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Assessing Key Stakeholders' Knowledge, Needs, and Preferences for Head and Neck Cancer Survivorship Care Plans

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Abstract

Cancer survivorship care plans (SCPs) are endorsed to support quality care for cancer survivors, but uptake is slow. We assessed knowledge, needs, and preferences for SCP content and delivery from a wide variety of stakeholders. We focused SCP content for head and neck cancer as it is a disease prone to long-term side effects requiring management from multiple providers. We conducted telephone-based, qualitative interviews. We purposively sampled head and neck cancer survivors ($n = 4$), primary care physicians in the community ($n = 5$), and providers affiliated with a large academic medical center ($n = 5$) who treat head and neck cancer, cancer specialists ($n = 6$), and nurse practitioners/supportive care staff ($n = 5$). Interviews were recorded, transcribed, and analyzed using direct content analysis. Few participants reported personal experience with SCPs, but most supported the concept. Several key themes emerged: (1) perceived ambiguity regarding roles and responsibilities for SCPs, (2) a need to tailor the content and language based on the intended recipient, (3) documentation process should be as automated and streamlined as possible, (4) concerns about using the SCP to coordinate with outside providers, and (5) that SCPs would have added value as a "living document." We also report SCP-related issues that are unique to serving patients diagnosed with head and neck cancer. Effort is needed to tailor SCPs for different recipients and optimize their potential for successful implementation, impact on care outcomes, and sustainability. Many cancer survivors may not receive a SCP as part of routine care. Survivors could engage their health care team by requesting a SCP.

Keywords Cancer survivors · Care coordination · Qualitative · Head and neck neoplasms · Survivorship care plan · Care quality

Introduction

There are more than 15 million cancer survivors living in the USA [1]. As the prevalence of survivors increases and survivors enjoy improved longevity [1], there are emerging challenges to ensuring optimal survivorship care. In their report over a decade ago, the Institute of Medicine (now National Academy of Medicine) reported that as a result of their cancer experience, survivors have persistent, long-term health needs that must be addressed [2]. Many cancer

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survivors must manage cancer-related symptoms, and side effects and late effects resulting from the cancer treatment they received, as well as unrelated chronic conditions such as hypertension and hyperlipidemia. Addressing and managing both survivors' chronic cancer-related and unrelated health needs require a multidisciplinary care team embracing survivorship care [3, 4]. Yet, for many cancer survivors that care may be poorly coordinated, particularly across multiple specialties (i.e., primary care, oncology, and others) [5].

Cancer survivorship care plans (SCPs) have been introduced as a tool to support survivors' transition from active treatment to survivorship care. SCPs are comprised of information about a survivor's cancer diagnosis, a summary of the treatment they received, and provide essential information about a survivor's health care needs to future health care providers (e.g., needed surveillance and frequency, anticipated treatment side effects). While there are commonalities in content across SCPs, there is no standardized model of survivorship care [6]. Specific standardized content and the way SCPs are integrated into clinical workflow may vary by health care organization and/or cancer type.

In 2006, the Institute of Medicine recommended widespread use of SCPs. However, penetration of SCPs in clinical practice has been slow, perhaps because of low perceived value [7]. Bringing implementation science principles into the cancer care continuum may facilitate closing the gap from moving efficacious research into cancer survivorship care delivery. By 2019, accredited institutions are required to give SCPs to all survivors finishing curative intent treatment [8]. Despite this endorsement, the evidence supporting SCPs impact on health outcomes is modest. Only a few randomized controlled trials have been conducted to evaluate SCPs [9–13]. And there is limited evidenced of improved health outcomes associated with SCPs [14]. The lack of clear evidence coupled with an immediate effort to implement SCPs indicates that there is a renewed need to optimize the content and delivery strategy associated with SCPs. Through innovative study designs, implementation science can provide a framework for developing and refining the evidence base supporting SCPs while simultaneously determining the most effective techniques to improve the distribution of SCPs, incorporate them into clinical practice, and intervene on the determinants of successful clinical implementation [15, 16].

