

Understanding the Delivery of Patient-Centered Survivorship Care Planning: An Exploratory Interview Study With Complex Cancer Survivors

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Abstract

Introduction: Understanding key elements of the survivorship care planning process, such as patient-centered communication (PCC) and health self-efficacy, are critical for delivering patient-centered survivorship care to cancer survivors with multiple chronic conditions (“complex cancer survivors”). Building upon our team’s recent research efforts to examine the survivorship care planning process from a patient-centered lens, this exploratory study leveraged an ongoing quasi-experimental trial to elucidate the experience of complex cancer survivors with survivorship care planning and post-treatment management.

Methods: We conducted a hypothesis-generating thematic content analysis on 8 interview transcripts.

Results: Survivors reported positive experiences communicating with their oncology care team but the presence of multiple chronic conditions in addition to cancer creates additional barriers to patient-centered survivorship care.

Conclusion: These findings support the need for further in-depth research aimed at improving PCC across all care teams and enabling self-management by delivering more personalized survivorship care planning that aligns with survivor’s needs, values, and preferences.

Keywords

survivorship, complex, quality, cancer, United States

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Introduction

In 2005, the Institute of Medicine (IOM) landmark report, *From Cancer Patient to Cancer Survivors: Lost in Transition*, highlighted the importance of comprehensive, multidisciplinary survivorship care planning to meet the complex needs of a growing survivor population.¹ In response, several models of survivorship care have been proposed, as well as guidelines and policies from leading organizations aimed at improving the quality of survivorship care planning.^{2,3} A central element of these models, guidelines, and policies is the provision of a written and communicated survivorship care plan (SCP) that summarizes treatments received and includes a follow-up plan that delineates care team responsibilities and incorporates available evidence-based standards. Calls for the wide-spread provision of SCPs have been accompanied by expectations that there will be improvements in health and healthcare outcomes.⁴ Unfortunately, the evidence around the beneficial effects of SCPs remains mixed and research to address gaps in survivorship care planning have mainly focused on addressing the unmet informational needs of survivors by tailoring SCP content or developing strategies to increase the use and/or delivery of SCPs into routine care.⁵ Few studies consider how other key elements of the survivorship care planning process, such as patient-centered communication (PCC), in addition to SCPs may impact health and healthcare outcomes.⁵

A patient-centered approach to survivorship care planning may be needed to improve quality of care received and health outcomes of a growing population of cancer survivors.⁶ Achieving the 6 core functions of PCC (i.e., fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling patient self-management) is becoming increasingly recognized as fundamental in the provision of high-quality survivorship care planning.^{1,7} PCC requires informed, active participation from survivors with care teams that have effective communication skills and support from an accessible, well-organized, and responsive health care system—and are thus dependent on available financial and staff resources.^{7,8} Several studies have established direct and indirect pathways linking PCC to key survivorship outcomes including health self-efficacy, engagement in adherence behaviors, and improvements to overall health.^{7,9-11} Unfortunately, inefficiencies and fragmentation of care delivery often results in suboptimal PCC and unmet needs for many cancer survivors, especially complex cancer survivors—survivors responsible for managing 2 or more chronic conditions (e.g., heart disease, diabetes, lung disease) in addition to their cancer-specific concerns.^{8,12} Though PCC has been associated with improved adherence to recommendations, satisfaction with care, and increased engagement in one's health, few studies have operationalized PCC in the context of survivorship care planning or alongside the delivery of an SCP.^{11,13-15}

Recently, our team has sought to address calls to explore the survivorship care planning process from a patient-centered lens.^{3,16} We conducted 2 large observational studies using data

