



Identifying patients' priorities for quality survivorship: conceptualizing a patient-centered approach to survivorship care

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Abstract

Purpose This study explored cancer survivors' experiences with and priorities for cancer survivorship care to describe a patient-centered approach to quality survivorship care.

Methods We conducted 22 focus groups with 170 adult survivors of breast, prostate, and colorectal cancer from six cities across the country and online. We used thematic analysis to identify participants' principles and priorities for quality survivorship care.

Results Based on our analysis of a limited group of cancer survivors, we identified two core principles that underlie participants' expectations for survivorship care and 11 practice priorities that reflect opportunities to improve patient-centeredness at the individual, interpersonal, and organizational levels. The principles reflect participants' desire to be better prepared for and equipped to accept and manage their chronic care needs post-cancer treatment. The priorities reflect practices that patients, providers, and cancer centers can engage in to ensure survivors' goals for post-treatment care are met.

Conclusions Results from the study suggest the need to expand conceptualization of high-quality survivorship care. The survivor principles and practice priorities identified in this study challenge the field to organize a more patient-centered survivorship care system that empowers and respects patients and provides a holistic approach to survivors' chronic and long-term needs.

Implications for Cancer Survivors Quality cancer survivorship care must reflect patients' priorities. The findings from this study can be used to develop a patient-centered framework for survivorship care that can be used in conjunction with quality guidelines to ensure survivorship care is organized to achieve both clinical and patient-centered outcomes.

Keywords Patient-centered · Cancer survivorship care · Survivors principles and priorities · Quality

Introduction

With nearly 17 million cancer survivors¹ in the United States and projected growth to 22.1 million by 2030, survivorship has become an important and distinct phase of the cancer trajectory, necessitating the need for quality health care beyond the completion of active treatment (i.e., surgery, radiation, chemotherapy, and/or hormone therapy) [1, 2]. Cancer survivors face unique challenges that require continued medical attention, such as late- and long-term effects of cancer and its treatment, psychosocial issues, risk of recurrence and

¹ A person is considered a cancer survivor from the time of diagnosis until the time of death [1]. However, because we are looking at the system of care provided to survivors post-treatment, we use the American Society of Clinical Oncology's "functional definition," which considers survivors to be those "individuals who have successfully completed curative treatment of those who have transitioned to maintenance of prophylactic therapy" [2].

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secondary cancers, and comorbidities, such as diabetes and obesity [3–5]. Moreover, many survivors do not understand what to expect from the health care system during survivorship or feel prepared to address and manage the myriad physical and psychosocial issues they often face [6–13]. The health care system as currently structured, however, often fails to meet the needs and concerns of this growing population [5]. Inefficiencies and fragmentation in care delivery mean that survivors may encounter problems obtaining optimal care when transitioning from active treatment to post-treatment care. These challenges can result in delayed detection of recurrence, health care over- or misutilization, poorly controlled comorbidities, and inferior quality of life [3–5].

Given the complex and highly individualized nature of cancer survivorship care, a more patient-centered approach to care delivery may be warranted to improve the survivorship experience and health outcomes. Patient-centered care, defined as care that prioritizes patients' values and needs, is fundamental to improving quality care and is associated with better health behaviors and health-related outcomes, such as better adherence to health promotion recommendations, increased efficacy in self-management, decreased suffering, and higher quality of life [14–16]. Patient-centered care also offers patients opportunities to engage in their own care, improving providers' understanding of what patients' value and increasing patients' willingness to adhere to recommendations and behavior modifications [17–19]. Models that embody these tenets of care have long been praised for their ability to advance clinical quality goals, particularly in chronically ill patients, by offering processes that better personalize care and increase the likelihood that, because important patients' needs are being met, clinical outcomes will improve [14, 20–24].

Expert consensus in survivorship care urgently calls for clearly defining high quality survivorship care and developing strategies to measure, standardize, and achieve it [5, 16]. The field varies, however, in how it conceptualizes quality [2, 25], and whether or how to incorporate patient-centered components in quality guidelines. Most existing quality standards rely on evidence-based clinical guidelines that outline recommendations for follow-up care, monitoring and surveillance, health promotion/risk prevention, management of health effects, coordination across providers, psychosocial assessments, and delivery of a survivorship care plan [5, 25, 26]. Few include comprehensive guidance on patient-centered practices that specifically address how cancer patients experience their care or how to personalize survivorship so that it meets patients' often unique needs.

The field of survivorship has quickly moved to improve the delivery of survivorship care by examining survivors' needs and preferences and integrating findings into organizational models of survivorship care. For example, a number of studies have identified the negative impact of fear, anxiety, and

depression on survivors' long-term outcomes and highlighted the importance of providing psychosocial support in survivorship programs [16, 22, 26–28]. Another area of research demonstrates that meeting survivors' information needs helps them adjust expectations of care, increase self-efficacy, and promote healthy behavior changes, all of which may improve clinical outcomes [22, 28–32]. Other studies have shown how provider-patient communication and shared care planning can lead to sustained behavior change [23], aid in survivors' recovery from discomfort, reduce the need for tests and referrals [20, 28, 33], and support a range of emotional health outcomes, including mitigating the negative impact of fear, anxiety, and depression on survivors' long-term outcomes [22, 26, 27, 32, 34]. A separate body of work addresses gaps in the survivorship care delivery system, finding that survivors need better access to comprehensive, coordinated, and integrated services [2, 3, 16], smoother transitions as they move from the treatment phase to the survivorship phase [35–38], and opportunities to weigh in on who their primary survivorship care provider should be [28, 39, 40]. While all these studies provide important recommendations to address survivors' care needs, implementation of solutions has been piecemeal and evidence of effectiveness is limited. As a result, the field has been slow to codify patients' needs and preferences in formal guidelines on quality survivorship care.

Recently, Nekhlyudov and colleagues developed a broad-based framework of quality survivorship care in an effort to standardize protocols for managing survivors across different cancer types [25]. Domains in the quality framework include prevention and surveillance for recurring and new cancers, surveillance and management of physical and psychosocial effects, surveillance and management of comorbid chronic conditions, and health promotion and disease prevention. The quality framework also acknowledges the importance of access to needed specialty care and other health care professionals, communication and decision making between clinicians and patients, and care coordination across providers. All of the elements presented in the framework are critical to providing high-quality survivorship care. However, the framework's emphasis on a clinical perspective of care without full consideration of patients' priorities for a more personalized care experience misses an important opportunity to strengthen survivorship care by driving acceptance of patient-centered practices through their inclusion in quality standards.

This study advances understanding of a patient-centered approach to quality survivorship care. Using a qualitative approach, we explore how survivors understand survivorship and what their expectations are for post-treatment care based on their own lived experiences and preferences. We identify practice priorities that represent survivors' most important needs and propose how these elements of care can strengthen existing quality standards and inform guidelines and best practices.

Methods

Study approach

This paper presents results from the formative phase of a larger comparative effectiveness research project (CER), Evaluating Cancer Survivorship Care Models, the primary purpose of which was to examine the impact of survivorship care across different types of programs using original, patient-centered measures. A full explanation of the methods has been described elsewhere [41]. In the research presented in this paper, we aim to identify survivors' expectations and priorities for care and offer suggestions for how a patient-centered survivorship approach can be used to improve quality standards. The George Washington University Institutional Review Board approved the study (#101308).

We conducted an applied, qualitative study to achieve our study aims [42]. A qualitative phase was considered critical to the goal of the overall CER as it allowed the research to maximize the survivor perspective in developing measures of patient-centered survivorship care [43]. We used focus groups to elicit a broad range of cancer survivors' insights into their health and well-being post-treatment, their experiences with the health care system during survivorship, and the needs and preferences that are most important to them. The group dynamic allowed participants to identify shared experiences as well as differences and to discuss their views and opinions about what they would like to see improved in the post-treatment cancer care system. The method proved particularly useful in creating a dialog, and thereby generating data, about common concerns and important priorities that represented survivors' desire for more patient-centered care.

Given the importance of patient-centeredness in the field of quality health care, we used the Institute of Medicine's (IOM) definition of quality from *Crossing the Quality Chasm* to guide our formative work, and focused on IOM's consumer perspective of quality, which highlights the importance of patients' perspectives in quality efforts [9]. IOM's consumer perspective of quality reflects consumers' needs and preferences in the following four main dimensions of care: (1) staying healthy, (2) getting better, (3) living with illness, and (4) changing needs. The focus groups probed survivors' experiences to identify gaps in and barriers to post-treatment care and probe their recommendations for a health care system that meets their needs in these four areas (see [Appendix I](#) for focus group guide). Moderators asked patients to discuss their biggest problems getting care now that treatment had ended and what services could be provided to help with those problems (dimensions 1 and 2). Moderators also asked participants to discuss what it is like to live with the ongoing issues related to cancer and its treatment and how the health care system could better support survivors and their

changing needs (dimensions 3 and 4). Finally, groups were asked to talk about what an ideal survivorship care program would look like.

Study sample and data collection

We conducted 22 focus groups with a total of 170 survivors of breast, prostate, and colorectal cancers (one- to five-years post-treatment). We targeted patients with these types of cancer due to the high likelihood of five-year survival [44]. The Cancer Support Community (CSC), a non-profit organization that provides support and education to cancer patients, helped to recruit survivors in the following 6 communities and online: Chicago, Illinois; San Francisco, California; Greenville, South Carolina; Bedminster, New Jersey; Washington, DC; and Bozeman, Montana. These cities were selected based on broad geographic representation across US regions; urban/rural mixture; and the presence of a CSC affiliate. We held three focus groups in each city, one group per cancer type, so that in each location we held one breast cancer group, one prostate cancer group, and one colorectal cancer group ($n = 160$ in person participants). We also held three virtual focus groups with colorectal cancer survivors ($n = 10$ online participants), who have a strong online support network. This recruitment approach helped bolster participant numbers for colorectal cancer survivors, which was lower than the other two cancer groups.

