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ORIGINAL ARTICLE

Problems in transition and quality of care: perspectives of breast cancer survivors

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Abstract
Purpose We conducted a qualitative study to explore breast cancer survivors' perceptions and attitudes about their current healthcare utilization, screening, and information needs.
Methods We completed eight focus groups of breast cancer survivors. We included women, adult survivors, with an initial diagnosis of breast cancer in the year 2000, treated, and without a recurrence as per medical record. To analyze transcripts, we used grounded theory methods, wherein unexpected themes and direct answers emerged from consensus between co-coders.
Results Focus groups included 33 participants, the majority of whom were white (84.8%), college-educated (66.7%), and covered by private medical insurance (75.7%) or Medicare (27.3%). Participants' perceptions and attitudes about care were framed in terms of personal experiences (including facing barriers to screening, feeling in limbo in the healthcare system, having problems with communication with and between physicians, confusion about symptoms, and using self-prescribe remedies), personal attitudes (including strong opinions about what survivorship means, concerns about recurrence, and changes in self-perception and agency), and social influences (including modeling others' behaviors, changes in social life, and listening to family).
Conclusion Survivorship attitudes, recurrence fears, memories, and self-perceptions were influential personal factors in addition to self-efficacy. Solutions such as providing a cancer treatment summary might resolve many of the problems by consolidating and making readily available the numerous medical history and recommendations that survivors accrue over time, switching from provider to provider. Clinicians must also implement communication changes in their interactions with patients to enhance positive attitudes and behaviors, and leverage social influences.

Keywords Qualitative · Breast cancer survivors · Healthcare transition

Introduction

The National Cancer Institute estimates that there are currently 10.5 million cancer survivors in the US [1]. One model conceptualizes survivorship across a three-staged spectrum [1]—an acute phase from diagnosis through treatment induction, an extended phase from remission to treatment completion, and a permanent phase with diminishing likelihood of recurrences, but lingering social, economic, emotional, and late physical.

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Few studies have assessed transition and quality of care in survivors. While evidence is inconclusive whether survivors receive sufficient primary care, it does suggest that screenings are managed well [2, 3]. Breast cancer survivors received more preventive services than control groups [4]. There is little information about breast cancer survivors' perceptions of transition of care and healthcare needs as they progress toward survivorship, but the few available studies show that their attitudes may play an important role in their well-being. Fear of recurrence can lead survivors to improve health behaviors that they feel can help prevent recurrence and are protective toward cancer [5]. Quality of life can be negatively impacted by survivors' negative beliefs about symptom management and by perceived negativity from their healthcare providers [8]. Intrusive, negative thoughts can lead to stress-related problems including emotional distress and physical functioning [9, 10]. Finally, satisfaction with healthcare is associated with survivors' psychological well-being and trust in their community's generosity and goodness [6, 7].

Our qualitative study is among the few that solicit participants' own opinions and attitudes about their current healthcare utilization, screening, and information needs. We anticipated that asking survivors themselves to qualitatively share their needs about survivorship care would reveal areas for quality improvement unexplored by prior studies.

Methods

We identified potential participants from the Tumor Registry at the University of Texas MD Anderson Cancer Center, a comprehensive electronic database of all patients seen at this institution. We included adult survivors with an initial diagnosis of breast cancer in the year 2000, treated and without a recurrence as per medical record. We excluded participants who were geographically inaccessible (i.e., greater than 1 h travel time to our institution). We also required that participants speak English and have the cognitive ability to complete an initial screening interview, wherein we asked date of birth and other basic questions to gauge mental capacity. Patients were interviewed in 2008, so, on average, they had been survivors for 8 years.

Patients identified as eligible were mailed a solicitation letter asking them to participate in a focus group. The letter also included a self-addressed, stamped "do not contact" card that participants could send in the event that they wanted to refuse participation. All participants who did not send back the rejection card were called to invite them to participate and screen for eligibility. Participants were compensated for their time ($30) and parking costs. They were also provided lunch during the focus groups. The study was approved by the Institutional Review Board at the University of Texas MD Anderson Cancer Center.

We conducted eight 2 h focus groups, with an average of five (range 2–10) participants each, an optimal size and number to ensure an intimate, trusting environment for participants' disclosures and still retain significance, variety, and applicability of overall ideas generated [11, 12].