from the Health Information National Trends Survey (HINTS) to derive samples of cancer survivors from prominent cancer sites.^{17,18} These studies were informed by existing frameworks for survivorship care planning research¹⁹ and the Patient-Clinician Communication Model,²⁰ positing that the receipt of an SCP should facilitate PCC, resulting in changes to subsequent outcomes including health self-efficacy and overall health. We used structural equation modeling to simultaneously test direct and indirect pathways linking SCPs to PCC, health self-efficacy, changes in health behavior, and overall health in a sample of breast and colorectal cancer survivors.¹⁷ We found no direct or indirect pathways linking SCPs to these outcomes suggesting that the receipt of an SCP alone is unlikely to facilitate changes in all 6 PCC domains, health self-efficacy, or overall health. However, PCC was directly associated with health self-efficacy and to overall health hinting that PCC may play a critical role in the survivorship care planning process. In another study, we performed multivariable regression to examine the association between PCC and health self-efficacy—antecedents of self-management—by the presence of 2 or more chronic conditions in addition to cancer in a sample of breast, prostate, and colorectal cancer survivors. We found a significant positive association between PCC and health self-efficacy for the entire sample that was attenuated by the presence of multiple chronic conditions. Thus, PCC alone may be insufficient in engaging complex cancer survivors to self-manage their care—highlighting the need to understand the survivorship care planning as an ongoing experience.¹⁸

While both studies highlight the importance of PCC and health self-efficacy in delivering patient-centered survivorship care, gaps on how best to support and deliver care to complex cancer survivors remains.^{18,21,22} To this end, the purpose of this exploratory study was to elucidate the experiences of cancer survivors with multiple chronic conditions with survivorship care planning beyond the receipt of an SCP by focusing on the communication exchange between survivors and care teams during the survivorship care planning visit. Additionally, we elucidated survivors' current experiences managing one's health following the completion of active cancer treatment to identify potential gaps in the survivorship care planning process, important for generating hypotheses and highlighting areas for further research.

Methods

This exploratory qualitative study used semi-structured interviews with complex cancer survivors to understand survivorship care planning from a patient-centered lens and generate hypotheses to inform future research and quality improvement efforts. This study was approved by the University of Texas Southwestern Medical Center and The University of Texas Health Science Center at Houston Institutional Review Boards, with additional site approval by Parkland Health & Hospital System Office of Research Administration.

Our recruitment strategy leveraged an ongoing longitudinal pragmatic quasi-experimental interventional trial of stage I, II, and III breast and colorectal patients with at least 1 chronic condition receiving cancer care at an integrated safety-net health system in Texas.²³ Using a purposeful sampling strategy, we identified survivors who completed active treatment in the last 18 months with characteristics representative of the demographic and cancer related distribution of the safety-net system (70% racial/ethnic minorities, two-thirds breast cancer) and who had not previously participated in an interview as part of the larger parent study. Due to challenges recruiting males, we limited the sample to women only to increase the potential to reach saturation. Between May and June 2019, a member of the research team trained in qualitative methods contacted 22 eligible patients by phone and completed 8 interviews. We did not perform further sampling to prevent cross-contamination with the parent study and because the data was sufficient for the exploratory nature of this study. All interviews acquired informed consent and were audio-recorded and professionally transcribed by a HIPAA-compliant third-party vendor.

Data collection and analysis was informed by findings from previous studies performed by our team, focusing on key elements of patient-centered survivorship care. The semi-structured interview guide focused on survivors' discussions with their oncology care team during the survivorship care planning visit and their overall post-treatment experience (see Online Appendix A). Specifically, we asked survivors to recall the information they received and discussed with their oncology care team during the survivorship care planning visit—defined as the last treatment visit when survivors should have received an SCP. To further understand gaps in the survivorship care planning process, we also asked survivors to describe their post-treatment experience and used probes to understand how survivors were managing their overall health.

Two members of the research team performed exploratory thematic content analysis using a deductive-inductive approach.²⁴ Each transcript was first reviewed in its entirety to allow themes and domains to emerge. A deductive code structure based on findings from our previous study highlighting the 6 domains of PCC, health self-efficacy, health behaviors, and overall experience was applied to 3 transcripts during an initial open coding session. As new ideas emerged, the research team considered inductive themes and domains, allowing the codebook to evolve.^{25,26} The revised codebook was then applied to all transcripts. The team coded the transcripts independently before coming together to compare codes. All coding discrepancies were resolved through consensus and analysis continued until no new ideas emerged eluding to saturation.²⁷ All analyses were performed in NVivo 11.²⁸

Results

Our interview sample was between the ages 49-70 (mean 57 years), and approximately two-thirds were non-Hispanic Black. The majority were under- or uninsured (receiving some form of county medical assistance), and most had a diagnosis of

Table 1. Participants' Sociodemographic, Clinical, and Cancer Characteristics.