We used purposeful sampling to identify study participants with the following criteria: survivors of non-metastasized breast, colorectal, and prostate cancer; within one to five years of diagnosis; having completed active treatment (i.e., surgery, chemotherapy, and radiation); and being 18 years or older at the time of diagnosis. CSC affiliates recruited in-person focus group participants through flyers, social media (FaceBook and Twitter), and listservs. For the virtual colorectal cancer groups, CSC affiliates did a second recruitment push, posting a call for participation through FaceBook, Twitter, and listservs. In addition, the study team also partnered with the Colorectal Cancer Alliance, which agreed to post recruitment materials on their social media outlets and send out materials to their own online support network and chat rooms. For the virtual focus groups, we targeted a smaller number of participants to facilitate their ability to virtually engage in and discuss with each other topics of importance [45]. All virtual focus groups were synchronous using the BlueJeans video-conferencing platform, and all participants were able to use both audio and video capabilities, which enhanced their ability to interact with each other. Researchers used the same focus group guide to gather data and were able to pose questions, moderate discussion, observe body language, and follow interactions in much the same way as with in-person groups.

Data analysis

We conducted thematic data analysis to explore important issues in survivorship care raised in focus group discussions and to identify participants' top priorities for improving care. All focus groups were audio recorded, transcribed verbatim, and analyzed using QSR International NVivo 11 software. The lead researcher developed an iterative coding structure, starting with deductive parent codes derived from the focus group guide and adding inductive codes that emerged from the focus group data. A team of researchers met after each transcript was coded to discuss the coding approach and structure to increase intercoder reliability. We analyzed data in the aggregate, including all three types of cancers and all 7 locations (six cities and 1 virtual) because our study aim was to identify a set of priorities relevant to participants regardless of geographic location or type of cancer. Comparative analysis by cancer type was not within the scope of the research.

We used a three-step analytical approach to identify themes, determine and corroborate whether a theme is a priority, and reduce bias. Patient priorities were identified using the following strategies [46]: (1) We used cross-case coding queries to identify patterns of co-occurring codes in the data, which allowed the team to develop multidimensional, conceptual themes relevant to all 22 focus groups. We then looked at the prevalence of themes within each focus group and the recurrence of themes across all focus groups to determine the most common issues raised by participants. Prevalence was determined by the number of times a theme was discussed (based on coding frequency) within a group and recurrence was determined by how many groups discussed a theme. Frequency is presented in Table 2 in the aggregate across all 22 groups. (2) The team also examined the intensity of themes to determine the emphasis placed on a particular issue during discussions. As researchers coded transcripts, they wrote short memos when they determined a topic was being discussed with intensity, for example, if a topic dominated the conversation in a group and/or participants expressed emotion (e.g. anger, frustration, sadness, exuberance) while discussing the topic. Investigators who observed the focus groups were trained to note when emotions arose during the groups. These emotions were inserted into transcripts of the focus groups. (3) The team also used context coding to identify key issues that were described as a desire or priority by participants. A matrix coding query in NVivo allowed researchers to look for patterns where emerging themes were also coded as a priority.

The research team used well-documented systematic research processes common to qualitative research to improve the rigor, validity, and consistency of data collection and analysis [45]. Focus group moderators underwent extensive data collection and analysis training to standardize these processes and maintain reflexivity about how

their own values, beliefs, and assumptions could have biased their collection, analysis, or interpretation of study data. We also triangulated our analytical technique using three different strategies for identifying themes and priorities. In addition, multiple researchers coded sections of each transcript and discussed their application of the coding structure to improve inter-coder reliability. The team also held extensive discussions of the results to identify consistencies in interpretation, challenge assumptions and predispositions to certain interpretation, and reduce potential bias. Finally, we conducted respondent validation where we asked a group of survivors from the focus groups and the study's advisory board to review our findings and comment on whether our interpretation authentically reflects their experiences.

Results

Focus group participant characteristics

A total of 42% of those who participated in the focus groups had been diagnosed with breast cancer, 23% with colorectal cancer, and 38% with prostate cancer (data not shown).² More than half of the focus group participants (59%) were female, and the average age at diagnosis was 57. Participants were predominantly white (78%) with roughly 15% self-reporting as African-American and 7% self-reporting in another racial category (data not shown). A total of 3% self-identified as Latinx. Nearly all the participants (97%) were insured.

Participant demographics varied somewhat by state and cancer type (Table 1). Washington, DC, had the most diverse focus groups with 80% of participants self-reporting as black and 16% self-reporting as Latinx. The diversity was driven by the breast cancer group, which had 92% black participants and 27% Latinx participants. The Washington, DC, participants were also younger at diagnosis than the average with median age of 50, but less diverse in gender with 80% reporting female. This outcome was driven by the breast cancer and colorectal cancer groups, both of which had 100% female participants. Chicago also had more diverse participation than the average with 32% of participants reporting as black and 5% reporting as Latinx, due to more diversity in the breast (50% black and 10% Latinx) and colorectal cancer groups (33% black). The San Francisco colorectal cancer group had 10% of its participants reporting as Latinx. In New Jersey, we had a larger percentage of male participants than the average (68%), driven by a colorectal cancer group where 80% of participants were male. South Carolina groups had higher participation from women than the average, driven by a colorectal cancer group with 82% female participants.

² Totals add up to more than 100% because some survivors had been diagnosed with more than one cancer type.

Table 1 Focus group participant characteristics ($n = 170$)

Location and cancer type	Age at diagnosis (mean)	Gender (% female)	Race~ (% White)	Ethnicity (% Latinx)	Insurance status (% yes)
Chicago (total)	55	59	68	5	91
Breast, $n = 10$	51 ^a	100	50	10	100 ^a
Prostate, $n = 9$	60	0	89	0	89
Colorectal, $n = 3$	50	100	67	0	67
San Francisco (total)	61	55	82	3	100
Breast, $n = 11$	57 ^a	100	73	0	100
Prostate, $n = 10$	64	0	80	10	100
Colorectal, $n = 12$	61	58	100	0	100
Montana (total)	59	55	97	0	97
Breast, $n = 14$	54	100	100	0	100
Prostate, $n = 14$	62 ^a	0	93	0	93
Colorectal, $n = 5$	65	80	100	0	100
South Carolina (total)	57	68	93	0	100
Breast, $n = 10$	52 ^a	100	90	0	100 ^a
Prostate, $n = 7$	62	0	86	0	100 ^a
Colorectal, $n = 6$	58	83	100	0	100
New Jersey (total)	58	38	83	0	100
Breast, $n = 5$	56	100	100	0	100
Prostate, $n = 14$	60	0	71	0	100
Colorectal, $n = 5$	53	80	100	0	100
Washington, DC (total)	50	80	20	16	96
Breast, $n = 15$	49 ^a	100	6.7	27	87
Prostate, $n = 5$	57	0	20	0	100
Colorectal, $n = 5$	47	100	60	0	100
Virtual colorectal groups (total=10)	58	60	80	0	100
Total	57	59	78	3	97

^a Indicates data are missing for one participant. Calculations based on denominator-1

~ The total race calculation was based on $n = 165$ because 5 participants entered Latinx as their race. These participants were included in the calculation for the Latinx category but were considered to have missing data for the race category

In general, gender participation in the colorectal cancer groups leaned toward more female participants; two colorectal cancer groups, one in Chicago, and one in Washington, DC, comprised all female participants. The San Francisco and virtual colorectal cancer groups were more gender balanced with 42% and 40% male participation, respectively. Insurance status across all locations approximated the average and ranged from a low of 91% insured in Chicago to 100% insured in San Francisco, South Carolina, New Jersey, and the virtual groups. The one outlier was in Chicago where the colorectal cancer group comprised only 67% insured participants.

Survivors' principles and priorities in survivorship care practice

We identified 13 themes that emerged as important issues for survivors' health and well-being post-cancer treatment. We

characterize the themes as principles and priorities because they provide insight into participants' standards for care and their most important considerations as they navigate this phase of their cancer. Each theme is discussed briefly subsequently with Table 2 providing additional quotations to further illustrate the theme.

