

# Adult Cancer Survivors Discuss Follow-up in Primary Care: 'Not What I Want, But Maybe What I Need'

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## ABSTRACT

**BACKGROUND** Nearly one-third of office visits for cancer are handled by primary care physicians. Yet, few studies examine patient perspectives on these physicians' roles in their cancer follow-up care or their care preferences.

**METHODS** We explored survivor preferences through qualitative, semistructured, in-depth interviews drawing on patients recruited from 2 National Cancer Institute–designated comprehensive cancer centers and 6 community hospitals. We recruited a purposive sample of early-stage breast and prostate cancer survivors aged 47 to 80 years, stratified by age, race, and length of time from and location of cancer treatment. Survivors were at least 2 years beyond completion of their active cancer treatment

**RESULTS** Forty-two survivors participated in the study. Most participants expressed strong preferences to receive follow-up care from their cancer specialists (52%). They described the following barriers to the primary care physician's engagement in follow-up care: (1) lack of cancer expertise, (2) limited or no involvement with original cancer care, and (3) lack of care continuity. Only one-third of participants (38%) believed there was a role for primary care in cancer follow-up care and suggested the following opportunities: (1) performing routine cancer-screening tests, (2) supplementing cancer and cancer-related specialist care, and (3) providing follow-up medical care when "enough time has passed" or the survivors felt that they could reintegrate into the noncancer population.

**CONCLUSION** Survivors have concerns about seeing their primary care physician for cancer-related follow-up care. Research interventions to address these issues are necessary to enhance the quality of care received by cancer survivors.

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## INTRODUCTION

More than one-half of individuals with a diagnosis of cancer are expected to survive for more than 5 years. For cancerous breast and prostate tumors, 5-year survival exceeds 90%.<sup>1</sup> Cancer survivors require extended follow-up cancer care after completion of their active cancer treatment. Survivors' follow-up management entails more than routine surveillance for recurrence of cancer.<sup>2,3</sup> It also requires proactive care, which includes systematic planning for cancer prevention and patient-centered surveillance based on the survivor's personal risk, cancer therapy, genetic predispositions, lifestyle behaviors, and other comorbid health conditions.<sup>2,4,5</sup>

Increasing numbers of studies document the importance of primary care clinicians (eg, family physicians, internists, physician assistants, nurse practitioners, and, in some cases, gynecologists) in increasing cancer survivors' screening for recurrence<sup>6,7</sup> and in providing comprehensive extended follow-up care.<sup>8-13</sup> Approximately 70% of cancer survivors have

comorbid conditions that require a comprehensive approach to their medical care.<sup>14,15</sup> Of the 36.6 million annual physician office visits made for cancer care, nearly one-third (32%) are made to primary care physicians.<sup>2</sup> The American Society of Clinical Oncology projects a medical oncologist shortage by 2020 that will necessitate a multifaceted strategy to meet future cancer follow-up care demands.<sup>16</sup> These data suggest that primary care physicians may increasingly provide the main medical home (ie, usual source of care) for survivors who have completed treatment.<sup>2,17</sup>

Few data are available on the types of physicians (primary care vs cancer—medical, radiation, or surgical oncologists—or cancer-related specialists) that traditionally provide care for adult cancer survivors.<sup>3,18,19</sup> Additionally, we know little about their practice patterns for providing cancer screening or surveillance testing for cancer recurrence.<sup>3,18,19</sup> Several studies suggest that survivors who see both oncologists and primary care physicians are more likely to receive recommended follow-up care than are survivors who see one or the other.<sup>6,7</sup> Additional literature documents that primary care physicians, as well as specialists, are concerned about providing cancer follow-up care.<sup>20-25</sup> Although some research suggests that patients are interested in having their primary care physicians be familiar with issues relevant to cancer survivorship,<sup>26-28</sup> there is little research that examines patients' preferences for extended follow-up care.<sup>21,26,27</sup> The current study therefore focused on long-term survivors of localized breast and prostate cancer and explored their preferences regarding the role of the primary care physician in their extended cancer follow-up care. The overarching goal was to identify the preferences of a rapidly growing patient population characterized by the challenges of future health problems related to their previous cancer therapy and for whom many years of follow-up care can be expected.

## METHODS

### Setting

This exploratory qualitative study recruited cancer survivors in New Jersey who had received their cancer treatment from 1 of 5 community hospitals (AtlantiCare—The Cancer Care Institute, Somerset Medical Center, South Jersey Healthcare, UMDNJ—The University Hospital, and Virtua Fox Chase Cancer Program) or from 2 National Cancer Institute (NCI)—designated comprehensive cancer centers (The Cancer Institute of New Jersey and Fox Chase Cancer Center). These institutions were chosen to represent the diversity of the area's cancer treating facilities (ie, community hospitals, teaching hospitals, and comprehensive

cancer centers). This study was approved by the institutional review boards at the University of Medicine & Dentistry of New Jersey and Fox Chase Cancer Center, as well as by the 5 community hospitals.