Age (mean)	57
Race/Ethnicity	
NH White	3
NH Black	5
Insurance Status	
Medicare	1
Medicaid	3
Uninsured/Financial Assistance	4
Chronic Conditions	
Chronic Obstructive Pulmonary Disease	2
Hypertension	7
Diabetes Mellitus	6
Heart Disease	2
Chronic Kidney Disease	1
# of Chronic Condition in addition to cancer	
1-2	6
>2	2
Cancer Site	
Breast	5
Colorectal	3
Stage	
I*	3
II	2
III*	3
Months since the end of initial treatment	
6-12	7
>12	1
Provider seen at last treatment visit	
Oncologist	1
Surgeon	2
Advanced Practice Provider and Nurse	3
Oncologist and Nurse	2

*Indicates that stage data was not available in the cancer registry or electronic record for participants, thus based on self-report.

hypertension and diabetes that pre-dated their diagnosis of cancer (Table 1). Analyses of semi-structured interviews identified 4 overarching themes, which subsumed several domains. We present these themes in 2 categories—themes specific to the process of survivorship care planning and themes related to survivorship following the care planning visit.

Experiences With Survivorship Care Planning

We asked the survivors to reflect on their last treatment visit with their oncology care team, at which survivorship care planning should take place. Questions focused the 6 core functions of PCC and the information received. Table 2 provides a description of the themes and domains with exemplary quotes for experiences with survivorship care planning.

Patient-oncology care team communication. The survivors recalled their last treatment visit stating that their oncology care team provided updates on their physical condition, reviewed the next steps in their cancer care, and gave them written information to take home. The content of the written information included upcoming appointments, contact information, instructions on

Table 2. Themes, Domains, and Exemplar Quotes for Experiences With Survivorship Care Planning.

Themes	Domains	Exemplar quote(s)
Patient-Oncology Care Team Communication	Written and verbal information exchange	They [oncology providers] provided me with the information. Not just tell me, they also gave me the printout of what I needed to do and how I needed to take care of myself and what to expect (49-year-old, NH black, stage III colorectal cancer survivor). [The papers] you know, stuff like if I'm hurting or sore and it showed me how to take care of the wound that I had on my stomach, and if I have any problems, I call the nurse if I feel pain (53-year-old, NH black, stage II colorectal cancer survivor).
	Eliciting questions and concerns	She [provider] actually go over it with me and then ask me if I have questions about what she just talked about and if I have a question, I'll ask her (59-year-old, NH black, Stage III breast cancer survivor).
	Ensuring patient understanding	I'll talk to the oncologist and then she'll say—do you understand?—and I'll be like—Yes. And she'll say—Okay, well explain to me what I told you (54-year-old, NH white, stage I breast cancer survivor).
	Responding to patient needs	I was scared and I told my doctor and they said—We at [hospital], we're always going to take good care of our patients and that's what I like to hear. If a doctor to tell me that, I'm not scared no more (53-year-old, NH black, stage II colorectal cancer survivor).
	Gaps in communication	Well, he just needs to be informative, my primary care physician. I mean I know he sees a lot of people, but he's like—Oh, okay well what did they [oncology] say? Well, you should know what they said (52-year-old, NH black, stage III colorectal cancer survivor).
Oncology Care Team Responsibilities	Setting up appointments Scheduling/ordering labs/radiology Referring to non-oncology providers and resources	He sets up the appointments I ask for and stuff, and he gets to the bottom of the problem. If he can't, he sets you up with somebody else that can (56-year-old, NH white, stage II breast cancer survivor).

how to take care of oneself, and a list of possible symptoms that warrant their attention. Although the survivors did not explicitly state that they received an SCP, they found the written information to be helpful by serving as a reminder for upcoming appointments.

Several survivors remarked that their oncology care team reviewed all information, elicited questions, and ensured that they understood the next steps in care by asking them directly or by having them repeat back what was discussed. When probed to see if the oncology care team responded to their emotions and overall needs, the survivors described how their oncology care team showed interest in and sensitivity to their needs by providing ongoing support and encouragement, which helped to alleviate negative feelings or worries about the next steps in their care. Although the survivors generally reported positive communication experiences, 2 survivors perceived that non-oncology care team members, such as primary care providers, were not informed about their cancer treatment, and another described how she did not like seeing a different person at each visit.