Data collection

Trained moderators hosted all focus groups. No moderator had direct patient care responsibilities for any participants or had met participants before. Moderators used a script of questions organized into seven original themes—general health, lifestyle, late effects of cancer therapy, current healthcare utilization patterns, perceived healthcare needs, current health screening practices and prevention behaviors, and perceived information needs. The scope of this article focuses primarily on three original themes: current healthcare utilization, perceived healthcare needs, and current health screening practices. Table 1 lists the questions each of the three entailed.

We audio-recorded and transcribed each focus group. Assistant moderators took notes that were used for checking the accuracy of transcriptions.

Data analysis

We used grounded theory methods to analyze focus group transcripts [13, 14]. Grounded theory involves coding

Table 1 Theme questions

Current healthcare utilization patterns
1. Nowadays, how often do you visit the doctor because of health issues related to cancer or its treatment?
2. Who is (which healthcare providers are) currently taking care of your healthcare needs related to cancer?
3. From whom would you prefer to get your healthcare in relation to your cancer-related health needs?
4. What problems do you have accessing necessary healthcare related to your cancer?
Perceived healthcare needs
1. What healthcare needs particular to survivorship do you have that aren't being met?
2. In your opinion, what has prevented these particular needs from being met?
3. How might these needs be met?
Current screening practices
1. How often do you participate in screening for recurrent, new or second cancers?
2. What barriers complicate your participating in screenings?
3. Do you believe you participate in enough screenings? Not enough? Too much? Why?
4. Has your experience with cancer changed the way you take care of your health?
5. What are the ways you take care of yourself now?

quotations for emerging themes and building consensus as to the importance and relationships between themes, with the following three stages: (1) an open coding stage, wherein two investigators coded each transcript independently then met to compare codes and resolve discrepancies through discussion; (2) an axial coding stage, wherein we streamlined our coding schema by conjoining similar codes, eliminating duplicate codes, and categorizing codes in major themes; and (3) a selective coding state, wherein we discussed the relationships between major themes and the framework interconnecting and explaining them. In addition to recording direct answers to the questions in our moderator script, we also categorized the new and unexpected themes that emerged.

Transcripts were imported into NVivo©, a software which was used to record our consensus themes, tally code frequencies, and run queries on code relationships. To ensure our data reached theoretical saturation, we used a constant comparison method, wherein we tested and applied our axial coding categories on subsequent transcripts [13, 14]. No new themes emerged by the end of our analysis. The transcripts were independently reviewed and coded by two team members, who met to discuss the interviews and the coding structure. Agreement was reached and saturation confirmed by consensus. Often, co-coders agreed that one reference (i.e., quotation in the transcript) reflected several emerging themes. Moreover, individuals often offered more than one answer on a topic. Therefore, the total number of references does not equal the total number of codes.

Results

Focus groups included 33 breast cancer survivors gathered from 284 patients to whom we sent solicitation letters. Patient characteristics are shown in Table 2. The majority of participants were non-Hispanic (n=32, 97.0%) and white (n=28, 84.8%). Most were college educated (n = 22, 66.7%) and either employed full-time (n=11, 33.3%) or retired (n = 13, 39.4%). Most were covered by private medical insurance (n=25, 75.7%) or Medicare (n=9, 27.3%). Most were married (n=21, 63.3%).

Emerging themes

We coded emerging themes or answers related to participants' healthcare needs that our original questions did not specifically anticipate or solicit. Table 3 shows these emerging themes both (1) when they were volunteered in response to a direct question and (2) when they were volunteered elsewhere in the transcript. Three overarching categories of themes were paramount—survivors' personal experiences, attitudes, and their social realms of influence. Overall, survivors face unique experiences and barriers, given their added comorbidities, medications, adverse events, and fragmented provision of care by multiple practitioners of various specialties.

