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Results of Engineering, Primary Care, Oncology Collaborative Regarding a Survey of Primary Care on a Re-Engineered Survivorship Care Plan

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Abstract

Survivorship care plans (SCPs) may facilitate cancer survivorship care shared between oncologists and primary care, particularly for patients more likely to receive care across healthcare systems such as rural patients. However, limited research has addressed primary care clinicians' information or workflow needs with regard to SCPs. This study's objective was to assess primary care clinicians' perceived usefulness with a *re-engineered SCP* previously developed by applying engineering approaches and informed by primary care preferences. An emailed survey of primary care clinicians assessed perceived usefulness with the *re-engineered SCP*. Clinicians were recruited across the USA from primary care practice-based research networks (PBRNs) with high concentrations of rural practices. Over 90% of respondents $(n = 111)$ agreed that (1) the *re-engineered SCP* was useful $(n = 95)$ and (2) they would want to receive a similar SCP ($n = 93$). The majority demonstrated high agreement regarding the SCP's relevance, understandability, content, and ability to help provide better survivorship care. Perceived usefulness was consistent between rural and non-rural clinicians. Suggested improvements involved decreased length, addition of a bulleted list, and electronic health record integration. Results indicate that the majority of primary care clinicians perceive the *re-engineered SCP* as useful. However, primary care clinicians indicated continued barriers despite end-user specific alterations. Future research should investigate additional strategies to support primary care survivorship-related workload, provide essential SCP content, and improve survivorship care delivery.

Keywords Survivorship care plans · Clinician satisfaction · Primary care clinic · Primary care provider · Cancer survivor · Survivorship

Introduction

Advancements in cancer treatment and screening, in conjunction with an aging population, have resulted in growing numbers of US cancer survivors [1–3]. By 2030, the predicted number of US survivors will exceed 22 million [3]. The majority of these survivors will live for more than 5 years following their diagnosis and will have been presumably treated with curative intent [1]. Each survivor has highly individualized needs that may significantly change over time and that are driven by multiple factors, such as cancer diagnoses, treatments received, and host factors, including age and comorbidities [3]. Over time, complications from cancer treatment can become more likely than recurrence for some survivors. For example, breast cancer survivors on extended endocrine therapy (e.g., more than 5 years) may face higher risk of sustaining an endocrine therapy-associated fracture than developing a recurrence [4]. Many survivorship care tasks, such as monitoring for osteoporosis resulting from breast cancer therapy [5], can be well-managed by either primary care or oncology [5]. With heightened demands on oncology services, there are growing needs for survivorship care to be shared with or transferred to primary care. The anticipated increased transition of survivorship care to primary care [2,

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3] associated with an increasing primary care workload [6] presents challenges and opportunities for improvements in coordination, communication, and collaboration between oncology and primary care [7].

Cancer survivors are understood to be an "at-risk" population, but there are less well-studied sub-groups such as rural survivors of cancer [8–12]. Approximately 20% of US cancer survivors reside in rural areas, yet they may be disadvantaged when receiving survivorship care [11, 12], partly because of the increased fragmentation from care spread across multiple health systems that are often separate from the primary care system [13]. Rural survivors are known to face increased risks of late and long-term morbidity as well as mortality [9]. These disparities have been attributed to reasons including, but not limited to: greater travel distances to access health services [11] which contributes to "appointment stacking" with associated risk of information overload [10]. Furthermore, rural survivors self-report receiving little information addressing non-medical aspects of their care including spiritual care, support groups, and or other individualized needs [8, 12]. Improved communication between oncologists and primary care clinicians could mitigate many of these mentioned challenges, and a survivorship care plan (SCP) has been proposed to facilitate shared-care communication. Despite the fact that primary care physicians (PCPs) [14, 15], advanced practice practitioners (APPs) [14], nurses [14], and survivors [16] all report the value of and willingness to use SCPs, there are consistently low rates of SCP delivery and implementation for rural [8, 12] and overall survivor populations [16]. Thus, optimizing SCPs to meet primary care needs would be a first step towards enhancing SCP use, and might be more impactful for rural cancer survivors who are likely to experience a greater burden accessing oncologists due to the disparities mentioned above.

The use of SCPs and sharing survivorship care between oncologists and primary care clinicians is not novel. Primary care clinicians have expressed preference to share survivorship care between oncologists and primary care [15], but the process is not always efficient and requires tools and resources to support coordinated care [17]. SCPs have been endorsed by national groups as a tool supporting communication, coordination, and collaboration between oncology, primary care, and survivors [15, 16]. Without coordinated care, work can be duplicated, resources wasted, responsibilities misunderstood, and required care not delivered [15]. However, reported clinician barriers to SCP use include SCP length, excessive resources required for creation and delivery, and gearing towards patient use as opposed to clinicians as end-users [7, 16]. Ongoing research has focused on improving SCPs [17, 18], yet limited literature has addressed primary care clinician information needs and support for decision-making [14, 19]. One preference repeatedly requested is SCP integration with the local electronic health record (EHR) to accommodate clinicians' workloads as well as the ability to update [17, 18]. Therefore, *re-engineering* SCPs to accommodate end-users' needs and facilitate use within the clinical workflow would ideally foster higher rates of delivery and implementation and ultimately enhance delivery of required care for vulnerable survivor populations [12].