Two core principles emerged from the study and illustrate participants' expectations and hopes for how the concept and system of care for survivorship can be improved to better meet their needs. These principles underlie eleven practice priorities that reflect participants' perspectives on the most important elements of the survivorship care process and how they can be improved. Following the ecological model of health [47], we organize these priorities according to individual, interpersonal, and organizational levels of influence. They represent the following: (1) the value of having survivors who are well-adjusted and supported by a survivorship care system; (2) the

Table 2 Survivors' principles and practice priorities for survivorship care

Principles and priorities	Illustrative quotes	References ^a
Survivors principles		
Principle 1. Underscoring the chronic nature of survivorship to prepare survivors	Survivorship is a chronic condition And if people started looking at it that way, we would have that general guideline and road map of five years out, ten years out, eighteen years out, things to look for ... and deal with.—Chicago Breast Cancer Group	330
Principle 2. Creating an integrated, holistic system to better manage ongoing issues in survivorship	But afterwards when it is all done it is almost like they drop you I think there is got to be someone that they refer you to at that point to say these are the kind of things. This is what you need to change in your life if you are going to survive this disease.—New Jersey Breast Cancer Group The goal is ultimately to reach optimal health post-treatment right? But what does that mean? So, I think kind of a treatment plan that factors in my unique situation, but also kind of what is ideal would be really, really helpful.—Washington, DC Colorectal Group	322
Practice priorities at the individual survivor level		
Priority 1. Understanding expectations of survivorship care and how to “live with cancer”	I think they need to be more upfront about what to expect afterwards. At least if you can go in somewhat prepared, like being able to talk to someone who has been through it beforehand I think aftercare sucks.—Virtual Colorectal Cancer Group [I]n my own experience, you can be left with a, a lack of understanding on what a normal “recovery process” is and [that] can cause anxiety.—Montana prostate cancer group	387
Priority 2. Having peer networks for emotional and social support	I think, like he said a support system you really, really need that when the doctors fail and cannot give you what you need. You need someone to say, “this is what is going on now and if you get through this, this what is going to go on then, we are going to help you through”—Chicago Prostate Cancer Group Part of what I got from [a support group] was that I also ended up with a group of friends And we learned so much from each other. And ... talked about some of the stupidest things that we are experiencing But you know it is helpful ... [W]e depend on each other for information [N]obody else is giving us information.—San Francisco Breast Cancer Group	283
Priority 3. Getting information and resources to help manage care	Oh, I would just like to put in a plus [hospital name] They were phenomenally organized and phenomenally supportive [T]hey've got a whole information center. You know a patient education department. So, it's like their own library [to] go to and what you do not get there you know ... I just asked.—San Francisco Prostate Cancer Group I like the checklist thing. And, then also resources Because ... it is really hard to find things on the internet because there is so much stuff. But I think if there were recommended sites or whatever that would be really helpful.—Montana Breast Cancer Group	245
Priority 4. Getting mental health support	I think doctor's need to have a larger support system in their office They should have, you know ... a therapist that you could talk to. You know somebody who can, who really understands ... stress, you know.—New Jersey Breast Cancer Group [I]s there someone to see about you know just psychological issues or you know to get talked through things.—Montana breast cancer group	198
Practice priorities at the interpersonal level		
Priority 5. Having supportive and responsive providers	So I found that the doctors and even the oncologist too ... was very opened to hearing [my problems], I mean ... he listened to me.—San Francisco Colorectal Cancer Group	185
Priority 6. Being an empowered and engaged patient	I think what I do is I try to take responsibility. I try to participate in a partnership with physicians. Often times..., folks are not empowered, do not understand that their relationship is a partnership. It just is not on the physician ... I have a responsibility to ask specific questions and to be educated about whatever my situations are.—Chicago Prostate Cancer Group	183

Table 2 (continued)

Principles and priorities	Illustrative quotes	References ^a
Priority 7. Engaging in meaningful communication and shared-decision making between providers and survivors	My personal physician . . . , he is a great educator for me He sits down and explains. He will ask me what I am doing for my diet. What I am doing for my balance and my core.—South Carolina prostate cancer group My urologist gave me several options. They are not going to make the decision for you because it’s your body But he gave me lots of information [that] spoke about the different things.—San Francisco prostate cancer group	133
Practice priorities at the organizational level		
Priority 8. Seamless care coordination and transitions across providers	Because . . . your oncologist thinks you are done. And, she says okay go to see me in two years So, it ends up being really fragmented I almost feel like cancer or oncology could use . . . an oncologist with an internal medicine background that deals with a survivor and all.—Chicago Colorectal Cancer Group Whether it be physical, mental, spiritual, find someone that could facilitate all that and coordinate all that. You need to have someone to coordinate all that. I think it would have been beneficial to have some one individual like that after I was done chemo. There was a lot [of] disconnect.—Virtual Colorectal Cancer Group	299
Priority 9. Offering practical life support	And, [I] would want an insurance person in the office on the financial piece of it that has dealt with the 26th chemo treatment that’s not being covered . . . So, somebody that can deal with your fiscal nightmares.—Chicago Colorectal Cancer Group I guess I would like to see the insurance industry realize that there are problems that we have afterwards so that—and the doctors or someone could help us get coverage for. I mean I cannot go to acupuncture because I cannot afford it. Everybody keeps recommending it, but I cannot go.—San Francisco Breast Cancer Group	136
Priority 10. Creating infrastructure/processes to increase access and facilitate continuous care	Not only is [health system] a great support but they said that [I am] in the system. [T]hey have all [my] information from the day [I was] diagnosed. So that if [I] do develop a problem later due to side effects . . . call I have to do is call and then they will get me in immediately.—South Carolina Breast Cancer Group	106
Priority 11. Providing a full spectrum of care without access barriers	[C]omplementary treatment should be part of the survivorship. Like I said, acupuncture, hypnosis [but] insurance will not pay for it [T]o have this as part of the medical team and network and safety net . . . is very important.—Breast Cancer Survivor I would want a personal trainer that is educated enough to handle a survivor and knowledgeable at least for a follow up six months to a year afterwards to follow you and to help you through getting back to physical health.—DC Colorectal Cancer Virtual Group	104

^a Total number of times a theme was discussed across all sources

importance of patient engagement, partnership, and communication between patient and provider; and (3) the need for delivery system changes to improve the patient-centered quality of survivorship services. This structure also aligns with the philosophy of patient-centered care, which proposes patient-centeredness is the result of personal, professional, and organizational relationships [48, 49].

Survivors’ core principles

The core principles represent two of the most common and important themes in the study and illustrate how survivors’ view survivorship care both in their daily lives and as a system of care. These principles reflect participants’ discussions around the need for survivorship care to better support

survivors’ adjustment process after treatment and their desire for a more person-oriented, holistic delivery system. The core principles can be seen as standards that are operationalized by the priorities identified in the study.

Core principle 1: underscoring the chronic nature of cancer survivorship to better prepare survivors (n = 330)³ This principle describes the sometimes-difficult adjustment that many participants experienced when they realized their battle with cancer was not over when treatment ended. This adjustment required a re-orientation of their expectations from curative intent, where cancer and its effects are eradicated, to chronic condition, where the consequences of cancer continue well

³ The number cited in parentheses after each priority refers to the total number of times a theme was discussed across all 22 focus groups.

into survivorship. The majority of survivors in the study experienced post-treatment health issues, many of which permeated their lives physically, emotionally, and socially. Discussions of participants' survivorship experience often centered on the desire for health care professionals to underscore the chronic nature of cancer *after* treatment so that patients better understand the full cancer trajectory and what may be in store for them in the following months or even years. Most participants felt that this message was not clear, and many said that they were unprepared and unequipped for the ongoing health struggles they have faced.

Many survivors expressed disappointment and anger that they cannot put the cancer experience behind them due to ongoing physical, emotional, and social side effects. Some even reacted negatively to the concepts of "cure" and "survivor," explaining they feel they will never be cured of cancer, even if they are cancer free. One colorectal cancer survivor described her post-treatment outlook as a "new normal" where cancer is always present, "It doesn't matter if they call you a survivor, you're never really a survivor That's been a sticking point between me and my family; they don't understand that my mindset is [the cancer] is just not here now and [it] will probably come back and it's just a matter of time."

Core principle 2: creating an integrated, holistic system to better manage the ongoing issues experienced in survivorship ($n = 322$) Most focus group participants expressed the need for a system of cancer care that does not abruptly end after treatment but continues on with a holistic focus of helping survivors manage all the biopsychosocial challenges they face post-treatment. Many said that they want help with monitoring and surveillance for new and recurring problems, as well as with the management of ongoing health concerns, promotion of healthier lifestyles, and provision of services that support their new outlook on health and well-being. They noted, however, that this type of support is not always systematic or available long-term. As one breast cancer patient said, "I think more ... places need to ... literally get a program of transition so that [survivors] can have a place to go ... so that we can get the coping skills and know what we need to know and ... how to ask questions. We [need] a resource person to go back to." Many participants also noted the importance of making sure this system of care responded to their particular needs, since the survivorship care experience can vary for different patients.

Practice priorities at the individual survivor level

Four priorities reflect the need for better practices that support individual patients' ability to accept and adjust to the experience of survivorship. They highlight participants' desire to understand and be informed about their own health, to be emotionally grounded in their new normal, and to have a social support network that understands what they have been through.

Priority 1: understanding the expectations of survivorship care and how to "live with cancer" ($n = 387$) In each of the focus groups, participants discussed the importance of understanding and being prepared for what to expect both physically and emotionally after treatment ends and being better informed about the role the health care system plays in supporting them. Many of these discussions centered on the challenges of shifting from a high-touch acute approach to a more consultative survivorship approach, which many did not think was adequate given their ongoing needs. Several participants stressed the need for a more formalized strategy that "teaches" survivors how to live with the post-treatment effects of cancer and how to take more control of their health and health care during this phase. The idea of a survivorship "class" came up in many of the groups. Most participants felt that they understood next steps related to monitoring and screening for new or recurring cancers but felt less confident about how to manage late- and long-term physical and psychosocial issues or ways to be more active in their own care. A number of participants also said they wanted more transparent discussions about "what happens next" and how they should proceed with their care, especially knowing they will not be seeing their oncologist as regularly as during treatment. As one breast cancer survivor noted, "It does seem like they need to have some sort of survivorship plan So, if they had a whole program for newly graduated ... cancer survivors ... it would help the psychological issues because you don't have that freak out of, now what do I do? You would have a little more hand holding."

In most groups, participants discussed the uncertainty they felt and expressed the desire to better understand what types of late or long-term symptoms they might experience, who to call when concerns come up, when to seek out follow-up care, where to find social support and other survivors going through similar experiences, and how to reduce the risk of a recurrence or other secondary cancers. In all the focus groups, participants voiced the need for this type of "roadmap" to survivorship. A few participants had been provided a written survivorship care plan that helped outline surveillance expectations for post-treatment care, but the majority said they were not receiving any formalized guidance.