### Sampling Frame

We recruited a purposive sample of ambulatory, early-stage (I or II) breast and prostate cancer survivors for whom the Institute of Medicine (IOM) authors recommend longitudinal survivorship health care (ie, defined as health care other than hormonal therapy 2 or more years from completion of cancer therapy). Patients with severe comorbid conditions that required extensive specialist care coordination (eg, congestive heart failure, myocardial infarction, angina) were excluded. To assess the impact of diversity, the study patients were stratified according to (1) the number of years from treatment (2 to 5, 6 to 9, and 10 years or more) and (2) the location of cancer treatment (community hospital vs cancer center). Additionally, we oversampled African Americans and recruited an age-representative sample of New Jersey cancer survivors (ie, one-half were older than 65 years).

### Data Collection

In-depth, individual interviews were conducted from March through October 2009. Interviews were conducted in English by telephone (95%) or in person (5%) according to participants' preference. Survivors were referred to the study through their cancer treatment facilities. Study investigators worked with staff in the clinical research offices of the cancer centers and hospitals, the survivor clinics, and individual clinicians to identify eligible patients. Potential participants were mailed a letter from the principal investigator (S.V.H.) that introduced and explained the study and contained information about their rights under the Health Insurance Portability and Accountability Act of 1996 and two informed consent forms with a return envelope. Follow-up telephone calls were initiated approximately 3 to 5 days after mailings were sent to gauge study interest. Those interested in participating were asked to return one signed copy of the documentation and were scheduled for interviews. Participants received a \$35 American Express gift card for completing the interview.

Interviews ranged from 30 to 90 minutes and were conducted by 2 coauthors with extensive qualitative interviewing experience (J.H. and J.L.). A semistructured interview script was developed using the Cognitive-Social Health Information Processing (C-SHIP) model<sup>29-31</sup> as the conceptual framework (see the Supplemental Appendix at <http://annfam.med.org/content/10/5/418/suppl/DC1> for in-depth



interview questions). C-SHIP comprises 2 key cognitive constructs (cancer-relevant goals and values that are culturally linked, and cancer-relevant thoughts and beliefs about disease management and health outcomes that affect patient expectations), and 1 key self-regulatory component (cancer-relevant self-management competencies and skills for planning, decision making, and generating and maintaining goal-oriented health behaviors), as well as an emotional component (cancer-relevant affects and feelings). Interview questions were developed to elicit information regarding cancer follow-up care for each of these domains.

The interview elicited information about the transitions of survivors from active cancer treatment, focusing on their understanding of who was providing their follow-up care and their satisfaction with the quality of the follow-up care they had received. The interview did not probe explicitly about comorbid conditions, although patients were asked to give self-ratings of health. Interviews were digitally recorded and transcribed verbatim. Interview transcripts and interviewer field notes served as the data source for this analysis.

### Coding and Analysis

Our qualitative analysis used an immersion/crystallization approach.<sup>32</sup> This approach consisted of an iterative process that included cycles of reading, summarizing, and rereading the data.<sup>32-34</sup> Sections of text were reviewed by 2 sociologists and 1 health psychologist (S.V.H., J.H., and J.L.), who separately and independently read through the data and applied codes to segments of the transcripts. The analysis team met weekly to discuss data analysis, interpretation, and coding while interviews were ongoing, thus facilitating our ability to achieve data saturation for key C-SHIP constructs explored in the study. Differences in interpretation of the data were resolved through discussion. For coded text where there was discrepancy between coders, determination of final code assignment was achieved through discussion and group consensus; we therefore achieved 100% agreement in terms of interrater reliability for coded text segments. We used ATLAS.ti<sup>35</sup> software to facilitate our qualitative analyses and SPSS 18 for Windows (SPSS Inc) to complete the descriptive analyses.

## RESULTS

Sixty-two patients were invited to participate in the study; 24 breast cancer and 18 prostate cancer survivors completed interviews for a participation rate of 67% (Table 1). Individuals who chose not to participate were comparable to respondents in terms of race and age, although men were significantly more likely to refuse participation than women (70% vs 30%,  $P = .05$ ).

The median age of participants was 64.5 years, and 76% were women. Self-reported race and ethnicity were 69% white, 26% black, 2% Asian, and 2% Latino. Blacks were overrepresented in the sample and more likely to come from the community hospitals ( $\chi^2 = 8.948$ ,  $P = .030$ ). Approximately three-quarters (78%) were married. Ninety percent reported that they were currently under the care of a primary care physician. All participants reported having received cancer follow-up care within the past year from a cancer specialist (ie, medical oncologist, surgical oncologist, radiation oncologist, 76%), cancer-related specialist (urologist, 36%) and/or a primary care physician (family physician, general internist, or gynecologist, 19%). Some participants reported seeking care from multiple physicians.

Most participants (52%) indicated that cancer survivors should see a cancer specialist rather than a primary care physician for extended follow-up cancer care (Table 2). The one-third (38%) who described a potential role for primary care physicians in providing follow-up cancer care were more likely to report having a college education (67%) compared with those who did not (27%,  $P = .021$ ). There were no differences between participants in terms of age, race, household income, number of years since treatment, treatment location, or self-reported health. Participants who described primary care roles often qualified their support saying, "If he's informed, I don't see why not... if you're comfortable with your primary care" (participant survivor [PS] 7), and "My primary care physician probably could do it. I just felt more comfortable going to an expert" (PS 2). Most described shared care between the oncologist and primary care physician as the only context in which a primary care physician should provide follow-up care. One survivor noted, "I would love to see a survivor plan be part of the treatment plan... then it could actually be part of my primary care physician's folder...and everybody would be on the same page" (PS 14).