To optimize the format, content, and delivery of SCPs and to ensure their eventual uptake, we conducted a qualitative study to gain insight from multiple stakeholders. This is an important first step toward future implementation efforts. We focused on head and neck cancer because these survivors have a variety of post-treatment side effects that require management from multiple providers.

Methods

Interview Guide Development We convened a multidisciplinary team with representatives from medical oncology, radiation oncology, primary care, health services research, and implementation science to iteratively develop a semi-structured qualitative interview guide. The objective of the interviews was to obtain perspectives from multiple stakeholders about their knowledge, informational needs, and preferences for survivorship care plan delivery. The interview guide addressed several domains: acceptability, appropriateness, feasibility, fidelity, implementation, and sustainability (Table 1). We selected these domains because of their relevance for implementing interventions into practice [17].

Participant Recruitment and Incentives To ensure that diverse perspectives are represented, we purposively sampled different types of stakeholders. We recruited head and neck cancer specialists (i.e., medical oncologists, radiation oncologists, and surgeons), head and neck cancer nurses and administrative support staff, and head and neck cancer survivors. Primary care providers who were affiliated with a large academic medical center (e.g., Duke University Medical Center) and primary care providers from the community were also recruited. We recruited participants who were heterogeneous regarding race, gender, and—for medical providers—time since completion of training. For the two samples of primary care providers, special effort was made to recruit primary care providers whose patient panel includes cancer survivors. Potential participants were sent an introductory email describing the study. Interested participants were then contacted via email and telephone to schedule an interview. Upon completion of the interview, participants were given $40 as a token of appreciation for their time.

Data Collection and Analysis We conducted semi-structured telephone-based interviews. Interviews were audio recorded using "Sparky" devices (Digitalks, Fountain Valley, CA). No identifying information was associated with the recording. We collected interviews until thematic saturation was reached (i.e., when the interviewers reported hearing no new patterns or themes from the interview participants). Interviews were transcribed in smooth verbatim style and analyzed using directed content analysis. Following a directed content analysis approach, the research team used existing theory and prior research on SCPs to develop the initial codebook before beginning the analysis [18]. Interviews were independently coded by two reviewers. Any text not categorized with the predetermined scheme was also identified and coded with emerging categories. A third reviewer adjudicated challenges between the first two reviewers. Coding was conducted iteratively. Data was managed using NVivo 11 (Australia, QSR International Pty Ltd). This study was approved by the Duke Health Institutional Review Board.

Table 1 Example of primary care provider qualitative interview guide

1. Acceptability

Now I'd like to talk with you about your experiences with survivorship care plans and thoughts about them. When we contacted you about this interview, you should have received a copy of a survivorship care plan.

- Tell me about your previous experience receiving survivorship care plans.
- What additional information should a survivorship care plan include?
- Who do you think is the best person to *review* the survivorship care plan with patients and why?

2. Appropriateness

Let's look through the content areas in the survivorship care plan. Thinking about the treatment summary….[ask questions] Thinking about the family cancer risk assessment…[ask questions] Thinking about the follow-up care plan…[ask questions] Thinking about the possible late-and long-term effects section…[ask questions] Any general thoughts? [ask questions]

- What information would you use?
- What information do you not need?
- Is anything missing?
- How much detail do you want to know?
- Any other changes or enhancements you would suggest for the SCP?

3. Feasibility

- What would make it more feasible for you to integrate the survivorship care plan into your workflow?
- How would you like to access a survivorship care plan?

4. Fidelity, implementation, and sustainability

- What challenges do you foresee in coordinating care for cancer survivors?
- What assistance would your clinic need to integrate survivorship care plans into your workflow?
- Would your clinic need additional training to use survivorship care plans efficiently?

Table 2 Characteristics of interview participants ($n = 25$)

	Percent/mean	SD (min, max)
Type of participant		
Cancer specialist	24%	–
Cancer survivor	16%	–
Academic primary care	20%	–
Non-academic primary care	20%	–
Nurse	20%	–
Gender		
Male	48%	–
Female	52%	–
Age		
30–39 years	28%	–
40–49 years	28%	–
50–59 years	32%	–
60+ years	12%	–
Years since completion of training	15	20.5 (5, 35)

Years since completion of training was not reported or not applicable for 13 participants

designed to last approximately 30 min and lasted between 18 and 50 min (mean = 29 min, SD = 9 min).