Table 2 Participant demographics

Characteristics	n=33 (%)
Race	
White	28 (84.8)
Black	5 (15.2)
Ethnicity	
Spanish–Mexican	1 (3.0)
Education	
Less than high school	1 (3.0)
High school diploma	2 (6.1)
Trade school	1 (3.0)
Some college	9 (27.3)
Bachelor's degree	12 (36.4)
Advanced degree	10 (30.3)
Age	
Mean (range)	59.7 (42–75)
Employment	
Full-time	11 (33.3)
Part-time	5 (15.2)
Homemaker	1 (3.0)
Disabled	1 (3.0)
Retired	13 (39.4)
Insurance	
HMO	1 (3.0)
PPO	24 (72.7)
Medicaid	1 (3.0)
Medicare	9 (27.3)
Income	
<$10,000	2 (6.1)
$15,000–19,999	1 (3.0)
$25,000–29,999	1 (3.0)
$30,000–39,999	2 (6.1)
$50,000–74,999	6 (18.2)
$75,000–99,999	5 (15.2)
$100,000–124,999	3 (9.1)
≥$125,000	5 (15.2)
Refused to answer	6 (18.2)
Marital status	
Single	3 (9.1)
Married	21 (63.6)
Widowed	1 (3.0)
Separated	1 (3.0)
Divorced	7 (21.2)

HMO Health Maintenance Organization, *PPO* preferred provider organization

Table 3 Most frequent codes

Category	Code	Subcodes	Definition	Direct responses to questions	Direct responses to questions+additional utterances found elsewhere in transcripts
Experiences	Facing barriers to screening and listing screening types		When participants list the types of cancer screenings in which they participate and the problems thereabout	13	22
	Feeling in limbo in the healthcare system		When patients feel displaced because the clinic or providers' specialty is either too general or too cancer-specific	9	19
	Communicating with providers	Complying with providers' directives	When participants describe following medical directives; when they make statements of trust in and adherence to physician instruction	9	16
		Paying providers' compliments	When participants praise providers, healthcare facilities, or other aspects of their medical care	8	12
		Complaining about providers	Troubled or problematic interactions (past or present), inaccurate information, unhelpful care, etc., involving physicians, nurses, PAs, pharmacists, and any others in the medical community	7	14
	Determining whether current health problems are cancer-related	Describing other health utilization	When participants mentioned confounders and other health problems above and beyond those caused by cancer and its treatment	9	14
		Unclear determining whether current health problems are cancer-related	When participants are unclear if a current health condition is related to cancer or its treatment	4	4
	Using nonprescribed remedy		Survivor's knowledge and use of remedies for mitigating late effects through prescribed or nonprescribed methods. Includes remedies used to ease or help with the complications of other remedies	7	13
Attitudes	Perception of survivorship		Attitudes, valuations, and opinions about the significance, definition, characteristics of survivorship on whole; an outlook on survivorship	10	12
	Reoccurrence concerns		Attention paid and emotions felt about the probability or risk of recurrence	9	14
	Retrospective self-perception		Framing discussion of survivorship experiences by describing life during cancer diagnoses and treatment	7	11
	Self-agency		Statements about survivors' control or lack of control over health	6	10
Social issues	Modeling behaviors of others		Telling a narrative about another person's experience	6	8
	Weighing the effects on family		Volunteering stories about other family members' experiences with cancer	6	6
	Weighing the social effects of care		When participants describe the effects of long-term side effects on their social lives	4	5

Personal experiences

Survivors were frustrated in their personal experiences by what they perceived were barriers to care and felt unsure about screening, interactions with physicians, symptoms, and use of remedies.

Facing barriers to screening and listing screening types

In addition to sharing how often they participated in screenings, participants listed the types of screenings that they undergo, most of which included mammograms, bone density scans, pelvic exams and PAP smears, and colonoscopies. They shared physical problems associated with screenings including discomfort during the mammogram, scars and fibroids that complicate performing self-exams.

> "I have a lot of scar tissue that I have to deal with and because I had a breast reduction, and I have fibroids, I have to feel around all the time. So you do get familiar you know what is normal and what's not."

Logistic problems were also a concern including inconvenience making appointments and delays in receiving test results.

Feeling in limbo in the healthcare system

Survivors felt that they had no providers within the healthcare system exclusively devoted to their unique needs. They preferred seeing oncologists, but felt guilty because, in their opinion, patients with active cancer needed oncologists for matters more pressing than theirs.

> "If I had a choice, I would come [to the cancer center] for everything. I just feel like that [my oncologist] has so many patients,…if I started to come here for every little thing, I could be taking up some time that they could be taking care of somebody [with] more critical needs."

They also felt dismissed by cancer specialists at the time that transfer of care takes place.

> "I had already been dismissed by the radiologist a couple of years ago, and then by the surgeon 1 year ago and then my oncologist [who] said you are doing well and we are going to send you to…the survivorship clinic."