When describing their preferences for cancer specialists in managing their follow-up care, participants focused concretely on aspects that they liked or did not like about their follow-up care, while defining what they believed was—or was not—part of their follow-up care. Their narratives were most readily coded around the C-SHIP cognitive constructs of values and goals and patient expectations and beliefs about care that acted as barriers and self-regulatory, action-oriented facilitators of primary care engagement. Several themes emerged regarding barriers, including (1) a need for specialized, expert care; (2) an expectation for care continuity; and (3) the belief that primary care physicians are not engaged in cancer care. Themes relating to their beliefs

**Table 1. Demographic Characteristics of Participating Survivors (N = 42)**

Characteristic	Cancer Centers (n = 23)		Community Hospitals (n = 19)		Total (N = 42)	
	Mean No.	% or Range	Mean No.	% or Range	Mean No.	% or Range
Race/ethnicity <sup>a</sup>						
White	19	83	10	53	29	69
Black	2	9	9	47	11	26
Asian	1	4	–	–	1	2
Latino	1	4	–	–	1	2
Age, y	64.5	47-80	64.5	49-77	64.5	47-80
<65	11	48	10	53	21	50
≥65	12	52	9	47	21	50
Education <sup>b</sup>						
Less than high school	1	4	1	5	2	5
High school, some college	11	48	11	58	22	52
College or more	11	48	6	32	17	41
Marital status (married or cohabiting)	18	78	13	79	33	78
Currently employed (yes)	13	57	8	42	21	50
Household income <sup>b</sup>						
<\$20,000	1	4	3	16	4	10
\$20,000-\$59,000	6	26	7	37	13	31
\$60,000-\$99,000	6	26	4	21	10	24
≥\$100,000	7	30	5	26	12	29
Cancer type						
Breast	13	57	11	58	24	57
Prostate	10	43	8	42	18	43
Years from active treatment						
2-5	8	35	6	32	14	33
6-9	7	30	8	42	15	36
≥10	8	35	5	26	13	31
Self-rating of health						
Excellent or very good	12	42	9	41	20	48
Good	10	44	5	26	15	36
Fair or poor	1	4	6	31	7	17

<sup>a</sup>  $\chi^2 = 8.948$ ,  $df = 3$ ,  $P = .030$ .

<sup>b</sup> Because of nonresponse, percentages do not add to 100%.

**Table 2. Participating Cancer Survivors' Perceptions of Which Physician Should Monitor Follow-up**

Theme <sup>a</sup>	Illustrative Quotes
Cancer specialist only n = 22, 52%	<p>"If there's anything, considering anything, in reference to cancer treatment, I would see my oncologist for it. [I] just because that's their specialty...I'd rather see the oncologist, someone that is familiar, who does it every day. I just wouldn't think that a primary or my gynecologist would know, be as knowledgeable" (PS 36).</p> <p>"You gotta have an oncologist. I would advise anyone not to go to a family doctor or a general practitioner, you gotta be an oncologist. You know, I'm a firm believer. My head hurts, I'm going to the head doctor. My foot hurts, I'm going to the foot doctor" (PS 34).</p>
Shared care: cancer or cancer-related specialist and primary care physician n = 16, 38%	<p>"I mean, as far as being a liaison between me and that oncologist or me and the surgeon, that's what my primary care is for, in my opinion. That's how I used him, to be my go-between. To explain the things in the files that I didn't understand" (PS 7).</p> <p>"Um, maybe ob-gyn [could be involved in follow-up]... When I go there yearly for the clinical exam, they'll usually question about the breast cancer and stuff like that" (PS 12).</p> <p>"I think all of them [primary care physician, urologist and oncologist] should be concerned with the [follow-up] care. [Knowing my] history is OK..., too. But they should be involved together because...primary care knows more about...me other than the cancer" (PS 13).</p>
Does not matter n = 1, 2%	<p>"I don't think that makes a difference really.... [S]omebody would have to be trained specifically in an ancillary part of the adjustment process, you know. It would have to be—to be of any value, it would have to be specific to that, and I'm not sure that's even possible" (PS 4).</p>

PS = participating survivor.

<sup>a</sup> Because of nonresponse (n = 3, 7%), percentages do not add to 100%.

about care that facilitated primary care engagement in follow-up included (1) initiating routine tests, (2) providing supplemental care to cancer specialists, and (3) serving as the follow-up care physician when survivors no longer need specialized care (Tables 3 and 4).

### Barriers to Survivorship Follow-up Care With a Primary Care Physician

#### Values and Goals: Need for Specialized, Expert Care

The study participants talked about needing expert care for their follow-up care. Most (79%) believed that cancer follow-up care requires a specialist's knowledge of cancer that primary care physicians do not possess, saying, "as far as a family doctor goes, cold-wise or 'this, that and the other thing,' he's fine; but not as far

as a specialty" (PS 41). They described primary care physicians as generalists responsible for care of vague or minor health concerns. Most participants reported having a primary care physician who they saw for routine or acute problems. They also described actively bypassing their primary care physician when seeking cancer follow-up care, saying, "my primary's a good primary...not a person I would take a serious problem to" (PS 23).