Priority 2: having peer networks for emotional and social support ($n = 283$) Participants in all the focus groups discussed the value of having sources of peer support where survivors can meet and discuss concerns with others who have had similar experiences. Many said support groups had been a great resource for information, emotional support and social interaction. As one prostate cancer survivor noted, "There needs to be a giant Gilda's club [a cancer support peer group] as a requirement for every facility in the country, where you can go ask questions when things are happening." Many in the study noted that support groups can be especially helpful for

survivors who feel their family and friends have less empathy for them once treatment has ended. Several participants said peer support often provides validation of their experiences and offers suggestions on how survivors can talk to their loved ones to help them better understand their needs in this phase of care.

Priority 3: getting information and resources to help manage care ($n = 245$) Many participants in the focus groups aligned the desire to understand and be prepared for the challenges associated with survivorship with the need for information and medical resources that will improve their ability to manage their care. One prostate cancer survivor voiced the importance of having a source for good, reliable information, “Everyone has said the information is out there. So, if you had a person ... who specialized in ... after treatment situations [who] you can sit down and talk to, then you start to be able to take advantage of all of the information that’s out there.”

Common services for which focus group participants wanted resources included descriptions of late- and long-term effects, nutrition and fitness services, screenings and scans, rehabilitation resources, and alternative therapies. The concept of a “directory of services” relevant to cancer survivors was identified as a resource that could be useful as survivors navigate the web of care they can draw on to improve their quality of life.

Priority 4: getting mental health support ($n = 198$) In all the focus groups, participants clearly articulated the need for mental health support to help them address the emotional consequences of their illness and to attain a well-balanced outlook on the survivorship phase of their cancer. Most were looking for this kind of support from both their providers and their personal support systems, but felt the former was sometimes lacking. Some wanted formal services, but more often they just wanted acknowledgement of their fears and reassurance from their clinicians. One colorectal cancer survivor exemplified this concern when they noted, “You know there was nobody there to talk to me about this You can [be] cured for however long but that fear is constantly in the back of your mind. When’s it going to come back? If it comes back, how much harder is it going to be? And I feel there’s not a lot of programs out there to help with the psychological aspect of that.”

Participants in all the focus groups discussed feeling angry about the changed lifestyle that accompanies their “new normal” and anxious about the fear of recurrence. Several also said they struggled with depression related to post-cancer adjustments. Most participants felt that discussion of these issues with their oncology team was lacking and wished they had more support. Some suggested it would be helpful to integrate mental health care into their oncology practice to better address survivors’ experiences with mental health issues.

Other mental health resources discussed by survivors included help with body image concerns, especially in terms of self-confidence related to intimacy following breast, colorectal or prostate cancer surgery. One colorectal cancer survivor articulated a concern voiced by many in the focus groups, “It would be nice to have some psychological help because those who do have a colostomy bag ... have these body image issues.” We heard similar worries from survivors who had undergone mastectomies and prostate surgery.

Practice priorities at the interpersonal level between survivor and provider

The next three priorities reflect the importance participants placed on partnership and communication between patient and provider. They highlight the value of having an empathetic provider who acknowledges and respects the survivors’ needs, the responsibility patients have to be engaged in their care, and the benefit of having meaningful communication and shared-decision making in the partnership.

Priority 5: having supportive and responsive providers ($n = 185$) According to a number of focus group participants, having a provider who is supportive, respectful, and prepared to discuss and problem solve issues is essential to ensuring an effective alliance between the provider and survivor. For many survivors in the study, this meant having a provider who is respectful and sensitive to their concerns, who has reviewed their history and past issues, and who actively listens, asks questions, and considers their preferences. A large number of participants felt frustrated when they did not get this kind of support. As one breast cancer survivor noted, “[My] vaginal dryness thing I had mentioned it to the oncologist a couple of times, and it was like, well that’s just a side effect. And, I’m like ‘well dah.’ But it doesn’t help, you know I had to search out to find somebody to listen to me.”

Most participants also appreciated providers who try to problem solve with survivors but are also willing to allow patients’ the autonomy to make decisions about their care. One colorectal cancer survivor described an especially positive experience with their oncologist because of the partnership they felt, “They definitely collaborated with me on what options I had They gave me the autonomy to make that decision, so no complaints there.” A number of study participants said they felt providers are too dismissive of late and long-term effects, thinking they are either imaginary or something a survivor should “just live with.” One breast cancer patient explained, “And the other thing that really bothers me too is that it doesn’t seem to bother them about the side effects You keep telling them and it’s like they don’t believe you or something.” This dynamic can cause tension between survivors and providers. As one breast cancer survivor noted, “I think we need more support in just people trusting what we say about ourselves

[I]t feels like it's an ongoing struggle to convince doctors when you know there's something wrong with you." There was a clear consensus across all focus groups about the importance of having a health care system that trains and educates providers to be respectful of patients' preferences and to acknowledge the ongoing health problems survivors face after treatment has ended.

Priority 6: being an empowered and engaged patient (n = 183) In all the focus groups, survivors talked about wanting to feel empowered to take care of themselves. According to many participants, this means survivors must have the skills and knowledge to advocate for themselves, ask important questions, request information and resources, and take health care decisions into their "own hands." According to one prostate cancer survivor, "You've got to be proactive. You can't just sit back ... you got to make decisions and you've got to go to the people, and you got to learn something about [it] You're a full partner in your medical care." Many participants emphasized that survivors have a responsibility in the patient/provider partnership to educate themselves and express preferences, but also to listen to and respect the provider so that decision-making is a shared process. One colorectal cancer survivor described their approach to the partnership by noting the importance of asking questions and exploring options with their provider, "I'm also very good [about] saying 'why is that? Why are you going to do that? Or why not do this.' ... I think we really appreciate when people act that way and do research and come in educated and then can be a team member rather than just saying, 'here I am, what are you going to do with me?'"

Priority 7: engaging in meaningful communication and shared decision making between providers and survivors (n = 133) In all groups, participant emphasized that candid and open communication with providers is essential to ensuring an effective partnership. Survivors who felt they could ask questions and discuss their options with their doctors said they had more of a role in decision making and more confidence in how to proceed with their care. One prostate cancer survivor noted how appreciative he was to have the type of communication with his provider that allowed his preferences to be heard:

I went and we had a discussion and I told him ..., "I really want to discontinue these because of the side effects." And ... we talked about the benefits. He said, "well let's try this, how about taking them on Monday, Wednesday and Friday and let's see how that works?" And with that negotiation we were able to come to an agreement and that's how I take that medication at this time.

Participants who raised this issue in their groups said that ongoing discussions and follow-up information are critical to empowering them to take appropriate action around their health and health care post-treatment. Not having this kind of communication was frustrating for many in the groups. One prostate cancer survivor described how uninformed he felt about the long-term effects of his surgery because of a lack of communication:

I asked the neurology department to send me a report of the operation and they said, "oh yeah we can do that." They didn't do it I wanted to see his description of what he had done with the erectile nerves, how many of them did he take and so and so forth. I never got that report and it still rankles me ... that I can't really point to that and say well he took 20% of the nerves or he took 80% and so I'd know what to expect..

Lack of communication between survivors and providers is a problem that many focus group participants said caused unnecessary anxiety and stress, particularly around sensitive issues like body image and intimacy. As one prostate cancer survivor noted, "[T]o sit down with a doctor that I can develop a trust with has been very difficult I have yet to have a real conversation with anyone to help relieve whatever fears it might be, when you have prostate cancer. 'What can you do? What can you not do? What should I expect? What I should not expect?'" These gaps in communication were a common grievance voiced across the focus groups.

Practice priorities at the organizational level of cancer care

The final four priorities represent changes participants called for to the system of care that treats and supports survivors after treatment.

Priority 8: seamless care coordination and transitions across providers (n = 299) When discussing challenges related to getting care, all focus groups talked about the need for better care coordination and clear processes for transitioning care back to their primary doctors. These gaps were one of the more common critiques of the health care system across the groups, suggesting it is a significant problem in how cancer survivorship care is currently organized. Many participants noted the lack of coordination across providers interferes with their ability to coordinate screenings and other tests, manage ongoing health issues, and obtain other services that can help them feel better and stay healthy. According to one colorectal cancer survivor, the lack of coordination and communication post-treatment can make survivors feel more alone and confused than when they were going through treatment:

Basically, the minute your active treatment ends, I felt like I was on my own again. While I was going through treatment, I emailed my oncologist and I would get a response so quickly. I had felt like there was coordinated care between the radiologist, my GI doctor, my oncologist, my primary care All of them talked to each other. As soon as I was done with active treatment, they stopped talk[ing] to each other.

Some participants also reported that too many referrals without effective care coordination can make it feel like they are being bounced from one provider to the next. One breast cancer survivor said she gets frustrated when her doctors do not problem solve with her but instead sidestep the issue with a referral, “[The doctor says] ‘you know I can’t really answer those questions, I will write you a referral,’ [This] is what I get from pretty much each and every one of them Anything that wasn’t really cancer, I got referral, referral, referral.”

In all the focus groups, participants also raised the importance of having a better understanding of whether, when and how to transition from their oncologists back to their primary care doctors and wanted more guidance on how to coordinate them. One prostate cancer survivor described how he wanted the transition from oncology to primary care to occur, but noted that the current health care system does not allow for this kind of seamless transition:

[I]n a perfect world there should be a meeting face to face where you make the transition [T]hat should be clearly stated—[you’re] transitioning now from the specialists to your primary care person. And, that could be accompanied with the road map that [we’ve] been talking about and to me that would give the patient the feeling that these people who are in charge of me ... know what they’re doing

Several participants said they want their oncologists to share care responsibilities with their primary care physicians (PCPs), because they do not always feel comfortable discussing cancer-related issues with their PCPs. One colorectal cancer patient describes these concerns, “[A]fter we finished treatment it’s just like, ‘oh well, your primary care can handle everything now.’ And sometimes I think maybe primary care is a little scared of you, because you’ve had all of these issues, and they’re scared they’re going to miss something if something else pops back up.”