Survivors sought to have their healthcare needs met by assorted medical professionals including primary care physicians and gynecologists to pharmacists and nurse practitioners. However, these providers were often reluctant to provide advice or treat them, referring them back to cancer specialists.

> "The other thing that is hard too is primary care... [Healthcare providers] usually don't want to deal with you anymore and if it is any little old thing they say you need to go to your oncologist."

Survivors feared that having to repetitively transfer medical records and explain their medical history to various care providers degraded the quality of their care.

> "I think some things may be slipping through the cracks"

Communicating with providers

Survivors' attitudes about their healthcare providers played an important part in their needs assessment. They often expressed their trust in providers' directives on exercise, medication, screening, and referrals to other physicians. However, they also shared many concerns. They complained about communication problems, lack of attention, and lingering questions left unaddressed.

> "[W]hen I was going to my gynecologist, it was just difficult to relay what information they actually wanted or if that was something that we needed to look into more."

Other complaints included lack of coordination between providers regarding patient records and treatment history (e.g., attempts to draw blood from the arm with lymphedema), perceived insensitivity about patients' feelings and opinions regarding treatment, billing department errors, and frequency of visits with mid-level providers rather than physicians. Participants recommended provider education initiatives for primary care and family physicians.

> "Either there has to be a gigantic education process of general practitioners in the market place about how to work with cancer patients or … look down the survivorship path and how to deal with [it]."

Other participants offered praise for providers who were sensitive to survivorship needs and efficient about caring for their multiple, complex health concerns.

> "I am very fortunate that I am here. These doctors speak to one another and take care of the whole person not just this little piece."

Determining whether current health problems are cancer-related

Often, preexisting conditions and other confounders caused confusion about attribution of symptoms, making it difficult for survivors to tell if cancer and its treatment, or other issues (i.e., comorbidity or aging), caused their discomfort and health problems.

> "I am getting to where my back and legs hurt when I stoop to try and get something and then get back up. But I don't think that mine are cancer related or chemo related as much as if it would have happened if I would have gone through menopause naturally."

Given their variety of preexisting conditions, survivors were often reluctant to attribute the cause of many of their current health concerns to cancer and its treatment.

Using nonprescribed remedies

Many survivors reported using nonprescribed remedies as an alternative to going to the doctor and using medicine as a means of prevention and health promotion. Most reported using over-the-counter medicines for pain; physical therapy, massage and exercise for fatigue and pain, and homeopathic medicines and supplements for overall health.

> "I am looking for things to get my body back to as natural as possible…I am taking all of these supplements…I feel good about taking them."

Survivors also discussed an additional layer of side effects and adverse effects that they endured from over-the-counter medications or complimentary remedies used to "cure" cancer or treat long-term effects from therapy.

Personal attitudes

Participants revealed several overarching perspectives and outlooks that influenced their perceptions about their care needs.

Perception of survivorship

Survivors usually defined survivorship in relationship to what it meant to experience cancer; these overarching attitudes often shaped their expectations for care. One survivor saw herself as a life-long cancer center patient:

> "Once a patient at MD Anderson, always a patient at MD Anderson. [T]hat's how I feel about it."

Another survivor drew the line to what extent she faulted cancer for her current needs.

> "So I have had some back problems...[But] you...can't blame everything on cancer."

Survivors also expressed various views about life after cancer including deterministic attitudes, wanting to embrace life to the fullest and evaluating life events in terms of still being alive. For example, a deterministic attitude influenced how one survivor prioritized prevention.

> "As far as prevention goes,…I will do what they tell me to do, but what is going to happen to me is going to happen to me and nobody on earth is going to prevent that."

In contrast, another survivor described how survivorship infused her life with more value.

> "I definitely started putting family first...I could be totally missing something if I just didn't live in the moment."

Recurrence concerns

Participants viewed many standard aspects of care through the lens of fear of recurrence, with heightened tension about follow-up calls from physicians, time waiting for test results, and their responses to physicians' questions during office visits.

> "They send you a letter in the mail, and they thought they found something and I wasn't leaving until they decided to repeat this test. You know you can never be that busy... if they think they have found something repeat it. Or work them in, I mean I would have stayed here all day. I didn't want to have to wait...Just to relieve my mind."

> "Truly, I don't think about [recurrence] until about 2 weeks before my annual checkup and I start tightening up and my blood pressure goes through the roof and I can't get myself down until after the appointment."