#### Expectation of Care Continuity: Primary Care Physicians Lack Familiarity and Personal History With Cancer Care

Participants described familiarity, continuity, and history as additional barriers to seeing their primary care

**Table 3. Participating Cancer Survivors' Perceived Barriers to Primary Care Physicians Providing Follow-up Care**

Theme	Subthemes	Illustrative Quotes
Values and goals: primary care physicians are not experts in cancer follow-up care n = 33, 79%	Primary care physicians are not knowledgeable about cancer or follow-up care	"They do not have the training to deal with it. The experience, the training, the know-how. Just, I just don't think it's acceptable. Even if you live out in a rural area where there's no oncologist available, I would think that you would make sure that wherever you had your treatment, you go back there once or twice a year" (PS 21).  "I think [survivors] should be seeing doctors that are oncologists.... Because that's what they deal with all the time. A general surgeon, a general practitioner, might be staring at it right in the face and for whatever reason not realize what it is, especially if it's an early-stage onset...." (PS 4).
	Survivors want "the best" specialty care they can get	"I love my family doctor. But he is...he's a...board certified internist, I guess is the correct term; and he's a great doctor.... I'm not a...I don't know how to quite phrase this, if I owned a Ferrari I wouldn't take it to the local mechanic to have fixed" (PS 26).  "I want to go to the best. I'm not saying [my primary care physician] wasn't good. But I'm going to go to the best" (PS 70).
Expectation of care continuity with doctors n = 24, 57%	Original treatment team knows patient's history	"Dr. X knows what he did—the surgery. He kind of shared with me that he did something...a little different with me than he normally does to preserve as much of the urethra as possible. So, you know, because he knows what he did, I would prefer having him for follow-up for the prostate cancer" (PS 2).  "To me, what happened to me was ideal. I had the same...I had the same doctor...you know, basically confirmed the diagnosis, recommended treatment, carried out the treatment.... So, ideally if you can deal with one physician all the way through the process, you form a bond" (PS 26).
	Survivors form personal bonds with their original oncologists	"Yeah, sure I connected with [my oncologist] pretty well because we are about the same age, and she has kids in the same school system where my son is. So it was nice, and she was a working mom, and I'm a working mom, so she definitely connected, or made an effort definitely to connect with me on that level" (PS 5)  "At one point about a year ago, I thought I was at the once-every-6-months stage, and she said, 'Do you mind if we still keep it at 4 months? Because I'll miss you if you don't come as often.' And I just hugged her because it really made me feel that, 'Yep, you're not a number. You really do mean something'" (PS 3).
Beliefs about care: primary care physicians are not engaged in cancer care n = 19, 43%	Primary care physicians ignore cancer-related issues or relegate questions to oncologists	"I feel I always have to tell the primary that I'm a breast cancer patient. Just to put into context, you know, in case I have to consider other things that could be the reason for what my symptoms are. But they don't ever invoke that. It's always me bringing that forward" (PS 31).  "[M]y primary care physician just asks me how I'm doing, but I guess he's assuming that I'm just, you know, visiting these other doctors. I don't think his specialty is in [cancer follow-up]" (PS 15).  "I don't think your primary's really ever good for your cancer follow-up, because my primary doesn't do breast exams. Um, he leaves it up to my oncologist. So basically, any oncology issues that I think are oncology, I would call my oncologist, not my primary" (PS 37).
	Survivors are torn about when to use primary care physician or oncologist	"I recall having an incident where I had like a lump...between my throat and my shoulder blade.... I went to the oncologist, and they felt that I should have gone to my primary for that. But I think when I feel a lump, my first reaction is, could that be cancer?" (PS 38).  "[T]his sarcoma started on the outside of the other breast. Which nobody had a clue about.... I did see my primary for that, and she didn't know what it was. She didn't have a clue, and she really did not help me with that. When I look back, I really feel like she should have said, 'You need to see your oncologist.' She didn't, and I didn't, right away, until it got worse. And it got worse, and I knew something was really, really wrong, and then I went to [cancer center]" (PS 23).

PS = participating survivor.