Many participants said their oncologists should set expectations about how and when to coordinate the transition, but also respect what the survivor wants and try to come to an agreement with the patient and the primary care physician about what is best. Some said this would help survivors and their primary care physicians

feel comfortable moving forward and managing their care together.

Priority 9: offering practical life support (n = 136) Practical life support was identified in most focus groups as another important aspect of survivorship care and a patient’s road to recovery. Several participants described health insurance problems, employment issues, and financial troubles resulting from their cancer, which cause stress, anxiety, and other negative outcomes that impact their quality of life. Health insurance problems were the most prominent practical life problem among survivors in the focus groups. One breast cancer participant explained that her out of pocket costs have put her in a difficult position that affects the management of her care, “And in terms of insurance issues, even if you have good insurance my co-pays and prescription co-pays are outrageous and there is no help for that. You either get the medicine, you pay for it, or you don’t get it.” She stressed the need for better information and support to help her resolve these kinds of issues, “So even if it was information [or] if they had seminars or have handouts to help people know what resources were available” to help offset costs and deal with insurance issues. In discussions of these challenges, many participants identified the need for support that can help survivors both navigate and resolve problems around financial concerns and insurance coverage, which often cause undue stress for months and years after treatment has ended.

Priority 10: creating infrastructure and processes to increase access and facilitate seamless, continuous care (n = 106)

Most participants highlighted their desire to have a better system of care, where they have continuous and coordinated access to needed services. In almost all focus groups, participants expressed frustration at the lack of infrastructure or organizational systems to support these goals and mitigate the fragmentation they feel. In these discussions, focus group moderators asked participants to think about their ideal survivorship care system and what a “medical home” might look like for survivors. Many participants talked about the need for better structures or resources, such as a point-person who knows their personal circumstances, to help them manage their care after treatment. A colorectal cancer patient explained:

I think ultimately you have to [have a]... liaison between [your doctors] because that’s the person you have contact with the most and they should be kind of following a pattern [asking] when’s the last time you talked to your oncologist, when’s the last time you talked to your radiation person, when’s the last time you talked to this [doctor], trying to keep

you on track. If there were some kind of plan or protocol that could be setup so you could say okay this is what should be done.

Some talked about the value of having a case manager to help them obtain and coordinate care. Others talked about having a multidisciplinary team or practice, where they could obtain all their care in one place during one visit. Some said they would like a formal network of clinicians across different disciplines to help facilitate recommendations and referrals. Most groups agreed there needed to be better information systems to promote communication among providers and with the patient. In all examples discussed, the main goal was to create a more robust system to mitigate feelings of fragmentation and falling through the cracks that many of them had experienced. As one colorectal cancer patient described, “When you become a cancer patient it’s too hard to find one person at a time to fix it. That’s why a system would really need to be in place It’s a foundation, like building a city I think survivorship needs an infrastructure of some sort that has a basic template.”

Groups also talked about the role of the clinician in a medical home in terms of facilitating referrals and coordination, listening to patients about their preferences, and serving as the main point-person for care. For participants who had this kind of continuity and coordination, they described overwhelmingly positive experiences with their care and the impact it has had on their health post-treatment.

Priority 11: providing a full spectrum of care without access barriers ($n = 104$) According to many focus group participants, having a cancer care system that provides a full range of services is critical to ensuring they can achieve improved outcomes and better quality of life. Many noted the importance of having better access to specialty clinical services, but also emphasized the importance of psychosocial care, nutrition and fitness programs, rehabilitation services, and complementary and alternative therapies (CAT), such as acupuncture or Reiki. Several participants criticized the health care system for making it unduly difficult to find and pay for some of these services. According to one prostate cancer survivor, this gap in care is a significant failing of the health care system, “[I]t’s more [about] treating a person holistically. And it has to do with not only the physical aspects and the emotional aspects but the dietary aspects and what [I] should or should not be eating. It just sort of goes a lot further I think it’s sorely missing”

Moreover, as a number of participants noted, access and payment barriers have forced them to forgo services they thought would be helpful in their healing process. For example, one colorectal cancer survivor noted that lack of integration has made it difficult to get some services, “There’s no rehab built into this system; it’s not intended to do that. We got rid of [the cancer], now here’s your bottle of [medication] Figure it out on your own

.... There’s obviously a major disconnect there.” A breast cancer survivor lamented that she could not see a nutritionist because of cost, “I see [name] and they have a nutritionist in there. And she’s like a hundred and thirty dollars to see the first time and then if you continue to see her ... you got to pay I haven’t done it simply because I don’t have a hundred and thirty dollars to go.”

Discussion

Throughout its maturation as an area of practice, cancer survivorship care has increasingly asserted the importance of defining and measuring quality care [5, 25]. Yet, the field has not resolved the role of patient-centeredness in conceptions of quality or attendant guidelines and standards. Most survivorship care models have been developed based on evidence-based clinical practices, without adequate consideration of practices that improve the patient experience or meet patients’ subjective needs. As a result, the field is overlooking how patient-centered care can advance the achievement of clinical goals. Our study addresses this opportunity by describing a patient-centered approach to survivorship care where practices that reflect clinical importance are promoted within the context of practices that reflect a more personalized care experience.

Experts in patient-centered care emphasize the importance of keeping patients’ paramount in the development of care standards [43]. By using a semi-grounded, qualitative design that explores survivors’ personal experiences, our study elevates the patient voice in the development of a patient-centered approach by looking specifically at participants’ goals for survivorship care and their priorities for improvement to achieve those goals. While the sample used to identify priorities reflects a small group of cancer survivors with representation from only three types of cancer, our findings offer an important starting point for how to conceptualize patient-centered survivorship care from the perspective of patients themselves. The study identifies two underlying principles that illustrate most participants’ standards for survivorship care and eleven distinct practice priorities that operationalize these principles at individual, interpersonal, and organizational levels. Together these principles and priorities illustrate a comprehensive, patient-driven approach to patient-centered care.

Notably, our work suggests many patients are not fully prepared to deal with the long-term impact of cancer on their physical, emotional and social lives. While the depiction of cancer as a chronic disease is not new to the field [50], patients’ perception of it in these terms may be more limited than providers realize. Most participants felt their clinicians did not adequately prepare them for the chronic nature of their disease, particularly after treatment had ended. Many said they

were not expecting the indelible changes that health concerns, psychosocial issues, and practical life problems have had on their life routines, their interactions with the health care system and their overall mindset around their health and well-being. These findings suggest a shortcoming in current survivorship care models where the intent of care has not been adequately translated to patient understanding or realization. Moreover, most participants expressed frustrations with how poorly organized the system of care is after treatment, which exacerbated their unease. Many felt uncertain and ill-equipped to handle their post-treatment health issues as a result.

The two principles for survivorship that emerged from the study reflect this gap and underscore the value many participants place on being better equipped to understand, adjust to and prepare for the chronic aspects of their recovery and the range of issues they may face after treatment. These were clear standards for an optimal survivorship care experience and define the need for the following: (1) a more patient-centered lexicon that focuses on survivors' process of understanding their post-treatment health status and (2) a holistic survivorship care system that can personalize care and align with the needs of each survivor.

The 11 practice priorities demonstrate how many study participants believe survivorship care can be improved to achieve these goals. Consistent with the literature on comprehensive survivorship care and survivors' care needs [2, 16, 22, 26–29, 50, 51], these practices represent most participants' priorities for better management of late and long-term effects, having emotional and psychosocial support, improving patient understanding and expectations of survivorship, having a full range of services including health modification strategies, improving care coordination across clinicians, and getting practical life support.

Our study, however, also underscores the importance many participants place on providing these services within a patient-centered framework where care is personalized and responsive to survivors' unique preferences and needs. These priorities attend to the behaviors, attitudes, relationships, and structures that can support the study's core principles and the overarching philosophy of compassionate, responsive patient-centered care. Specifically, the practices highlight the importance of respectful patient-provider partnerships that allow patient autonomy and decision-making authority; clinical and social resources that help patients feel prepared, adjusted, and emotionally grounded as they advocate for their needs; and a delivery system that is organized so that processes work seamlessly and do not hinder patients' efforts to manage their health. These findings differentiate our study from others examining survivors' care needs as they emphasize important tenets of patient-centeredness and more equally balance the emphasis of needs between clinical recommendations and personalized care.

At the individual level, participants' priorities emphasize how survivors can take better care of themselves when they and their

psyche are adequately supported by the health care system. Many participants reported wanting strategies to help adjust expectations post-treatment, resources to help identify and address specific health concerns, and clinical and social support to help them feel emotionally and socially grounded in their new normal. Studies suggest a patient-centered system that allows for and supports these priorities can help patients become better informed, emotionally adjusted survivors, who understand the full trajectory of their health [16, 22, 26, 29, 30, 52].