They also described how they cared for themselves now.

> "So I guess from you know, knowing cancer prevention, it just for general health, I am a lot more positive and a lot more careful and do a lot more than I have ever done before."

Retrospective self-perception

Participants phrased answers by comparing their current health condition to their lives before and during cancer treatment. Although our questions asked participants to describe their current status, participants often shared anecdotes about their own past problems and experiences in order to explain their current healthcare preferences and behaviors. One participant explained how her past diagnosis excuses her from having to perform self-exams.

> "[I perform self-exams] infrequently. My lump was not found through exam. Mine was found through mammogram. Mine was on the back wall so I would not have felt it or anything like that."

Self-agency

Asking survivors questions about their current healthcare utilization and practices also inspired them to share the degree to which they have control—or lack of control—in healthcare decisions and directives. Survivors' experiences with cancer, treatment, and late effects inspired them to take a more proactive role during medical appointments.

> "And I come in with my list...[I]t is important to keep asking. I mean even things that you don't think are related to what is wrong with you or what has been wrong with you."

Survivors asserted their will in adhering to exercise regimens.

> "I had lots of problems when I had lymph nodes removed. Just stretching it out and exercising it… it's a huge [help]. Keep pushing yourself you know to walk that walk...You need to do go that extra

> step until you loosen up and then do it consistently to keep it stretched."

They also asserted their treatment preference by using alternative medicine.

> "I stick to the natural path...with herbs or whatever because I don't take any medication."

Social influences

Several emerging codes illustrated how friends, family, co-workers, and others in the survivor's social milieu shape how survivors handle their healthcare.

Modeling behaviors of others

Often, others' healthcare decisions influenced survivors' own approaches to care.

> "I have a sister-in-law who had cancer in her early 40 s and what she did was a lot of medication and really altered her lifestyle in terms of eating...She has been a good example...[J]ust be a little more vigilant about lifestyle and insuring exercise more."

In contrast, another survivor shrugged prevention methods of others.

> "You hear people say drink green tea; it is so good for you…I am just not one to say, 'Oh I have to have a cup of green tea every morning or something.'"

Weighing the effects on family

Participants expressed the importance of screening and healthcare in terms of its importance to other family members.

> "I do my mammograms faithfully you know, and I remind my daughter to do hers, so I really don't worry about it."

> "I am very diligent about having my mammograms done but also I always have in the back of my mind is that I always worry about my daughter. I always want to make sure that she does them and I am on here constantly like have you done your mammogram and being careful and so that's my main concern."

Weighing the social effects of care

Social circles of influence inspired survivors' healthcare diligence. Family and friends helped survivors to adjust their schedules, diets, and other health habits for the better.

> "My husband is a great chauffeur. Keeping my level of stress low has been very, very important."

Spouses and significant others also helped survivors in assessing their health.

> "I was quite surprised when I found something. In fact, I had my daughter feel it and I said do you feel something there? And I had my husband feel it and I said do you feel something there?"

Late effects hindered social activity. Decreases in energy and sex drive—and the tension it triggered between spouses and significant others—topped survivors' list of late effects that must be addressed.

> "[I experience] the lack of even wanting even the desire to have sex...Because I am single, it's a big issue. [M]en take that as a response that I don't even like them."

Discussion

We conducted a qualitative study to evaluate the perceptions and needs with respect to healthcare of female survivors of breast cancer. While many surveys have examined quality of life issues in long-term cancer survivors, few have focused on their specific healthcare needs. Furthermore, while traditional surveys can document attitudes toward predetermined issues, qualitative studies as this one provide a rich, in-depth evaluation of participants' experiences, with emerging themes that can more fully describe individual experiences and perceptions.

Survivors' experiences accessing healthcare are fraught with difficulties finding a provider who can both address their particular needs and coordinate their care. Attitudes about survivorship, in general, fears of cancer recurrence, past experiences, self-perception, agency, and spirituality and faith, all influence survivors' expectations and perceptions about healthcare. Friends, family, and other survivors often motivate them. Overall, several factors complicate healthcare above and beyond problems related to coordination. While flaws in medical record accessibility and inconveniences of juggling multiple medical appointments with assorted providers clearly pose a challenge, other and nonsystemic problems also affect their quality of care. Providers and survivors have dissenting attitudes about their appropriate place in the healthcare delivery system. Distinctions are blurred between late effects of cancer and cancer therapy, and preexisting conditions. Fear of recurrence is a pervasive worry, even 8 years after cancer was initially diagnosed.