**Table 4. Preferences for Primary Care Physician–Led Follow-up Cancer Care**

Theme	Subtheme	Illustrative Quotes
Order routine tests for cancer follow-up n = 26, 62%	Keeping track of screenings	"Primary doctor—she keeps an eye, also, on my PSA. And if—and I always ask her how's the PSA. And tells me it's fine, and she gives me the readings. And I'm sure if it elevates in any way, she would tell me so" (PS 18). "[My primary care physician is involved in cancer follow-up] As far as paperwork. In other words, I request certain papers sent to him, or certain examinations be sent to him" (PS 17).
	Screening for late-term effects of treatment	"[My primary care physician] does do something for cancer follow-up. He does those EKG's...because I had the radiation or the chemo.... Well, the last time that I was there he sent me for a stress test because I had the chemotherapy and the radiation. He told me that. Because it's going to affect my heart.... He does it about twice a year" (PS 6). "I was having a lot of backache, and being that I had the cancer background, [my primary care physician] sent me for an MRI and everything. And they usually make sure I have my bone density scan and stuff like that" (PS 51).
	Primary care physicians could be a part of follow-up team	"So, it's almost like you need a primary with this survivorship plan in hand that's been viewed and had input from all of your other doctors. Here's the roadmap, and the primary care is going to help guide you along that line" (PS 14). "I mean, I kind of space them out so that I'm seeing a doctor every 6 months.... I see my primary care doctor for my physical and then I'm off 6 months for the [cancer center].... So that way I feel like I'm being watchful, at a 6-month time frame. Then I go see the gynecologist like 3 months later" (PS 5).
Provide secondary or supplemental care n = 16, 38%	Primary care physicians are first-stop doctors or gatekeepers	"My primary care...gets my blood work. Now, if something's wrong with my blood work, then I would go to a specialist" (PS 10). "If there's a concern...if it's out of the norm, I go see my primary care physician right away. She is quite diligent so I trust her. ...[I]f something were to come up, [my urologic surgeon] would still be there hopefully or somebody in his place that you know I can go to and the records would still be available" (PS 2). "You know, as far as [my obstetrician-gynecologist] examining me [for follow-up care], because examining the breast is part of what he does, I mean it's possible that he could detect something between my visits [to the oncologist]. And, uhh, you know, in that case [it is fine, but] just to go to him for the [follow-up] treatment of the cancer, no" (PS 9).
	During an extended survivorship period	"Well, basically, at the point I'm at now, [transitioning to a primary care physician] would probably be fine. Because I'm more comfortable with it now and I kind of have a feeling that...this is gonna be 5 years in November and after that period of time, your other doctor is quite familiar with it" (PS 19). "After I had talked to the surgeon, and they told me like, uh, there was really nothing they could do for me, that the rest was up to myself, you know, I felt like, hey, if they...if I'm in that state, and I have no PSA level that's showable, then I could ask to go to my family doctor and let him just keep a check on the PSA levels" (PS 16).
	When reintegrated into noncancer population	"Once I'm not taking any medications [laughter] I don't think I need to go to see someone specifically, so I don't know whether at that point it would even be considered follow-up care..." (PS 1). "Well, as Dr Z. [urologic surgeon] explained, [I need follow-up for] 20 years...I might, uh, when I get my physical every year, include a PSA, and when [my primary care physician] gets the information, rather than go away to [cancer center], you know, if he gets the results, and if he's satisfied or if he's not satisfied, I'll call, then I'll get in touch with Dr Z. again" (PS 34).

EKG = electrocardiogram; MRA = magnetic resonance imaging; PS = participating survivor; PSA = prostate-specific antigen.

physicians for follow-up care. Participants strongly preferred to remain in the care of the same doctors and treatment teams who oversaw their active treatment. One noted, "I would want to see the person who did the cancer surgery. That would be the person I'd want to see" (PS 8). For many, their primary care physicians were not engaged in that process. A breast cancer survivor commented that working with an "unfamiliar" doctor would add more stress to her life: "I've dealt with people who...haven't read your file. They don't know nothing about it and then they just start assuming" (PS 7). Participants also cited their personal relationships with their cancer doctors as important in continuing follow-up care. "[My oncologist] knew my family. She knew everything, always asked me how my kids were doing" (PS 51).

**Beliefs About Care: Primary Care Physicians Are Not Engaged in Cancer Care**

Participants (43%) perceived primary care physicians as not engaged in cancer care. Several described their physicians as not being attuned to the needs of cancer survivors. In particular, they were concerned that primary care physicians do not consider a patient's status as a cancer survivor in their diagnostic or treatment decisions. Participants were also concerned that primary care physicians do not monitor cancer "on a day-in and day-out basis" (PS 70). Participants described their primary care physicians as "ignoring" cancer-related issues because either they presume the patient is under oncologic care or they defer and refer cancer-related questions back to oncologists. "[My primary care physician] knew for quite a while there that I

was seeing 2 other doctors or 1 other doctor at least... so she pretty much ignored all cancer issues" (PS 23). Although most participants did not report seeing their primary care physician for their cancer-related issues, a few mentioned being conflicted about when to call their primary care physician or their cancer or cancer-related specialist, saying, "I didn't know that...we don't call our oncologist. We have to call our family doctor for our aches and pains, or whatever" (PS 22).

### Self-Regulatory Action-Oriented Strategies: Patients' Preferences for Primary Care Physicians' Engagement in Follow-up Care

#### Ordering Routine Tests for Screening

Although many participants preferred specialist care and did not perceive primary care to be appropriate for follow-up care, they paradoxically described contexts in which they believed primary care physicians could and did participate in their follow-up care (Table 4). Participants (62%) talked about situations in which their primary care physicians did perform cancer monitoring (eg, ordering or monitoring mammograms or prostate-specific antigen testing): "[My primary care physician] knows that I had cancer and, at times, we've coordinated these blood tests. So I go, you know, once for a blood test so they can do the PSA [prostate-specific antigen test]... I think it goes to both of them" (PS 9). Survivors commonly acknowledged that their primary care physicians received copies of their test results, asked how their cancer follow-up was going, or kept a record of screenings. "I do have a family doctor that I see...he always asks [about my cancer] and he's also in the loop as far as getting reports" (PS 3). Many survivors said that their primary care physicians prescribe medications or perform tests related to the effects of their cancer care, such as stress tests, electrocardiograms, and tests for lung capacity and bone density, or they conducted blood work.