Informational Needs

All stakeholder groups reported informational needs that could be addressed through widespread adoption of SCPs (Fig. 1). Several participants reported that the information would need to be tailored based on the type of stakeholder consuming the information. For example, a community-based primary care provider reported: "... You can create these forms where you know different fields are brought to light for different people… So while the cancer doctors need to know all that stuff about diagnosis and blah, blah, blah, blah, blah, I don't need to know that stuff as a PCP. I need to know their other medical diagnoses you know." Similarly, a primary care provider at the large academic center reported: "I might not know enough to make sense of the chemotherapy... Those of us who've been out of training for a while like I, I hear names of chemotherapy drugs that you know I don't know their mechanism or their adverse effects or any of that but I think it's still useful to have it in there and then you could look it up."

Both primary care providers and cancer survivors reported that side effects (e.g., unintentional weight loss, fatigue, neuropathy) and long-term treatment effects (e.g., needing dental work, muscle pain) are important items to document in the SCP as a mechanism to facilitate communication between specialty and primary care providers. Patients were interested in having more specific details about side effects related to their radiation and chemotherapy treatment. As an example, one cancer survivor said: "One way that occurs to me that [the

Results

Across all stakeholder groups, we contacted 55 potential participants. Thematic saturation was reached after 25 individuals had completed interviews. We identified thematic saturation when (1) the interviewers reported learning no new additional information from additional participants of the same type, and (2) we had collected sufficient information to address our research question. Participants consisted of head and neck cancer survivors ($n = 4$), primary care providers in the community ($n = 5$), primary care providers affiliated with a large academic medical center ($n = 5$), head and neck cancer specialists ($n = 6$), and nurse practitioners/supportive care staff ($n = 5$). Cancer specialists, nurse practitioners, and supportive staff were recruited from a large academic medical center. Participants were balanced regarding gender and, on average, were 48 years old (SD = 12; Table 2). For those that reported time since medical school ($n = 12$), the average participant was 15 years post-training (SD = 21 years). Interviews were

Fig. 1 Example key quotes by theme

… You can create these forms where you know different fields are brought to light for different people… So while the cancer doctors need to know all that stuff about diagnosis and blah, blah, blah, blah, blah, I don't need to know that stuff as a PCP. I need to know their other medical diagnoses you know. — Community-based PCP

Informational Needs

I might not know enough to make sense of the chemotherapy… Those of us who've been out of training for a while like I, I hear names of chemotherapy drugs that you know I don't know their mechanism or their adverse effects or any of that but I think it's still useful to have it in there and then you could look it up. — Academically-affiliated PCP

Baseline information that I would think [the SCP] would need to include… in terms of what I would want to see as a primary care provider would be [a] clear direction of what the patient needs as far as additional testing and surveillance and the interval at which those should be done and specifically which of those things are going to fall to me as being the responsible [PCP] provider to order and follow up on. — Academically affiliated PCP

Clarifying Roles & Responsibilities of Allied Professionals

[The SCP should offer] clear directions to the PCP of….issues that relate to the patient's…future cancer risk [and] consider including these in your ongoing care…" — Academically affiliated PCP

It would be nice if there was some place to or some way to keep up to date. There's not a lot of go-behind checks when we actually route things in [the EHR] Epic to know that it actually got to its destination. - Nurse

Delivery Preferences

[It] might be something to work out but somehow…either sending me a message through the electronic medical record or referring me to [the] note where [providers] spell out the care plan and then I could copy and paste it from there. — Academically-affiliated PCP

Any additional information that would allow the patient to feel like it is a more [of a] lateral conversation with the primary physician like understanding…what some of the terminology indeed means… could be helpful. Otherwise it just feels…like you're [sending] information from…one medical person to another when…I don't think that gives you the level of involvement the patient can and should have in his or her own care. — Cancer survivor