Three overarching themes emerged during the focus groups. These themes are related in a way that parallels Bandura's social cognitive theory. Social cognitive theory pinpoints three, interdependent, mutually influencial factors integral in developing, sustaining, and intervening upon behavioral patterns—behavior, personal factors, and environmental factors [15]. Several prior studies have used social cognitive theory to suggest means by which to increase patient confidence in self-management of disease and self-efficacy [16–21]. In terms of the current study, Bandura's concept of *behavior* resembles our *personal experiences* category, wherein participants volunteered stories about their healthcare actions, habits, practices, and history. Bandura's concept of *personal factors* maps closely onto our *personal attitudes* category, wherein participants shared their own beliefs, values, and feelings. Finally, Bandura's concept of *environment* is similar to our *social influences* category, which includes stories of how friends, family, and others in survivors' lives impact their experience and behaviors. Our findings demonstrate another useful application of the theory, namely, for understanding the complex dynamics of patient-centered care, wherein providers must be sensitive to social, behavioral, and environmental factors in order to deliver respectful, responsive healthcare.

Other studies confirm the importance of themes that emerged in our findings, including memories of cancer diagnosis, recurrence fears, and prevention concerns [22, 23]. Survivors manage feelings of uncertainty and recurrence by participating in active surveillance and information gathering [24, 25]. Our study demonstrates that other survivorship stories also influence patients' level of certainty about their condition.

Our study underscores the importance of physician type and communication. Survivors trust primary care physicians more for general care than knowledge about cancer follow-up and symptom treatment [26]. Moreover, they are sensitive about how providers communicate with them and prefer being treated within an overall management team [24]. Distrust in knowledge of primary care providers, feelings of guilt relying on cancer specialists, and difficulties integrating multiple sites of care might impede survivors' satisfaction with care. We also confirm prior findings on survivors' concerns about primary care providers' ability to provide care for cancer-related issues and difficulty communicating with cancer specialists [27]. Improved patient–provider communication, in turn, helps address thoughts of recurrence [28].

Our study is limited insofar as it is qualitative and is therefore not generalizable. It cannot map the causality linking reciprocally-related codes. Our sample was very homogeneous, and we did not organize focus groups by participant demographics. Therefore, we cannot discuss differences in attitudes between various ethnicities, socioeconomic groups, or age groups. Additional studies should examine whether heterogeneous focus group design yields consistent results.

Significance This is one of few studies to focus on survivors' opinions of the quality of their healthcare, a qualitative study that provides a rich, in-depth evaluation of participants' experiences, with emerging themes that can more fully describe individual experiences and perceptions. It provides healthcare professionals with first-hand information from patients with which to broaden and improve patient–provider communication and enhance healthcare delivery in the transition to survivorship care.

Previous studies have recommended providing comprehensive information and support to survivors, offering regular follow-up visits to improve provider–patient relationships, and giving survivors more choice in healthcare decisions [3, 30, 31]. Our findings suggest that a multifactorial, holistic approach to healthcare would achieve better results than merely an administrative one. Solutions, such as providing cancer treatment summaries to all practitioners involved in the care of breast cancer survivors, would help resolve many problems broached in our study by consolidating and making readily available the numerous medical issues and recommendations that survivors accrue over time, switching from provider to provider [29]. While administrative solutions can eliminate steps needed to get care, clinicians must also implement communication changes in their interactions with patients to enhance positive attitudes and leverage social influences.

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Conflicts of Interest None.

References

1. Mullan F (1985) Seasons of survival: reflections of a physician with cancer. N Engl J Med 313:270–273
2. Khan NF, Ward A, Watson E, Austoker J, Rose PW (2008) Long-term survivors of adult cancers and uptake of primary health services: a systematic review. Eur J Cancer 44:195–204