The oncology care team's responsibilities in survivorship care planning. We asked the survivors to describe what their oncology care team does to help them stay healthy following cancer treatment. The survivors remarked that their oncology care team would schedule appointments, order the necessary labs/radiology, and refer them to non-oncology care team members,

local support groups, financial assistance programs, and exercise and nutrition resources as needed. The survivors stated that information about the next steps in care was often included in the written report and communicated verbally by the oncology care team during the last treatment visit, but the amount and type of information received varied across survivors.

Survivorship Experience (Post-Treatment)

We asked the survivors to reflect on their experience since their last treatment visit to understand the impact of survivorship care planning on more distal outcomes. Table 3 describes the themes and domains with exemplary quotes.

Post-treatment experience. The survivors characterized their experience post-treatment as the presence or reduction in physical and mental health symptoms, unexpected side effects, and the journey returning to pre-cancer function. The survivors remarked that being able to do the things they used to before their cancer, such as daily living activities and work, was an indicator that they were doing well after treatment. Although survivors discussed the presence or absence of physical symptoms resulting from their cancer, such as pain, swelling, and fatigue, few acknowledged the existence of physical symptoms related to their other chronic conditions. Further, survivors did not openly discuss their mental health symptoms—characterized as stress, worry, anxiety, or depression—until probed by

Table 3. Themes, Domains, and Exemplar Quotes Related to the Survivorship Experience (Post-Treatment).

Theme	Domain	Exemplar quote
Post-treatment experience	Physical health	Well, I got a lot of other problems other than that so I still stay tired a lot . . . Yeah from my—and my bones hurt and stuff like that, but it's not from the cancer. It's from everything else that's wrong with me (56-year-old, NH white, stage II breast cancer survivor).
	Mental health	Mentally, uh not very good . . . Not very good, and I think it's mostly because of not knowing, you know, what the mastectomy would actually look like (59-year-old, NH black, Stage III breast cancer survivor).
	Return to pre-cancer function	I can do things that I wasn't able to do after the surgery. Four months after the surgery, I can do it now so I think I'm doing pretty good (59-year-old, NH black, Stage III breast cancer survivor).
	Unexpected experiences	You hear about going through the chemo and all the side effects and I guess I didn't expect it to be as bad as it was with the side effects for the chemo, but I mean I knew about them, I just had never personally experienced them so I wasn't ready for those side effects like the hair loss, the nausea, the vomiting. I wasn't expecting it to be as bad as it actually was (54-year-old, NH white, stage I breast cancer survivor).
Adherence behaviors	Cancer surveillance behaviors	Well, I need to continue with all of the follow-ups. I need to have my CT scans done on a regular basis to make sure that none of it has gotten any larger and that it's not in other places, things like that (54-year-old, NH white, stage I breast cancer survivor).
	Healthy lifestyle behaviors	So yeah just walking, just light general exercise . . . not overeating and I've started to lose some weight now. Let's see—yeah, I'm just making healthy choices food wise and exercise wise or movement wise (65-year-old, NH white, stage I breast cancer survivor). . . . because I mean they've always told me from the time I had my daughter that I needed to lose weight, and I just never did it so and I mean I've known that I needed to cut down on the sugar and the sweets and the cokes and things like that and there again, I didn't do it. It was my choice not to do it so I can't say that there's any experience that I've had that I wasn't really prepared for (54-year-old, NH white, stage I breast cancer survivor).
	Barriers to adherence behaviors	I'm not able to afford health insurance so that would be my only thing about me being able to follow up with my health, you know, because of the financial part of it but, you know, I have to worry about that when it happens (59-year-old, NH black, Stage III breast cancer survivor).

the interviewer. Only 1 survivor, diagnosed with depression, reported that they were currently experiencing mental health symptoms. However, 2 survivors mentioned experiencing poor mental health immediately following treatment resulting from unexpected side effects of cancer and treatment. Although the survivors stated that their oncology care team informed them about the side-effects of treatment, about half reported that they were not prepared for the severity and/or longevity of symptoms they experienced.