Clarifying the Intended Audience & Streamlining Documentation

SCP] might have use…[would] be a section about other related conditions. And note ones that might be most affected… like diabetes and all the other things a doctor might think of that has to do with what your long [term] care [that] might be related to your cancer treatments." When reviewing components of the SCP template, all provider stakeholder groups believed that offering greater detail about dental care, prognosis, hearing loss, muscle pain, and sexual health would help tailor SCPs to meet patient's personal needs. For example, one nurse practitioner said: "…when I'm seeing a patient I like to have a little bit more information… [about] possible late and long-term side effects. I wouldn't mind having a... sentence about…fatigue… sleep disturbances" and "… if they develop hearing loss from chemotherapy an audiologist may want to know what chemotherapy they had and it would be in the care plan." Overall, primary care providers reported pain and symptom management as essential content to include in SCPs.

Of note, an additional side effect reported by cancer specialists, primary care providers, and nursing includes the financial expenses of cancer treatment. Specifically, primary care providers and nursing participants noted that SCP information should include financial changes and whether a patient needs financial and insurance counseling. One community-based primary care provider said: "I think it's good to bring up financial stress. I think that's a big concern for cancer patients." Similarly, a nurse shared that with financial stressors, changes in livelihood are also common. This nurse noted that: "For some people it's the change of livelihood. I've had patients who…teach video programs for a living or have to talk on the phone and they can't answer the phone. They can't talk clearly so they [have] to have some sort of job change."

Survivors reported that they would like to better understand their long-term prognosis and the SCP might allow for an appropriate time to engage in a discussion about this with their cancer care team. Primary care providers were also interested in understanding the cancer specialist's prognosis because it might facilitate care goal setting: "If this is a person who is unlikely to survive their cancer I'm not going to worry too much about their cholesterol or their diabetes control and you know kind of focus more

on quality of life. So I think a prognosis would be good" (academically affiliated primary care provider).

Clarifying Roles and Responsibilities of Allied Professionals Cancer specialists, nurses, and primary care providers consistently reported that SCP documentation should be completed by a lead provider (i.e., clinical team or specific provider in oncology) and, importantly, the roles of the PCP for follow-up care should be clear, outlined, and with content summarizing their responsibilities regarding screening, and surveillance. For example, one academically affiliated primary care provider said: "Baseline information that I would think [the SCP] would need to include… in terms of what I would want to see as a primary care provider, would be [a] clear direction of what the patient needs as far as additional testing and surveillance and the interval at which those should be done and specifically which of those things are going to fall to me as being the responsible [PCP] provider to order and follow up on." Another academically affiliated primary care provider also stated that: "[The SCP should offer] clear directions to the PCP of….issues that relate to the patient's…future cancer risk [and] consider including these in your ongoing care..."

Delivery Preferences

Using Sustainable and Accessible Electronic Formats to Improve Provider Communication Overall, cancer specialists and primary care providers agreed that SCPs should have a centralized location and be easily accessible through electronic health records (EHRs). The note title should be consistent and found with a searchable note title without difficulty. Moreover, providers expressed that SCPs would be most valuable if electronic SCPs could be frequently updated with pertinent information about patient needs and care over time. A nurse noted: "It would be nice if there was some place to or some way to keep up to date. There's not a lot of go-behind checks when we actually route things in [the EHR] Epic to know that it actually got to its destination." An academically affiliated primary care provider had a comparable sentiment and stated: "[It] might be something to work out but somehow…either sending me a message through the electronic medical record or referring me to [the] note where [providers] spell out the care plan and then I could copy and paste it from there." Similarly, a cancer specialist recommended that SCPs should not be standalone, one-time-use documents. Instead, SCPs should be editable documents that track salient aspects of care that change over time: "This plan [should be] more of a living document that would also…lay out what the upcoming appointments are and it may be easier for patients to detect when there's an issue." In addition to locating information through electronic medical records, patients would similarly have access to their documents to known electronic systems from their health care system (e.g., EPIC MY CHART).

