved relationships ($n = 63$) were positive changes in relationships with family members, significant others, and friends. Many stated that they had become closer to and more appreciative of others, and had developed some new bonds with other survivors. One participant said, “It is one of the best things that has ever happened to me; [it] made family relationships better.”

Self-improvement ($n = 45$) meant a change for the better in the person, such as an increase in emotional control (i.e., calm, stronger), becoming more compassionate toward others, developing new skills, or obtaining a degree. For example, one participant said, “[It] enabled me to do things I didn’t have the nerve to do before because it gave me courage.”

Twenty-seven participants mentioned that a benefit of their survivorship experience was an increased drive to help others, which the authors labeled “help orientation.” They saw helping others as their personal responsibility and an opportunity to give back or share their personal experience with others who were battling BC. For example, one participant said, “[I have] the ability to help others in ways I’ve never imagined before.”

Participants who cited “increased attention to health” ($n = 23$) as a benefit spoke of a greater emphasis on personal health and focusing on their personal needs. One of them said that now “[I] take better care of myself, [I am] more likely to say no to things.” Another said, “[I] view health as more important because if you don’t have health, you really don’t have anything.”

Finally, 13 participants mentioned that a benefit of their experience was “spiritual change” which involved renewed faith, deeper sense of spirituality, and connection with God. As one participant explained, “It has led me to God. I learned a lot about myself, my life, and letting go of all those problems I was dealing with and looking at them in a different way.”

Discussion

Survivors undergo a process for defining their status as survivors. It is not a default status but, rather, an identity that is embraced at different times by different survivors. Morris et al. (2011) reported that women who had BC found a new identity as a result of participation in a challenge-based peer support program (i.e., a 1,000-mile motorcycle ride). That appeared to be similar to what the authors discussed as a defining moment. However, Morris et al. (2011) reported only one defining moment that was similar to the current study's participants' defining moments.

The process of defining oneself as a survivor appears to be similar to what is described as "meaning-making" in the literature (Park & Folkman, 1997). That is particularly evident among those participants who defined survivorship as "completion of a process." The completed process frequently was cancer treatment, as has been reported in the literature (Lechner et al., 2003). Lechner et al. (2003) hypothesized that the difficulties of cancer treatment may prompt patients with cancer to search for meaning.

Although "becoming a survivor" seems to be an active process overall, this does not seem to be the case of those whose defining moment was "outside confirmation." Kaiser (2008) mentioned women who had "never really thought about it" (p. 85), yet she interpreted that survivorship for these women was undesirable. The current authors found no indication of this in their sample. Those who learned they were survivors by "outside confirmation" may not have felt an intense threat and, therefore, did not engage in meaning-making. More research is needed to test such a hypothesis.

The meanings of survivorship reported by participants were not only heterogeneous, but sometimes contradictory. For example, those who defined survivorship as conquering emphasized a search for control; for others, survivorship meant "beyond one's control."

As reported in the literature (Antoni et al., 2001; Ashing-Giwa et al., 2006; Carver & Antoni, 2004; Cordova et al., 2001; Dow, 1990; Dow et al., 1996; Morris et al., 2011; Stanton et al., 2002), the current study's authors found that a new appreciation of life, deeper spirituality, personal improvement, improved relationships, and help orientation were benefits of the cancer survivorship experience. To this list of benefits, participants added increased attention to their own health. Most of the participants in the current study reported finding benefits from the cancer experience. However, that may not be the case for the general population of survivors. The voluntary nature of the current study's participants and the recruitment from the Susan G. Komen for the Cure organization may have resulted in over-representation of women who have a positive perception of their experience.

The subgroup analyses conducted were not meant to falsify or confirm hypotheses. Rather, their contribution was to raise some issues to be explored in future research. Survivors who were diagnosed before age 51 were more likely to define survivorship as a new outlook on life. Those who were diagnosed after age 50 may have already, by virtue of their age, grappled with the limitations imposed by age and life events that led to a reordering of their priorities before their cancer diagnosis (Park & Folkman, 1997). In the current sample, women who were diagnosed before age 51 also had spent a longer time as survivors. Thus, an alternative explanation is that women who were diagnosed before age 51 were more likely to feel that having had cancer meant "a new outlook" because they had spent a longer time as survivors. In a study of BC survivors, Ashida et al. (2009) showed that those who are diagnosed young more often embrace a "fighting spirit" (p. 550). However, in the current study's data, no statistical difference was found by age at diagnosis in the proportion of participants who defined survivorship as "conquering."

The current study has several strengths. First, survivors' perspectives were captured in their own words and they described how they defined the meaning of survivorship, which appeared to be distinct from the benefits they found. To the authors' knowledge, this is the first study to focus on survivorship's defining moment. Based on the themes derived from survivors' experiences, survivorship is described in a rich variety of ways, but recurring themes also existed that may offer avenues for developing and tailoring support programs. Second, results were explored by age at diagnosis and a large number of participants were diagnosed before age 51. Third, the sample size was relatively large for a qualitative study.