Practices related to the partnership between survivors and providers were also identified as priorities in the study and reflect how a patient-centered approach to care may facilitate a more active role for some patients in the management of their care. Our study suggests that many participants want to feel empowered to advocate for themselves to ensure clinicians acknowledge and respect their needs and preferences. Some participants also want to share in decision making, which requires that clinicians be open and responsive to patients and that the two participate in effective communication. The patient-provider partnership is especially important in the transition from treatment to survivorship and from survivorship to primary care, when patients may have concerns about their risk, the appropriate level of care they need moving forward, and who is in charge of that care [22, 26, 32, 33, 53]. These practices represent a shift in the locus of control from the provider to the survivor and demonstrates that some survivors want more control of their own care so they can achieve meaningful outcomes within their own personal context. This finding has clinical import as well, as such trademarks of patient-centered care have been found to alleviate stress and anxiety, promote patient-self-efficacy, improve pain and functioning, and increase self-management of chronic diseases, including the sequelae of cancer [23, 24, 26, 31, 53–58].

At the organizational level, our study also indicates the importance of having a well-integrated, easily accessible and navigable system to help survivors live fulfilling lives, while dealing with ongoing cancer-related health issues no matter the gravity. Participants' priorities highlight a survivorship delivery system that is continuous and coordinated with clear processes and expectations for transitioning back to and sharing care with primary care clinicians. According to our findings, the system should also include a broad range of services, such as CAT, diet and fitness services, and physical rehabilitation, as well as practical life support that addresses individual contextual factors. In the patient-centered literature, this type of system is often characterized as a medical home because of its emphasis on providing comprehensive, holistic care within the context of survivors' preferences, clinical need and personal circumstances [59–61]. Participants in our study emphasized the importance of having better systems and processes in place to provide more of a medical home experience in survivorship. For example, many expressed the need for case managers, referral networks and information systems to

help ensure communication is continuous and care is seamless. A well-organized system of care with these tenets of a medical home can increase patients' knowledge, self-management skills, use of recommended therapies, and quality of life [31, 59–61].

Limitations

As with all research, our study has limitations that could impact the validity and reliability of the findings. Because of the study's focus on the concept of survivorship, it likely omits the perspectives of patients who do not identify with the term because of the low acuity of their illness or the minimal effects experienced after treatment. These patients may move more easily beyond their cancer treatment to a sense of normalcy. We also used purposeful sampling to identify our sample, which limits our findings. While the sample size in the study is consistent with qualitative research norms, our sampling strategy focused on breast, prostate and colorectal cancer survivors who use Cancer Support Community resources, which may bias the results toward survivors of these cancers who share certain characteristics, such as being more in tune with or engaged in their own health and health care. Moreover, the non-random sample limits generalizability to a broader population of cancer survivors. As in all studies in which primary data are collected, the findings may also be influenced by researcher effects or reactivity effects, where, for example, participant responses may have been influenced by their interaction with the researcher. These effects may be more acute for the virtual focus groups where body language and other non-verbal cues are harder to read. Virtual focus group participants may not have felt as comfortable with the format of the groups making them less likely to open up or speak freely on some topics.

Implications for practice

Importantly, our findings indicate the merits of introducing patient-centered components of care to the development of quality domains and survivorship care guidelines. As the cancer field moves toward standardized guidance for quality survivorship care, as illustrated by Nekhlyudov and colleague's robust framework [25], it should also consider the importance of a unified approach to delivering patient-centered care. Few quality standards include patient-prioritized practices that specifically focus on how to ensure care is compassionate, respectful, and responsive to patient goals. Even fewer recognize the primacy of the patient and their preferences in the development process so that recommendations are both valid and genuine. Our study does both; it gives prominence to the patients' perspective by featuring their priorities as recommendations for care and offers guidance on how patient-

centered care can shape the concept and standards of quality moving forward.

Our work complements Nekhlyudov's model by highlighting many of the same quality domains but within a patient-centered context. In addition to systems and services that are included in most survivorship care models, it argues for practices that acknowledge and support many survivors' desire to be heard, known, and respected by helping them understand and adjust to their new normal so they are better equipped to engage in their own care. In addition, it recognizes the reciprocal relationship between patients and providers, and many patients' desire for shared-decision making and autonomy in care management. Finally, it offers suggestions for an organized system of care that advances survivors' preferences and choices and enables rather than hinders their efforts to manage their care and achieve better health outcomes. In this way, patient-centered standards can advance the goals of clinical quality guidelines.

Conclusion

Quality cancer survivorship care must reflect patients' priorities. Knowing what survivors' value can help cancer centers address gaps in care, improve the care experience, and increase behaviors and practices that support survivors' ability to accept and manage their care post-treatment. The findings from our study challenge the survivorship field to address clinical needs alongside individual preferences and priorities. Practices within the system should empower patients, promote strong patient-provider alliances, and provide a well-coordinated network of care, all of which could help survivors follow recommended clinical guidelines and achieve optimal outcomes.

To achieve these goals, survivorship experts should develop guidance on how to translate priorities into specific patient-centered indicators that can assess the patient-centeredness of survivorship care. Used in conjunction with clinical practice guidelines, these metrics can show cancer centers how well they are providing patient-centered care and test the impact practices have on outcomes recommended by clinical guideline. In this way, the field can identify best practices and propel adoption of patient-centered principals.

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Compliance with ethical standards

Conflicts of interest Research reported in this paper was funded through PCORI® Award number IH-12-11-5255. The results presented in this work are solely the responsibility of the authors and do not necessarily

represent the views of PCORI®, its Board of Governors or Methodology Committee.

None of the authors of this paper have any conflicts of interest. All procedures performed in the study involving human participants were in accordance with the ethical standards of George Washington University and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Appendix I. Focus Group Guide

Evaluating cancer survivorship care models: focus group guide.

Welcome participants

Hello, my name is _____. I work at The George Washington University in Washington, DC. We are here conducting a study on health care for cancer survivors in order to improve the care and services that survivors get after their treatment has ended. Our hope is to make recommendations that can be used by physicians to make sure the care they provide meets the needs of patients after their treatment or surgery has ended.

1. Explain the project

- As you know, cancer patients have many physical, psychosocial, practical, and informational needs that may show up months, years, or decades after treatment ends;

- But the current health care delivery system is not necessarily equipped to help with these issues because it is focused more on treatment rather than on the long-term, follow-up care you need after treatment has ended.

- Right now, health care systems make a lot of assumptions about what patients need **AFTER** their treatment has ended. But we want to find out from patients themselves what is most important to them when it comes to the care they get **POST-treatment**.

- So, we are going to ask you about

- what physical and psychological health problems you are still dealing with,
- what types of doctors you see most in your post-treatment care,
- how well they coordinate with each other,
- what the transition was like from your oncologist to your primary care doctor,
- what problems you are having getting the care you need and.
- what you would like to see the health care system provide to survivors.

- Ultimately, our hope is the information you give us will help improve long-term health care for patients in the post-treatment phase of life.

Evaluating Cancer Survivorship Care Models is the product of a joint collaboration between the George Washington University (GW) Cancer Institute, GW School of Public Health and Health Services, and the GW Medical Faculty Associates and is funded by the Patient-Centered Outcomes Research Institute.

Purpose of Focus Groups

- We are collecting data on survivorship care through focus groups like this one, where we go out into the community to talk to patients who have survived cancer so we can better understand their experiences.
- **We are interested in what you have to say because you are the experts on this topic and your opinion and perspectives matter to the success of our project.** Thank you for coming.

2. Ground rules and procedures for confidentiality:

3. Ground rules:

- The discussion in this group is confidential and voluntary. That means that we will not be connecting your name with what you say and your personal information will not be available to anyone outside the study team.
- Because this is a group discussion, we ask that all who participate respect the privacy and confidentiality of the group and not discuss personal information about people in the room.
- This is not an educational or support group. We are not doctors or medical staff and cannot make suggestions about your health or health care. We would like to hear about your experiences getting care as a survivor and where you might be experiencing problems.
- There are no right or wrong answers. Feel free to speak openly and give your own opinions.
- We need to hear from everyone. We want to give everyone an opportunity to talk about each topic, so each person needs to be somewhat brief. I may also ask people who are quieter than others if they would like to share an experience with the group.
- I may sometimes need to stop you so that we can get back on focus and get through our topics.
- This discussion will be audio-recorded for accuracy.
- This group is not connected with any specific health care facility, provider, or funder and will in no way impact your ability to get care.
- Please feel free to speak openly and candidly about the questions we ask you.

- We expect this meeting to last approximately 1 1/2 h.
- To show you our appreciation, we will give you a \$50 gift card. Please be sure to sign for the card.
- Usually people enjoy these groups as an opportunity to talk with others. Please relax and be as open as possible.

Icebreaker

Before we get started, I want to define some terms we will be using throughout the discussion. We will often refer to survivors of cancer and survivorship care.

- What we mean by a survivor is a cancer patient who has been diagnosed but has completed active treatment (like surgery, chemotherapy, or radiation). Survivors may still be taking maintenance treatments (like hormone therapies) but active treatment is done. What we are interested in learning about is your health care and lifestyle post treatment as a “survivor.”

- When we talk about survivorship care, we are talking about the follow-up medical care and clinical services that you need and use now that your treatment has ended. This care may be needed because of side effects from your treatment or long-term physical or emotional effects from the cancer. The care may be provided by your oncologist or other doctors you see for these issues.

1. Now, to kick off our discussion I would like to go around the room and ask each of you to tell us your name (first name only) and how long you have been a survivor.

Domain 1: Survivors state of health

Let us start the discussion by talking about some of the health and non-health issues you may still be dealing with since your treatment ended for your cancer.

1. Please describe the most challenging medical and/or psychological issues you have faced since the end of your treatment

Probes:

 - a. Medical/physical problems
 - b. Mental health/psychosocial concerns
 - c. Practical issues, e.g., financial issues, employment problems
2. Do you feel that these needs are being adequately addressed by the health care system? Why or why not?

Domain 2: Survivors priorities for survivorship and gaps in care

Let us specifically talk about what you want out of the health care system now that you are no longer in active treatment.