Clarifying the Intended Audience for SCPs and Streamlining Documentation Cancer specialists and cancer survivors questioned who the intended recipient of the SCP should be, as this would affect the level of medical content and detail to include in the document. For example, one cancer survivor stated: "Any additional information that would allow the patient to feel like it is a more [of a] lateral conversation with the primary physician like understanding…what some of the terminology indeed means… could be helpful. Otherwise it just feels…like you're [sending] information from…one medical person to another when…I don't think that gives you the level of involvement the patient can and should have in his or her own care." Conversely, providers desired specific cancer treatment information related to diagnosis, stage, needed surveillance, and what is being asked by providers in follow-up care. For example, one cancer specialist shared: "Chemotherapy treatment is nicely laid out in terms of…cycles and…having [something] similar like [a] table for surgery would be…useful."

To streamline SCP documentation, the main recommendations included highlighting clear contact information (of provider and patient), preferred method of contact, and a future appointment list. In addition to having clear labels for the SCP document, providers endorsed having pop-up reminders in patient's electronic records and having the plan auto-populate.

SCP-Related Issues Specific to Serving Patients with Head and Neck Cancer

Symptoms and Treatment Side Effects Participants reported a host of cancer symptoms and treatment side effects that may be experienced by patients with head and neck cancer that should be addressed in the SCP. Specifically, participants mentioned (1) issues with hearing (hearing loss, ringing in the ears), (2) jaw and dental problems (trismus, jaw pain, not being able to full open the mouth, teeth extractions), (3) problems swallowing and dry mouth, (4) lymphedema, (5) facial swelling or neck stiffening, (6) persistent fatigue, (7) poor posture, and (8) difficulty with speech. Less commonly, blindness, deafness, and loss of smell were also mentioned. The severity of these symptoms and preparing survivors to experience late and long-term effects was also mentioned. For example, one nurse stated: "The dental care, people needing to get their dentures refit maybe months after treatment is done because of the ongoing changes of the jaw. Muscle spasms, cramps, trismus, esophageal strictures, xerostomia, the dry mouth and the taste changes can be, I am still hearing people… complaining about years later. A at least a few cases I've had patients say if they knew how badly they were going to feel after treatment they would have never gone through it." Another nurse stated that: "…balance issues because they can't move their neck to react to what changes in the surface they're working on or to turn to look quickly at something knocks them off their balance because they don't move that fast…" could be another concern.

Interestingly, survivors reported that they may be hesitant to mention a side effect to their providers using the SCP. One survivor reported: "I didn't bring up the ringing in my ear because I'm wearing a hearing aid and you know that's just kind of a part of what I think of as who I am now and I don't necessarily consider that a side effect unless I'm reminded of it, you know?"

Integrating Multidisciplinary Care Teams A recurring theme among providers was the need to integrate multidisciplinary care teams beyond the scope of some other cancers. Provider participants mentioned the importance of engaging speech-language pathologists; audiologists; dentists; nutritionists; ear, nose, and throat specialists; and behaviorists providing smoking and alcohol cessation counseling, in addition to traditional members of the cancer survivorship care team (e.g., primary care, oncology).

SCP Facilitating Informational Clarity Because of the diverse group of diseases encompassed under the umbrella of head and neck cancer, there was ambiguity about several tests—most notably, understanding human papillomavirus (HPV) status, when and by whom thyroid-stimulating hormone (TSH) should be tested, and understanding best practices for chest imaging. Related to HPV status, an academically affiliated PCP asked: "I know that there is increasing incidents of head and neck cancers associated with HPV but do I as a provider need to know their HPV status, I don't know?" There was also uncertainty about the appropriate frequency for TSH testing and which type of provider was responsible for ordering the test and managing thyroid dysfunction. Similarly, across all types of providers, there was uncertainty about best practices for chest imaging. Providers were unclear on what type of imaging needed to be ordered and at what frequency. There was concern about the potential impact of over-imaging from both a health and financial perspective. An academically affiliated PCP stated: "You don't want…[for] the patient [to be] billed for or be exposed to that radiation and it wasn't really done properly and if you go to order a chest CT there is like so many choices you know." Having specific guidance about appropriate imaging practices in the SCP was viewed as an asset to both primary care and cancer care providers.