Engaging in adherence behaviors. We asked the survivors what they felt was the most important thing they could do to stay healthy following cancer treatment. All described the need to engage in adherence behaviors, such as cancer surveillance and healthy lifestyle behaviors. The survivors characterized engaging in cancer surveillance activities as doing “*exactly what the doctors tell me to do,*” such as attending follow-up appointments, and receiving appropriate labs/radiology to ensure that the cancer does not return or spread. The survivors did not mention the management of their other chronic conditions as part of cancer surveillance. The survivors also discussed the importance of engaging in healthy lifestyle behaviors, such as diet, exercise, and smoking cessation. They stated that they were currently engaging in at least 1 behavior.

Despite understanding and being told by their care teams about the importance of adherence behaviors, this did not always translate to the desired behavior. The survivors

identified several barriers to adherence, including a lack of or changes in health insurance, declines in physical health due to other chronic conditions, lack of social support, and transportation. As 1 survivor described:

I'm not able to afford health insurance so that would be my only thing about me being able to follow up with my health, you know, because of the financial part of it but, you know, I have to worry about that when it happens (59 year old, NH black, Stage III breast cancer survivor).

It is unclear if the oncology care team reiterated guidelines recommendations for cancer surveillance or healthy lifestyle behaviors during the last treatment visit or if the recommendations were included in the written information.

Emerging Themes: Health Self-Efficacy, Motivation, and Social Support

We asked the survivors if they felt good about their ability to manage their health following cancer treatment (health self-efficacy) and the survivors stated that they were more aware of the signs and symptoms of cancer and that their oncology care team gave them the “*tools*” they needed to take care of their health after cancer. In addition, the survivors described how going through cancer treatment gave them the motivation they needed to stay healthy so that they could be around for

family and friends. They also discussed the importance of having support from family, friends, and oncology care team members to assist with daily living activities, encouraging healthy lifestyle behaviors, and providing ongoing information and support.

Conclusion

This study moved beyond the content and delivery of an SCP to explore the survivorship care planning process and post-treatment from a patient-centered lens in cancer survivors with multiple chronic conditions. Despite reports of positive communication between survivors and oncology care team members, it's unclear if survivors received an SCP, gaps in PCC persist during and after the survivorship care planning visit, and efforts to support the unmet needs of our survivors with multiple chronic conditions remain inadequate.^{13,29} The management of other chronic conditions in addition to cancer was not at the forefront of survivors' or care team members minds and many survivors continue to experience barriers to engaging in adherence behaviors that are critical to overall health. Further in-depth research is needed to revisit the potential contribution of these insights to support the development and testing of strategies to address unmet needs and to optimize patient-centered survivorship care for different settings and populations.^{6,30,31}

Qualitative insights from this study support our prior work around the importance of PCC in delivering patient-centered survivorship care but further illustrate that the presence of multiple chronic conditions creates an additional barrier to PCC and self-management, even within our vertically integrated county health system.^{1,17,18,32-35} Insights from our study hint to structural barriers in PCC, care coordination, and self-management resulting from inadequate flow of information between primary care and oncology care teams. As the prevalence of multiple chronic conditions among cancer survivors continues to rise, models of shared care that involve primary care, oncology, and other specialties is critical for addressing the long-term follow-up needs of cancer survivors with multiple chronic conditions.^{30,36} While models of survivorship care delivery exist, further exploration to understand how structural barriers facilitate or hinder the delivery of survivorship care are needed to improve processes toward more personalized care that meets the specific needs of survivors.^{31,37} Based on insights from this study, future efforts may focus on models and strategies to increase survivor social support, intrinsic/extrinsic motivation, and linking survivors to necessary resources based on individual needs.³⁰

Despite reporting positive communication experiences with the oncology care team, our survivors were often passive recipients of information rather than active communicators with their care teams, hindering PCC. In addition, the majority of survivors in our sample were ill-equipped with the knowledge and skills needed to overcome barriers to managing their overall health and engaging in healthy lifestyle behaviors. Empowering cancer survivors with multiple chronic conditions to

assume a more active role in their healthcare in becoming increasingly important.^{38,39} Yet, survivors often become dependent on their care teams to get them through treatment and the inability to communicate effectively contributes to unmet needs. Survivors need care teams to pay attention to their needs and encourage them to communicate so that resources can be accessed to improve outcomes of survivorship care. While SCPs may help to facilitate an exchange of information, achieving patient-centered survivorship care will likely require educational and skills training targeting both survivors and care teams to promote ongoing PCC.⁴⁰