3. Sheppard C (2007) Breast cancer follow-up: literature review and discussion. Eur J Oncol Nurs 11:340–347
4. Earle CC, Burstein HJ, Winer EP, Weeks JC (2003) Quality of non-breast cancer health maintenance among elderly breast cancer survivors. J Clin Oncol 21:1447–1451
5. Rabin C, Pinto B (2006) Cancer-related beliefs and health behavior change among breast cancer survivors and their first-degree relatives. Psychooncology 15:701–712
6. Bettencourt BA, Molix L, Talley AE, Westgate S (2007) Satisfaction with health care, psychological adjustment, and community esteem among breast cancer survivors. J Psychosoc Oncol 25:59–75
7. Kaiser K (2008) The meaning of the survivor identity for women with breast cancer. Soc Sci Med 67:79–87
8. Yeom HE, Heidrich SM (2009) Effect of perceived barriers to symptom management on quality of life in older breast cancer survivors. Cancer Nurs 32:309–316
9. Helgeson VS, Snyder P, Seltman H (2004) Psychological and physical adjustment to breast cancer over 4 years: identifying distinct trajectories of change. Health Psychol 23:3–15
10. Lebel S, Rosberger Z, Edgar L, Devins GM (2008) Predicting stress-related problems in long-term breast cancer survivors. J Psychosom Res 65:513–523
11. Krueger R (1994) Focus groups: a practical guide for applied research. Sage Publications, Thousand Oaks
12. Morgan D (1993) Successful focus groups: advancing the state of the art. Sage Publications, Newbury Park
13. Strauss AC, Corbin J (1997) Grounded theory in practice. Sage Publications, Thousand Oaks
14. Strauss AC, Corbin J (1998) Basics of qualitative research: techniques and procedures for developing grounded theory. Sage Publications, Thousand Oaks
15. Bandura A (2001) Social cognitive theory: an agentic perspective. Annu Rev Psychol 52:1–26
16. Bandura A (2004) Health promotion by social cognitive means. Health Educ Behav 31:143–164
17. Benight CC, Bandura A (2004) Social cognitive theory of posttraumatic recovery: the role of perceived self-efficacy. Behav Res Ther 42:1129–1148
18. Bussey K, Bandura A (1999) Social cognitive theory of gender development and differentiation. Psychol Rev 106:676–713
19. Grol RP, Bosch MC, Hulscher ME, Eccles MP, Wensing M (2007) Planning and studying improvement in patient care: the use of theoretical perspectives. Milbank Q 85:93–138
20. Johnson MO, Neilands TB, Dilworth SE, Morin SF, Remien RH, Chesney MA (2007) The role of self-efficacy in HIV treatment adherence: validation of the HIV treatment adherence self-efficacy scale (HIV-ASES). J Behav Med 30:359–370
21. Wasson JH, Johnson DJ, Mackenzie T (2008) The impact of primary care patients' pain and emotional problems on their confidence with self-management. J Ambulatory Care Manage 31:120–127
22. Fu MR (2005) Breast cancer survivors' intentions of managing lymphedema. Cancer Nurs 28: 446–457; quiz 458–449
23. Gray RE, Fitch M, Greenberg M, Hampson A, Doherty M, Labrecque M (1998) The information needs of well, longer-term survivors of breast cancer. Patient Educ Couns 33:245–255
24. Bertero C, Chamberlain Wilmoth M (2007) Breast cancer diagnosis and its treatment affecting the self: a meta-synthesis. Cancer Nurs 30:194–202; quiz 203–194
25. Elphee EE (2008) Understanding the concept of uncertainty in patients with indolent lymphoma. Oncol Nurs Forum 35:449–454
26. Mao JJ, Bowman MA, Stricker CT, DeMichele A, Jacobs L, Chan D, Armstrong K (2009) Delivery of survivorship care by primary care physicians: the perspective of breast cancer patients. J Clin Oncol 27:933–938
27. Bussing A, Fischer J (2009) Interpretation of illness in cancer survivors is associated with health-related variables and adaptive coping styles. BMC Womens Health 9:2
28. Clayton MF, Mishel MH, Belyea M (2006) Testing a model of symptoms, communication, uncertainty, and well-being, in older breast cancer survivors. Res Nurs Health 29:18–39
29. Ganz PA, Hahn EE (2008) Implementing a survivorship care plan for patients with breast cancer. J Clin Oncol 26:759–767
30. Cappiello M, Cunningham RS, Knobf MT, Erdos D (2007) Breast cancer survivors: information and support after treatment. Clin Nurs Res 16:278–293; discussion 294–301
31. Partridge AH, Winer EP, Burstein HJ (2003) Follow-up care of breast cancer survivors. Semin Oncol 30:817–825