Primary care providers wanted information about survivors' predicted prognosis. SCPs are generally intended for patients that received curative intent treatment. In that regard, the SCP was also viewed as important source of information that might guide decision-making about future health maintenance. An academically affiliated PCP described it this way: "If I see somebody who has had an advanced head and neck cancer and perhaps they are unlikely to survive it long-term, that person should not be getting referred for mammography or colonoscopy or whatever. I mean those things become more

harm than help, so I think you could imagine somebody reading this and they would think oh, I'm supposed to get all the cancer screening even though this is a person who likely is going to succumb to their cancer."

Discussion

While participants reported opportunities for improving SCP content and delivery, overall there was support for their use in routine survivorship care. Several key themes emerged from the interviews. First, there was perceived ambiguity regarding roles and responsibilities for SCPs. While oncology was generally viewed as the owner of the document, the specific person in the oncology care team (e.g., medical oncologist, nurse) who should be responsible for the SCP was unclear. Developing a clear plan for who is responsible for what at various points in times was universally viewed as important.

Second, noting that there are different users of SCPs, there is a need to tailor the content and language based on the intended recipient. For example, while primary care providers reported a general interest in understanding that survivors received chemotherapy, they were much less interested in the specific therapeutic agent and dosing and more interested in the implications for surveilling survivors for late effects over time. Similarly, survivors requested less technical language and a forward-thinking document (e.g., less focused on reporting diagnosis and former treatment, more focused on what will happen next). In the context of head and neck cancer specifically, survivors were interested in understanding more about what late effects they might anticipate and what supportive services might be available to them (e.g., speech language pathology, nutrition, dental care, etc.).

Third, providers universally requested that the documentation process be as automated and streamlined as possible. Providers requested better documentation of side effects, expanding beyond the physical to also include issues of financial toxicity [19]. A previous study among primary care providers who treat head and neck cancer survivors found that only 32% of PCPs felt confident that they could manage long-term effects resulting from cancer treatments and only 29% were confident that they could provide appropriate cancer screening [20]. SCPs have the potential to equip PCPs with the information necessary to more confidently manage their cancer survivors' long-term care.

Fourth, several providers expressed concerns about using the SCP to coordinate with providers outside of their health care institution. While the EHR makes SCPs accessible to those within the originating health care system, one of the goals of SCPs is to facilitate care coordination in the survivorship phase. To date, SCPs have not demonstrated effectiveness with improving care coordination [21]. Challenges that

arise from electronically sharing information across health care systems' EHRs could compromise this important goal.

Finally, several oncology and nurse participants reported that the SCP would have added value as a living document that is routinely updated as a survivor completes surveillance tests, experiences recurrences, and reports new side effects. Keeping the SCP up to date was viewed as critically important for supporting communication between members of the care team. However, the responsibility for who should be managing and updating the SCP overtime was uncertain.

Participants confirmed many physical symptoms associated with head and neck cancer treatment, but also pointed out how the timing of these issues can be delayed—delay in presentation can delay identification and management unless all providers are aware of this potential risk. Another head and neck cancer-specific issue is that of surveillance testing, with care providers noting confusion in current practice on who is responsible for such testing. Coordination among providers is particularly salient given the number of stakeholders involved in HNC care. SCPs could assist with both the issues of surveillance testing and recognition of late effects.

This project had several strengths and limitations. While we reached thematic saturation, our results may not be broadly generalizable to other cancers types, other types of clinicians, or geographic areas. While we interviewed a wide array of key stakeholders in head and neck cancer care, all from the Research Triangle area of North Carolina, it is possible that results could differ from other geographic areas or from other cancers. We also did not interview caregivers of patients with head and neck cancer, who have an important role in survivorship care.

Based on participants' responses, we have four specific recommendations for improving SCPs: (1) It is important to provide customized content for three distinct stakeholder groups—the cancer care team, primary care providers, and patients and their caregivers. These groups have unique informational and language needs. (2) Develop a SCP that is flexible in use and can be updated over time. (3) When the SCP is initially written, there should be clear communication regarding which provider will be tasked with specific responsibilities over time (e.g., updating the SCP, overseeing cancer surveillance). Anticipating these responsibilities could improve coordination. (4) Determine which format survivors prefer to receive their SCP (e.g., through an EHR patient portal, printed on paper).

Compliance with Ethical Standards

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