However, the study had several limitations. First, the recruitment of women from two BC survivor groups may have biased the results somewhat in favor of those who are likely to be more positive about their survivorship experience. However, the women probably represent typical BC survivors' views of survivorship and their voices help to fill a gap in the understanding of the process of adjustment following cancer. Second, the lag time since diagnosis varied greatly among the participants. Meanings and benefits may change over time. A longitudinal study would be ideal to explore if changes in survivorship definitions occur over time. Third, although the sample size was too small for testing hypotheses, exploratory quantitative analysis enabled the authors to raise hypotheses for future research. Fourth, a functional operationalization of those younger than 51 years at diagnosis, including women who are premenopausal or who have children of elementary school age (Thewes et al., 2004), may aid in identifying the differences in women's meanings and benefits by age at diagnosis, if those differences exist. However, the current study's data provided no information on children in the household and age of menopause.

Implications for Practice

Often, service providers focus on the needs of survivors and the difficulties they encounter (Hewitt et al., 2006; Howlader et al., 2011). Although that is crucial, positive aspects of a cancer diagnosis also exist—namely, finding benefits—that should not be ignored (Lechner et al., 2003). Providers also should acknowledge the strength survivors exude by readjusting in the process of meaning-making and finding benefits from adversity. The current study's data support the notion that many but not all survivors engage in meaning-making (Lechner et al., 2006). In fact, expressive (e.g., writing about feelings) and supportive interventions can be advantageous, particularly for those who already are facing a serious challenge adapting to their cancer diagnosis (Lechner et al., 2006; Penedo et al., 2006). That kind of program may not be as useful for those who learned they were survivors by outside confirmation. As Kaiser (2008) pointed out, "Intuitively, positive meanings [of survivorship] should facilitate healthy adjustment by producing feelings of pride and social worth" (p. 81). The authors suggest that service providers might ask patients with BC about their views of survivorship to determine whether they are positive or negative. That kind of information is important for facilitating positive psychological adjustment after treatment.

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Table 1

Demographic Characteristics by Age at Diagnosis

Characteristic	Younger Than 51 Years (N = 78)		51 Years or Older (N = 34)	
	\bar{X}	SD	\bar{X}	SD
Age at diagnosis	41.9	5.7	56.9	4.8
Time since diagnosis (years) *	10.3	7.1	5.8	3.3
Characteristic	n	%	n	%
Excellent or very good health	47	60	24	71
Race				
Caucasian	65	83	31	91
African American	11	14	2	6
Other	2	3	1	3
Relationship status				
Has a partner	55	71	26	77
Lives alone	19	24	6	18
Missing	4	5	2	6
Education				
Less than college	14	18	8	24
Some college	28	36	5	15
College graduate	23	30	7	21
Graduate school	13	17	14	41
Income (\$)				
Less than 45,000	17	22	11	32
45,000–65,000	20	26	7	21
More than 65,000	33	42	10	29
Missing	8	10	6	18
Area of residence				
Urban	37	47	10	29
Suburban	17	22	6	18
Rural	24	31	18	53

* p < 0.001

Note. Because of rounding, not all percentages total 100.

Table 2

Tumor and Treatment Information by Age at Diagnosis

Characteristic	Younger Than 51 Years (N = 78)		51 Years and Older (N = 34)	
	n	%	n	%
Stage				
In situ	6	8	7	21
I	17	22	6	18
II	15	19	6	18
III	6	8	3	9
IV	2	3	–	–
Other	8	10	2	6
Missing	24	31	10	29
Type of surgical treatment^a				
Radiation therapy	53	68	27	79
Lumpectomy	49	63	24	71
Chemotherapy	48	62	18	53
Tamoxifen	32	41	18	53
Mastectomy	25	32	8	24
Had a recurrence	16	21	1	3

^aParticipants could select more than one type of surgical treatment received.

Note. Because of rounding, not all percentages total 100.

Table 3

Distribution of Defining Moment, Meaning of Survivorship, and Benefits of the Breast Cancer Experience by Age at Diagnosis

Characteristic	<u>Younger Than 51 Years (N = 78)</u>		<u>51 Years and Older (N = 34)</u>	
	n	%	n	%
Defining moment				
Back to normal	26	33	9	27
Completion of process	24	31	10	29
Outside confirmation	18	23	7	21
Strength	8	10	5	15
Group of survivors	8	10	3	9
Removal of cancer	7	9	4	12
Other	3	4	3	9
Meaning				
Conquering	23	30	13	38
A new outlook	25	32	5	15
Help others	17	22	3	9
Free of cancer	15	19	9	27
Beyond your control	12	15	9	27
Sisterhood	4	5	3	9
Benefits of the experience				
Appreciation of life	67	86	28	82
Improved relationships	44	56	19	56
Self-improvement	33	42	12	35
Help orientation	18	23	9	27
Increased attention to health	17	22	6	18
Spiritual change	8	10	5	15
No benefits	3	4	1	3

Note. Participants could select more than one answer for each characteristic.