1. What specific health care services have you needed since your treatment has ended?
2. What types of care have you found especially helpful? Why?
3. Have there been any health care services you did not get but thought you needed?

Probe:

- a. What kept you from getting these services?

4. Many hospitals have survivorship programs that are specifically designed to help cancer patients deal with their health care needs after treatment has ended. What types of services do you think these programs should have that would be helpful to you?

Probes:

- a. Let participants answer first. Then ask—Would you like a program that includes: (group services by tiers talking about 3 or 4 at a time).
- b. Why (or why not) would you like this type of care? Are these services available through other resources in the community?

5. Let us say your doctors wanted to develop a strategy of medical care to help you stay healthy now that you are a cancer survivor

- a. Who should be involved in the development of that strategy? Who should be in charge?
- b. When should the strategy be developed? E.g. during treatment, right after treatment, 1 year following the end of treatment
- c. What kind of information and instruction would you like to have included in the strategy?
- d. How often should you meet with providers as part of your survivorship care
- e. How would you like the strategy to be documented or discussed with you? E.g. a formal written plan that can be shared among patient and all providers
- f. How long/how many years should the strategy cover?
- g. Any other information

Domain 3: Survivors perception of care team

Now we are going to talk about how well your doctors coordinate with each other and with you about your care. We want

you to think about all the doctors and health care providers you see now that treatment has ended. This may include your oncologist, your primary care doctors, any mental health care providers, doctors you may be seeing for other chronic illnesses or for side effects associated with your cancer or treatment, or any other providers.

1. Before you developed cancer what types of health care providers did you go to for your general medical care. How regularly did you see that provider? Did you have a supportive and ongoing relationship with that provider? Please describe.
2. Now, think of all the types of doctors you are currently seeing to help you manage all your health care issues now that active treatment for your cancer has ended?

Probe: How many of you are regularly seeing (within the past year) (show hands)

 - a. Oncologist, radiation oncologist, and/or oncology surgeon
 - b. PCP, which would include NPs and PAs
 - c. Behavior health care provider
 - d. Other specialist—e.g. neurologists
 - e. Nurse practitioners
 - f. Nurses
 - g. Physician assistants
3. How well do you think these physicians work together to provide your care?

Probe:

 - a. Do they communicate regularly?
 - b. Do they transfer records and share follow-up plans?
 - c. Do they have clearly defined roles?
4. Which of these providers do you rely on most to help you when you have health concerns now that your treatment has ended? Who manages your overall care now? Why?
5. Now that you have completed active treatment, what roles and responsibilities do you want your oncologists to have in your follow up care? Your primary care physicians
6. Think about transitioning your care from your oncologist to your primary doctor. What do you think needs to happen so that you feel comfortable transitioning your care from your oncologist to your primary doctor or provider

Probes:

 - a. A formal transition process or appointment
 - b. A formal survivorship plan and treatment summary
 - c. Clear specification of who manages your overall care plan
 - d. Discussion of referrals back and forth

- e. Discussion of how coordination/communication works between primary and specialty care
- f. Any special programs/initiatives to improve continuum of care

Domain 4: Survivors sense of self-efficacy in managing their health post-treatment

Now, we are going to talk about how well you think you can manage your long-term health now that treatment has ended and what the health care system can do to help support you.

6. After treatment ends there are a number of things cancer patients should be aware of to make sure they stay healthy. What kinds of things should you be watching out for post-treatment?

Probes: For example,

 - a. Do you know which health care providers to call if you have questions about different health concerns or about secondary medical issues?
 - b. Do you feel you know what symptoms or problems to be looking out for
 - c. Do you know how frequently you should be having follow-up appointments
 - d. Do you know when you should get your next screening?
 - e. Do you know what health promotion and risk reduction steps you should be taking—e.g., healthy behaviors such as exercise, healthy eating
7. How are you keeping track of these things?

Probes:

 - a. What things have you found confusing?
 - b. Who is helping you with this?
8. What would help you feel prepared for what to expect from your care in the next year to 5 years

Domain 5: Elements of high quality survivorship care

1. What do you think are the most important elements of really good survivorship care?

Probes:

 - a. Explore elements of medical home.
 2. If you could change anything about your health care post treatment, what would it be?

Wrap Up

Please remember to respect the privacy of what we have talked about in this group and not share specific personal information about participants outside of this room.

Also, if you are interested in learning more about the study or finding out what we discover from these groups, please go to the website listed at the end of your information sheet, which is included in the envelope with your gift card. Or you can email us at survivorship@gwu.edu with your contact information.

References

- Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, et al. Cancer treatment and survivorship statistics. *CA A Cancer J Clin*. 2019;69:363–85. <https://doi.org/10.3322/caac.21565>.
- McCabe MS, Bhatia S, Oeffinger KC, et al. American society of clinical oncology statement: achieving high-quality cancer survivorship care. *J Clin Oncol*. 2013;31(5):631–40. <https://doi.org/10.1200/JCO.2012.46.6854>.
- Viswanathan M, Halpern M, Evans TS, Birken SA, Mayer DK, Basch E. Models of survivorship care. Agency for Healthcare Research and Quality (AHRQ) technical brief no. 14. 2014
- Edgington A, Morgan M. Looking beyond recurrence: comorbidities in cancer survivorship. *Clin J Oncol Nurs*. 2011;15(1):E3–E12.
- Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. Washington: National Academies Press; 2006.
- Arnes J, Crowe M, Colbourne L, Morgan H, Murrells T, Oakley C, et al. Patient's supportive care needs beyond the end of cancer treatment: a prospective longitudinal study. *J Clin Oncol*. 2009;27(36):6172–9.
- Lloyd S, Baraghoshi D, Tao R, Garrido-Laguna I, Gilcrease J III, Whisenant J, et al. Mental health disorders are more common in colorectal cancer survivors and associated with decreased overall survival (OA44). *Int J Radiat Oncol*. 2018;101(2):e18–9. <https://doi.org/10.1016/j.ijrobp.2018.02.083>.
- Carreira H, Williams R, Müller M, Harewood R, Stanway S, Bhaskaran K. Associations between breast cancer survivorship and adverse mental health outcomes: a systematic review. *J Natl Cancer Inst*. 2018;110(12):1311–27. <https://doi.org/10.1093/jnci/djy177> *Radiat Oncol*. 2018;101(2):e18–e19. doi:10.1016/j.ijrobp.2018.02.083.
- Klaassen Z, Arora K, Wilson N, et al. Decreasing suicide risk among patients with prostate cancer: implications for depression, erectile dysfunction, and suicidal ideation screening. *Urol Oncol Semin Orig Investig*. 2018;36(2):60–6. <https://doi.org/10.1016/j.urolonc.2017.09.007>.
- Van Stam A, Van Der Poel G, Bosch R, et al. Prevalence and correlates of mental health problems in prostate cancer survivors: a case-control study comparing survivors with general population peers. *Urol Oncol Semin Orig Investig*. 2017;35(8):531.e1–7. <https://doi.org/10.1016/j.urolonc.2017.03.028>.
- Andersen L, DeRubeis J, Berman S, et al. Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *J Clin Oncol*. 2014;32(15):1605–19.
- Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting; Adler E, Page K, editors. Cancer care for the whole patient: meeting psychosocial health needs. Washington: National Academies Press (US); 2008. 1. The psychosocial needs of cancer patients. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK4011/>. Accessed 1 Feb 2019.
- Cheung WY, Neville BA, Cameron DB, Cook FE, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. *J Clin Oncol*. 2009;27(15):2489–95.
- Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. *Med Care Res Rev*. 2013;70(4):351–79.
- Mosadeghrad AM. A conceptual framework for quality of care. *Mater Soc*. 2012;24(4):251–61.
- Kline RM, Arora NK, Bradley CJ, Brauer ER, Graves DL, Lunsford NB, McCabe MS, Nasso SF, Nekhlyudov L, Rowland JH, Schear RM, & Ganz PA (2018). Long-term survivorship care after cancer treatment—summary of a 2017 national cancer policy forum workshop. In *J Natl Cancer Inst* (Vol. 110, Issue 12). Oxford University Press. <https://doi.org/10.1093/jnci/djy176>.
- Institute of Medicine (IOM). Crossing the quality chasm: a new health system for the 21st century. Washington: National Academy Press; 2001. <http://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf>. Accessed 11/07/2018
- Blanch-Hartigan D, Chawla N, Beckjord EI, Forsythe LP, Moor JS, Hesse BW, et al. Cancer survivors' receipt of treatment summaries and implications for patient-centered communication and quality of care. *Patient Educ Couns*. 2015;98:1274–9.
- Nissen MJ, Beran MS, Lee MW, Mehta SR, Pine DA, Swenson KK. Views of primary care providers on follow-up care of cancer patients. *Fam Med*. 2007;39(7):477–82.
- Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, et al. The impact of patient-centered care on outcomes. *J Fam Pract*. 2000;49(9):796–804.
- Kuipers SJ, Cramm JM, Nieboer AP. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting 11 medical and health sciences 1117 public health and health services. *BMC Health Serv Res*. 2019;19(1):13. <https://doi.org/10.1186/s12913-018-3818-y>.
- Park M, Giap TTT, Lee M, Jeong H, Jeong M, & Go Y (2018). Patient- and family-centered care interventions for improving the quality of health care: a review of systematic reviews. In *International Journal of Nursing Studies* (Vol. 87, pp. 69–83). Elsevier Ltd. <https://doi.org/10.1016/j.ijnurstu.2018.07.006>.
- Miller KL. Patient centered care: a path to better health outcomes through engagement and activation. *NeuroRehabilitation*. 2016;39(4):465–70. <https://doi.org/10.3233/NRE-161378>.
- Kvale EA, Huang CHS, Meneses KM, Demark-Wahnefried W, Bae S, Azuero CB, et al. Patient-centered support in the survivorship care transition: outcomes from the patient-owned survivorship care plan intervention. *Cancer*. 2016b;122(20):3232–42. <https://doi.org/10.1002/cncr.30136>.
- Nekhlyudov L, Mollica MA, Jacobsen PB, Mayer DK, Shulman LN, Geiger AM. Developing a quality of cancer survivorship care framework: implications for clinical care, research, and policy. *J Natl Cancer Inst*. 2019;111(11):1120–30. <https://doi.org/10.1093/jnci/djz089>.
- Loonen JJ, Blijlevens NMA, Prins J, Dona DJS, den Hartogh J, Senden T, et al. Cancer survivorship care: person centered care in a multidisciplinary shared care model. *Int J Integr Care*. 2018a;18(1):4. <https://doi.org/10.5334/ijic.3046>.
- Willems RA, Bolman CA, Mesters I, Kanera IM, Beaulen AA, Lechner L. Cancer survivors in the first year after treatment: the prevalence and correlates of unmet needs in different domains.