Participants generally believed that primary care physicians could and should continue to perform these screening and monitoring functions. Yet, it was clear in their discussions that many did not perceive this type of monitoring as part of their follow-up care. For example, one prostate cancer survivor said at the beginning of the interview that his primary care physician did not do anything involving cancer follow-up care but later in the interview volunteered that "we [my primary care physician and I] always do the PSA" (PS 8). Similarly, a breast cancer survivor said, "[I see my] obstetrician-gynecologist annually, but I don't really consider it for cancer follow-up care" (PS 14).

#### Providing Supplemental Care

Although most study participants wanted to see a cancer specialist for their own cancer follow-up, almost

one-third (38%) said that primary care clinicians could be involved in follow-up for supplemental health care. "I'm getting breast exams because my general practitioner gives me a breast exam. At the [cancer center], the nurse practitioner gives me a breast exam. So, I'm OK with that" (PS 10). These survivors actively engaged their primary care physicians in their follow-up care so that they would have an additional safeguard. Some staggered appointments so that their primary care clinicians might catch something in between specialist visits or made a point to have test results sent to their primary care physicians. Yet, others said primary care physicians could be useful as a first-stop doctor—a "beginning diagnostician" to refer a patient to the proper specialist: "I think that they can be the beginning diagnostician... [T]hey called me back in, they did an exam of that breast to see if they could feel what the initial mammogram found... and then it went to, 'You need to see the surgeon'" (PS 3). One breast cancer survivor remarked, "I think that if there was anything out of the ordinary in my blood work or breast exam, I know [my primary care physician] would just, I would just be referred back" (PS 5).

#### When Enough Time Has Passed

Some participants (21%) described a point in the distant future when their primary care physicians could function as their primary follow-up care doctor. For most, this time was defined as after the first 5 years of follow-up or after any medications had been completed. For example, one survivor said, "I would guess after a certain period of time, I would think that would be all right. But I would think in the first couple of years, you'd probably want to stay with a specialist" (PS 15). Others commented that survivors could see their primary care physicians for follow-up when reintegrated into the noncancer population. For example, a prostate cancer survivor said, "Actually that would be a sign that things were normal, so to speak, or that this really was in remission. So as soon as that's feasible, that would be very nice" (PS 9).

## DISCUSSION

The cancer survivorship literature highlights a need to improve patient-centered communication and care coordination for long-term cancer survivors.<sup>3,36-38</sup> Most studies of cancer survivors' follow-up care use quantitative methods and large cohorts to assess survivor attitudes and health behaviors.<sup>21,24,26,27,38-40</sup> There are very few studies that focus on understanding the perspectives of survivors of adult cancers or that use interview methods to gain perspective on what informs their expressed preferences.<sup>28,41</sup> Our study is the first to

explore, in-depth in a US context, patient preferences regarding the role of primary care physicians in their extended cancer follow-up care for survivors of adult cancers. By using a patient-centered and qualitative approach, this study provides data to better inform our understandings of factors that guide patient preferences and ultimately affect engagement of primary care in extended cancer follow-up care. Thus, it provides a rich addition to the existing survey research that describes barriers and facilitators of primary care physicians' engagement in cancer follow-up care.

Participants in this study, similar to participants in survey studies,<sup>21,26,27,39</sup> reported strong preferences to receive initial follow-up from either cancer or cancer-related specialists. Additionally, they described limited cancer expertise, limited involvement with original cancer care, and lack of care continuity as barriers to primary care engagement in follow-up. These findings from survivors of adult cancers mirror results from earlier studies of adult survivors of pediatric cancers. For example, Oeffinger et al reported that 87% of adult survivors of pediatric cancer have a primary care physician, yet only 34% reported ever seeing one for a problem they thought was related to their cancer.<sup>42</sup> Importantly, 31% did not feel a primary care physician could handle a problem related to the previously treated cancer.<sup>42</sup> These results also mirror those reported by Mao et al in a survey study, where approximately one-half of a sample of breast cancer patients reported concerns about the primary care physician's ability to deliver care for cancer-specific issues.<sup>26</sup>

Although previous work suggests that cancer specialists are well positioned to provide monitoring regarding late and long term-effects associated with cancer treatment,<sup>43-46</sup> it is becoming increasingly clear that cancer survivors decline to see their oncology specialists regularly for survivor care well beyond the end of their initial cancer treatment.<sup>5,40,42</sup> Though most patients in the current study continued to see their cancer specialists, their experiences are not the norm, as documented by Pollack et al,<sup>19</sup> who found that only one-third of long-term cancer survivors continue to seek care from physicians whose specialties are related to their original cancer after 5 years of survival.