Although we address important gaps in the existing literature, our study has several limitations. Qualitative analysis does not support causal inference and cannot be generalized to other settings caring for cancer survivors with multiple chronic conditions. In addition, the small interview sample combined with challenges recruiting males limited our ability to look at other factors such as gender, race/ethnicity, socioeconomic, clinical, and cancer-related characteristics in a meaningful way. However, our sample was drawn from a safety-net setting with high numbers of survivors with multiple chronic conditions and the purpose of this study was to explore phenomenon seen in our prior studies. Our sample only included survivors completing treatment within the last 6-18 months to limit recall bias but excludes experiences from long-term survivors. We also did not measure social desirability, although candid reports in our study suggest this was unlikely. In addition, we did not ask specific questions about the impact of having multiple chronic conditions on survivorship more broadly. Limitations for how PCC was operationalized are also suggested. Semi-structured interview questions around PCC were broad focusing on the communication exchange between survivors' and oncology care teams during the last treatment visit. We did not explore PCC across the entire cancer care continuum or with other non-oncology care team members that play a key role in improving cancer care quality and outcomes, such as primary care. Routine and ongoing assessment of PCC experiences could help to inform quality improvement initiatives but more in-depth analysis is needed to examine if the needs, preferences, and values salient to cancer survivors with multiple chronic conditions are being met.^{6,15,41}

Despite these limitations, this is one of the first exploratory qualitative studies on the experience of survivorship care planning among cancer survivors with multiple chronic conditions within a safety-net health system. Understanding the first-hand experiences of these survivors provided meaningful insights into the subtleties and complexities around the survivorship care planning process that help to clarify findings observed in prior studies conducted by our team between key elements of survivorship care planning process (i.e., PCC and health self-efficacy) to other survivorship outcomes (i.e., adherence behaviors and overall health).^{17,18} Our exploratory approach also provided an opportunity to drill down to specific yet important outcomes of PCC previously identified in the literature including knowledge in survivorship care, satisfaction with information and care received, and self-efficacy in the

ability to identify signs and symptoms of cancer recurrence.^{11,13,29,41} Importantly, our findings raise key concerns around how PCC is operationalized that, if left unaddressed, could result in misleading information about the content and quality of communication exchanges, especially among survivors' with multiple chronic conditions with limited health literacy or low patient empowerment.¹⁵

Understanding survivors' perspectives, while considering implications of cancer amid other chronic conditions, is critical for optimizing the delivering of patient-centered survivorship care. Exploratory findings from this study help to build the foundation for future research by helping to identify potential gaps and multilevel barriers in current survivorship care planning processes and models and advancing our understanding of how best to deliver more personalized and targeted survivorship care planning efforts.^{4,5,15,21,30,31,33,37} As with SCPs, health systems and care teams have traditionally focused on implementing components that align with accreditation and payment structures rather than promote the survivor's needs, values, and preferences.^{2,42,43} Multilevel efforts to enhance PCC across all care teams and enabling self-management (i.e., health self-efficacy) hold great promise for advancing patient-centered survivorship care but more work is needed to improve the operationalization and measurement of PCC to capture nuances across different populations and settings.^{6,15,42} In addition, supplementing in-depth interview data with comprehensive patient-data is key for identifying survivors with limited abilities, resources, or social support to actively engage in PCC or self-manage their survivorship care.⁴⁴

Authors' Note

All procedures performed in this study involving human subjects were in accordance with the ethical standards of the University of Texas Southwestern Medical Center (STU # 102015-090) and The University of Texas Health Science Center at Houston Institutional Review Boards (STU # 19-0068), with additional site approval by Parkland Health & Hospital System Office of Research Administration. Informed consent was obtained from all individual participants included in the study.

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Supplemental Material

Supplemental material for this article is available online.

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