- Psychooncology. 2016;25(1):51–7. <https://doi.org/10.1002/pon.3870>.
28. Mayer K, Nasso F, Earp A. Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. *Lancet Oncol*. 2017;18(1):e11–8. [https://doi.org/10.1016/S1470-2045\(16\)30573-3](https://doi.org/10.1016/S1470-2045(16)30573-3).
 29. Craft E V, Billington C, O’Sullivan R, Watson W, Suter-Giorgini N, Singletary J, King E, Perfirgines M, Cashmore A, & Barwell J (2015). Supporting families with cancer: a patient centred survivorship model of care. In *Familial Cancer* (vol. 14, issue 4, pp. 637–640). Kluwer Academic Publishers. <https://doi.org/10.1007/s10689-015-9815-y>.
 30. Meraviglia M, Stuijbergen A, Parsons D, Morgan S. Health promotion for cancer survivors: adaptation and implementation of an intervention. *Holist Nurs Pract*. 2013;27(3):140–7. <https://doi.org/10.1097/HNP.0b013e31828a0988>.
 31. Tevaarwerk AJ, Klemp JR, van Londen GJ, Hesse BW, & Sesto ME (2018b). Moving beyond static survivorship care plans: a systems engineering approach to population health management for cancer survivors. In *Cancer* (vol. 124, issue 22, pp. 4292–4300). John Wiley and Sons Inc. <https://doi.org/10.1002/cncr.31546>.
 32. Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *Br Med J*. 2001;323(7318):908–11. <https://doi.org/10.1136/bmj.323.7318.908>.
 33. Barry MJ, Levitan SE, Billingham V. Shared decision making—the pinnacle of patient-centered care nothing about me without me. *N Engl J Med*. 2012;366:780–1.
 34. Leeper H, Milbury K. Survivorship care planning and implementation in neuro-oncology. *Neuro-Oncology*. 2018;20:VII40–6. <https://doi.org/10.1093/neuonc/ny110>.
 35. Institute of Medicine (US) Committee on Assuring the Health of the Public in the 21st Century. *The future of the public’s health in the 21st century*. Washington: National Academies Press (US); 2002. 5. The health care delivery system. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK221227/>
 36. Clarke L, Boum S, Skoufalos A, Beck H, Castillo J. An innovative approach to health care delivery for patients with chronic conditions. *Popul Health Manag*. 2017;20(1):23–30.
 37. Grover A, Joshi A. An overview of chronic disease models: a systematic literature review. *Global J Health Sci*. 2014;7(2):210–27. Published 2014 Oct 28. <https://doi.org/10.5539/gjhs.v7n2p210>. Accessed 15 Jan 2019.
 38. Maeng D, Martsolf R, Scanlon P, Christianson B. Care coordination for the chronically ill: understanding the patient’s perspective. *Health Serv Res*. 2012;47(5):1960–79.
 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):459–66. <https://doi.org/10.1007/s11606-009-1000-2>.
 40. Hudson S v, Ohman-Strickland PA, Bator A, O’Malley D, Gundersen D, Lee HS, et al. Breast and prostate cancer survivors’ experiences of patient-centered cancer follow-up care from primary care physicians and oncologists. *J Cancer Surviv*. 2016;10(5):906–14. <https://doi.org/10.1007/s11764-016-0537-4>.
 41. Mead KH, Raskin S, Arem H, Landry M, Seyoum S, Cleary S, et al. Evaluating different types of cancer survivorship care. Washington: Patient-Centered Outcomes Research Institute (PCORI); 2019. <https://doi.org/10.25302/7.2019.IH.12115255>. Accessed 14 Feb 2019.
 42. Creswell JW. *Research design: qualitative, quantitative, and mixed methods approaches*. 4th ed. Thousand Oaks: SAGE Publications; 2014.
 43. Tractenberg RE, Garver A, Ljungberg IH, Schladen MM, Groah SL. Maintaining primacy of the patient perspective in the development of patient-centered patient reported outcomes. *PLoS One*. 2017b;12(3):e0171114. <https://doi.org/10.1371/journal.pone.0171114>.
 44. National Institutes of Health. NIH fact sheets—cancer. National Institutes of Health. <https://report.nih.gov/nihfactsheets/viewfactsheet.aspx?csid=75>. Accessed March 22, 2019.
 45. Krueger R and Casey M. *Focus groups: a practical guide for applied research*. 5th ed. Sage Publications; 2009.
 46. Bazely P and Jackson K. *Qualitative data analysis with Nvivo*. 2nd ed. Sage Publications; 2013.
 47. Richard L, Gauvin L, Raine K. Ecological models revisited: their uses and evolution in health promotion over two decades. *Annu Rev Public Health*. 2011;32(1):307–26.
 48. Poitras ME, Maltais ME, Bestard-Denomme L, Stewart M, Fortin M. What are the effective elements in patient-centered and multimorbidity care? A scoping review. *BMC Health Serv Res*. 2018;18(1):446. <https://doi.org/10.1186/s12913-018-3213-8>.
 49. Epstein RM, & Street RL (2011). The values and value of patient-centered care. In *Annals of Family Medicine* (vol. 9, issue 2, pp. 100–103). Annals of Family Medicine, Inc. <https://doi.org/10.1370/afm.1239>.
 50. Miller KD, Pandey M, Jain R, & Mehta R (2015). Cancer survivorship and models of survivorship care a review. In *American Journal of Clinical Oncology: Cancer Clinical Trials* (vol. 38, issue 6, pp. 627–633). Lippincott Williams and Wilkins <https://doi.org/10.1097/COC.000000000000153>.
 51. Alfano CM, Mayer DK, Bhatia S, Maher J, Scott JM, Nekhlyudov L, et al. Implementing personalized pathways for cancer follow-up care in the United States: proceedings from an American Cancer Society–American Society of Clinical Oncology summit. *CA Cancer J Clin*. 2019;69(3):234–47. <https://doi.org/10.3322/caac.21558>.
 52. Salsman JM, Pustejovsky JE, Schueller SM, Hernandez R, Berendsen M, McLouth LES, & Moskowitz JT (2019). Psychosocial interventions for cancer survivors: a meta-analysis of effects on positive affect. In *Journal of Cancer Survivorship* (Vol. 13, issue 6, pp. 943–955). Springer. <https://doi.org/10.1007/s11764-019-00811-8>.
 53. Bailo L, Guiddi P, Vergani L, Marton G, & Pravettoni G (2019). The patient perspective: investigating patient empowerment enablers and barriers within the oncological care process. In *ecancermedicalsecience* (vol. 13). ecancer Global Foundation. <https://doi.org/10.3332/ecancer.2019.912>.
 54. Lawn S, Fallon-Ferguson J, Koczwara B. Shared care involving cancer specialists and primary care providers—what do cancer survivors want? *Health Expect*. 2017;20:1081–7. <https://doi.org/10.1111/hex.12551>.
 55. Beckham C, Burkner J, Burkner J, Feldman E, Costakis J. Self-efficacy and adjustment in cancer patients: a preliminary report. *Behav Med*. 1997;23(3):138–42.
 56. McCorkie R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, et al. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin*. 2011;61:50–62.
 57. Chen J, Mullins D, Novak P, Thomas B. Personalized strategies to activate and empower patients in health care and reduce health disparities. *Health Educ Behav: the Official Publication of the Society for Public Health Education*. 2015;43(1):25–34.
 58. McCanney J, Winckworth-Prejsnar K, Schatz AA, Nardi EA, Dwyer AJ, Lieu C, et al. Addressing survivorship in cancer care. *JNCCN J Natl Compr Cancer Netw*. 2018a;16(7):801–6. <https://doi.org/10.6004/jnccn.2018.7054>.
 59. Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population; Board on Health Care

- Services; Institute of Medicine; Levit L, Balogh E, Nass S, et al., editors. *Delivering high-quality cancer care: charting a new course for a system in crisis*. Washington: National Academies Press (US); 2013. Patient-centered communication and shared decision making. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK202146/>
60. Nutting A, Crabtree F, Miller L, Stange C, Stewart E, Jaén C. Transforming physician practices to patient-centered medical homes: lessons from the national demonstration project. *Health Affairs Project Hope*. 2011;30(3):439–45.
61. Reid J, Coleman K, Johnson A, Fishman A, Hsu C, Soman P, et al. The group medical home at year two: cost savings, higher patient satisfaction, and less burnout for providers. *Health Aff*. 2010;29(5): 835–43.

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