Findings from our study highlight a need to further explore when patient perceptions of cancer follow-up care converge and diverge from that recommended by the IOM. It also points to a need for interventions focused on decreasing the knowledge divide. Much of the existing research focuses either on limitations of primary care<sup>39,47</sup> or how the roles primary care physicians in cancer follow-up can be enhanced through additional training or better communication with their oncology colleagues.<sup>26</sup> Data from the current study and

the existing literature underscore an additional need for specialists to educate and discharge their patients with a better understanding of what cancer follow-up care is, its lifelong duration, and the potential for varying degrees of monitoring, as well as the role of the primary care physician. Many of our participants were unaware that cancer follow-up care extends beyond surveillance for recurrence. This knowledge gap is important and needs to be addressed. Such preparation will help survivors and their primary care physicians meaningfully engage in their follow-up care. In addition, research suggests that patients are interested in having their primary care physicians be familiar with issues relevant to cancer survivorship,<sup>26-28</sup> particularly in light of the current study findings that participants, especially those with higher levels of education, see some value in having primary care physicians engaged in their follow-up care.

This study has several limitations. First, our qualitative methods limit our ability to draw broad conclusions from the data. Second, specialty penetration in the northeast may have affected the views of our participants. Other studies of this type are necessary to determine whether the views of our participants are representative of a broader trend in patient attitudes in the United States. Finally, the study recruitment strategies are important to note. To maximize variation in follow-up care-seeking patterns, we chose to recruit patients through their treating oncologists rather than through their current follow-up care clinician. In addition, we focused on a patient population that did not have complex comorbid conditions. Both strategies may have yielded a sample of cancer survivors who have less regular contact with or lack long-term relationships with their primary care physicians.

Despite the limitations, our strategy of recruiting a purposive sample of patients who were treated in academic centers and community hospital settings facilitates a better understanding of the desires and needs of patients after completing cancer treatment. This study is one of the first to include the perspectives of patients treated in either community oncology offices or NCI-designated cancer center settings, thus adding breadth to voices that are reported in the existing literature.

Findings from this study support the need for primary care to engage meaningfully in the case management of our growing population of adult cancer survivors. This study highlights the need for future research and interventions to address both patient and patient-perceived physician knowledge gaps related to cancer follow-up care. For example, multilevel intervention approaches that focus on patient outcomes but that also address patient and physician-level knowledge

gaps may be warranted. Additionally, models of care and patient-centered, self-management studies may be needed to understand and enhance current care delivery. Such studies will be crucial to enhance the quality of care received by cancer survivors.

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**Key words:** cancer screening; cancer survivors; primary health care; qualitative research; patient-centered care; continuity of patient care; breast neoplasms; prostate neoplasms

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## References

- Jemal A, Siegel R, Xu J, Ward E. Cancer statistics, 2010. *CA Cancer J Clin*. 2010;60(5):277-300.
- Hewitt ME, Ganz PA, Institute of Medicine. American Society of Clinical Oncology. *From Cancer Patient to Cancer Survivor: Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium*. Washington, DC: National Academies Press; 2006.
- Hudson SV, Chubak J, Coups EJ, et al. Identifying key questions to advance research and practice in cancer survivorship follow-up care: a report from the ASPO Survivorship Interest Group. *Cancer Epidemiol Biomarkers Prev*. 2009;18(7):2152-2154.
- Miller SM, American Psychological Association. *Handbook of Cancer Control and Behavioral Science: A Resource For Researchers, Practitioners, and Policy Makers*. 1st ed. Washington, DC: American Psychological Association; 2009.
- Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol*. 2006;24(32):5117-5124.
- Doubeni CA, Field TS, Ulcickas Yood M, et al. Patterns and predictors of mammography utilization among breast cancer survivors. *Cancer*. 2006;106(11):2482-2488.
- Earle CC, Neville BA. Under use of necessary care among cancer survivors. *Cancer*. 2004;101(8):1712-1719.
- Grunfeld E. Cancer survivorship: a challenge for primary care physicians. *Br J Gen Pract*. 2005;55(519):741-742.
- Hudson SV, Hahn KA, Ohman-Strickland P, Cunningham RS, Miller SM, Crabtree BF. Breast, colorectal and prostate cancer screening for cancer survivors and non-cancer patients in community practices. *J Gen Intern Med*. 2009;24(Suppl 2):S487-S490.
- Grunfeld E, Fitzpatrick R, Mant D, et al. Comparison of breast cancer patient satisfaction with follow-up in primary care versus specialist care: results from a randomized controlled trial. *Br J Gen Pract*. 1999;49(446):705-710.
- Grunfeld E, Gray A, Mant D, et al. Follow-up of breast cancer in primary care vs specialist care: results of an economic evaluation. *Br J Cancer*. 1999;79(7-8):1227-1233.
- Grunfeld E, Levine MN, Julian JA, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *J Clin Oncol*. 2006;24(6):848-855.
- Grunfeld E, Mant D, Vessey MP, Yudkin P. Evaluating primary care follow-up of breast cancer: methods and preliminary results of three studies. *Ann Oncol*. 1995;6(Suppl 2):47-52.
- Ogle KS, Swanson GM, Woods N, Azzouz F. Cancer and comorbidity: redefining chronic diseases. *Cancer*. 2000;88(3):653-663.
- Sunga AY, Eberl MM, Oeffinger KC, Hudson MM, Mahoney MC. Care of cancer survivors. *Am Fam Physician*. 2005;71(4):699-706.
- Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists: challenges to assuring access to oncology services. *J Oncol Pract*. 2007;3(2):79-86.
- President's Cancer Panel. *Living Beyond Cancer: Finding a New Balance*. Bethesda, MD: National Cancer Institute, National Institutes of Health, Department of Health and Human Services; 2004.
- Keating NL, Landrum MB, Guadagnoli E, Winer EP, Ayanian JZ. Surveillance testing among survivors of early-stage breast cancer. *J Clin Oncol*. 2007;25(9):1074-1081.
- Pollack LA, Adamache W, Ryerson AB, Ehemann CR, Richardson LC. Care of long-term cancer survivors: physicians seen by Medicare enrollees surviving longer than 5 years. *Cancer*. 2009;115(22):5284-5295.
- Bober SL, Recklitis CJ, Campbell EG, et al. Caring for cancer survivors: a survey of primary care physicians. *Cancer*. 2009;115(18)(Suppl):4409-4418.
- Cheung WY, Neville BA, Cameron DB, Cook EF, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. *J Clin Oncol*. 2009;27(15):2489-2495.
- Del Giudice ME, Grunfeld E, Harvey BJ, Piliotis E, Verma S. Primary care physicians' views of routine follow-up care of cancer survivors. *J Clin Oncol*. 2009;27(20):3338-3345.
- Greenfield DM, Absolom K, Eiser C, et al. Follow-up care for cancer survivors: the views of clinicians. *Br J Cancer*. 2009;101(4):568-574.
- Lewis RA, Neal RD, Hendry M, et al. Patients' and healthcare professionals' views of cancer follow-up: systematic review. *Br J Gen Pract*. 2009;59(564):e248-e259.
- Nekhlyudov L. "Doc, should I see you or my oncologist?": a primary care perspective on opportunities and challenges in providing comprehensive care for cancer survivors. *J Clin Oncol*. 2009;27(15):2424-2426.
- Mao JJ, Bowman MA, Stricker CT, et al. Delivery of survivorship care by primary care physicians: the perspective of breast cancer patients. *J Clin Oncol*. 2009;27(6):933-938.
- Aubin M, Vézina L, Verreault R, et al. Family physician involvement in cancer care follow-up: the experience of a cohort of patients with lung cancer. *Ann Fam Med*. 2010;8(6):526-532.
- Hewitt ME, Bamundo A, Day R, Harvey C. Perspectives on post-treatment cancer care: qualitative research with survivors, nurses, and physicians. *J Clin Oncol*. 2007;25(16):2270-2273.
- Diefenbach MA, Miller SM, Daly MB. Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. *Health Psychol*. 1999;18(5):532-536.
- Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer*. 1995;76(2):167-177.
- Miller SM, Diefenbach M. CSHIP: A cognitive-social health information processing approach to cancer. In: Krantz D, ed. *Perspectives in Behavioral Medicine*. Mahwah, NJ: Lawrence Erlbaum; 1998.

32. Crabtree BF, Miller WL. *Doing Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1999.
33. Denzin NK, Lincoln YS. *Handbook of Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 2000.
34. Miles MB, Huberman AM. *Qualitative Data Analysis : An Expanded Sourcebook*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1994.
35. ATLAS.ti [computer program]. Version 5.2.4. Berlin: Scientific Software Development; 2006.
36. Grunfeld E. Optimizing follow-up after breast cancer treatment. *Curr Opin Obstet Gynecol*. 2009;21(1):92-96.
37. Grunfeld E, Earle CC. The interface between primary and oncology specialty care: treatment through survivorship. *J Natl Cancer Inst Monogr*. 2010;2010(40):25-30.
38. Arora NK, Reeve BB, Hays RD, Clauser SB, Oakley-Girvan I. Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. *J Clin Oncol*. 2011;29(10):1280-1289.
39. Kantsiper M, McDonald EL, Geller G, Shockney L, Snyder C, Wolff AC. Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers. *J Gen Intern Med*. 2009;24(Suppl 2):S459-S466.
40. Snyder CF, Frick KD, Herbert RJ, et al. Preventive care in prostate cancer patients: following diagnosis and for five-year survivors. *J Cancer Surviv*. 2011;5(3):283-291.
41. Brennan ME, Butow P, Marven M, Spillane AJ, Boyle FM. Survivorship care after breast cancer treatment—experiences and preferences of Australian women. *Breast*. 2011;20(3):271-277.
42. Oeffinger KC, Wallace WH. Barriers to follow-up care of survivors in the United States and the United Kingdom. *Pediatr Blood Cancer*. 2006;46(2):135-142.
43. Aziz NM, Oeffinger KC, Brooks S, Turoff AJ. Comprehensive long-term follow-up programs for pediatric cancer survivors. *Cancer*. 2006;107(4):841-848.
44. Bellizzi KM, Rowland JH, Jeffery DD, McNeel T. Health behaviors of cancer survivors: examining opportunities for cancer control intervention. *J Clin Oncol*. 2005;23(34):8884-8893.
45. Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol*. 2003;13(3):248-266.
46. Demark-Wahnefried W, Aziz NM, Rowland JH, Pinto BM. Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. *J Clin Oncol*. 2005;23(24):5814-5830.
47. Potosky AL, Han PK, Rowland J, et al. Differences between primary care physicians' and oncologists' knowledge, attitudes and practices regarding the care of cancer survivors. *J Gen Intern Med*. 2011;26(12):1403-1410.