To better address primary care survivorship-related needs, we applied an IOM-recommended systems engineering approach to re-design a sample EHR-based SCP [20]. Previously, our University of Wisconsin engineering, oncology, and primary care Collaborative focused on proposed SCP alterations [17, 18] and leveraging of the EHR [18]. However, limited previous research has tackled re-engineering SCPs informed by primary care preferences. Our research team undertook a series of primary care interviews to investigate the knowledge gap and subsequently employed an iterative design process to re-engineer the UW EHR-based SCP templates [21]. The objective of this study was to assess primary care clinician-perceived usefulness and satisfaction with this *re-engineered SCP.*

Materials and Methods

Setting

We report on the third phase of a multi-phase project conducted at the University of Wisconsin (UW) undertaken by a collaborative of engineering, oncology and primary care clinicians, survivor advocates, informaticists, and survivorship experts. In the preceding two phases, the research team conducted a series of semi-structured interviews which targeted an existing EHR-based SCP template's content, layout, format, and usability to generate a re-engineered sample care plan with the assistance of EMR analysts [21]. In the third phase, we developed a survey, informed by questions used in past work, to evaluate primary care clinician satisfaction and perceived usefulness with this *re-engineered SCP.* The study protocol was submitted and determined to be exempt from the UW's Institutional Review Board review.

Participant Population

Primary care clinicians were recruited from three primary care practice-based research network (PBRN) listservs selected for significant rural affiliations. Clinicians could include physicians (e.g., MD, DO, MD/PhD), advanced practice providers (e.g., NP, PA), or other health professionals (e.g., RN, MA, PT, OT). The listservs used to distribute the electronic survey included clinicians from 400 + clinics from three areas (North, West, and Mid-West geographic areas). The PBRN listservs (*n* = unknown) were emailed in their entirety; in addition to primary care clinicians, the listservs contained non-primary care clinicians, non-clinician affiliates, and educators. Consent to participate was based on respondents' decision to complete the emailed survey. Emails ($n = 13$) were removed from the listservs for those who had seen iterations of the SCP template in prior research phases, to minimize bias.

Survey and Sample Re-Engineered EHR-Based SCP

The survey was developed by the Collaborative, which included three physicians (combined expertise covers primary care, oncology, survivorship), a human factors engineer, two survivor advocates, and the UWCCC's Cancer Prevention and Outcomes Data (C-POD) service. Survey design and data collation were handled by C-POD. Questions were utilized from previous work [22] on provider evaluations of SCPs. Survey questions included (1) perceived SCP information relevance and understandability, (2) SCP layout, (3) perceived impact of SCP on survivorship care, and (4) a free text question "Do you have any suggestions to improve Survivorship Care Plans like this one?" Additionally, we captured basic clinician demographics, including rurality of the practice using "Please select the option that best matches or estimates the size of the community where you currently see patients." While, there is no consensus definition for rurality [9], this question accords with the Census Bureau definition where rurality is defined as territories containing 50,000 people or less [23].The 9-question survey (8 multiple-choice Likert question, 1 free text comment) was administered electronically via Qualtrics (~ 15 min to complete, including review of the sample *re-engineered SCP*). Each email contained access to a sample *re-engineered SCP* (8 pages, created for a fictious breast cancer survivor) and a hyperlink to the survey. An initial email was sent by each PBRN's director and followed by 2 reminders over the subsequent 2 weeks during January–March of 2019. The survey and sample *re-engineered SCP* are available in Supplemental Materials 1 and 3, respectively.

Data Collection and Analysis

Survey data was collected using Qualtrics™. The primary output was a response to: "This care plan would be useful in my clinical practice" on a Likert-scale (categories: strongly agree, agree, neutral, disagree, strongly disagree, no opinion). The IBM SPSS statistical software, version 25 (IBM Corp., Armonk, NY), was used to generate descriptive statistics on clinician characteristics and perceived usefulness regarding the sample *re-engineered SCP*. Exploratory analysis was performed to compare clinician perspectives by professional degrees, training, rurality, and gender; Pearson Chi-square test was used to determine statistical significance.

Results

Respondent Characteristics

A total of 111 providers responded to the first question. Four were excluded for not selecting either "I currently practice or am employed in a primary care setting," or "I previously practiced or was employed in a primary care setting." Thus, the study sample included 107 respondents. Respondents were predominantly in current practice (95 of 111, 87%) and had family medicine training (76 of 107; 71%). The time in practice averaged 19 years (range 2–43). Of the 90 respondents answering the demographic questions, the majority were female ($n = 60$; 66.7%) physicians ($n = 48$; 53%); one-third ($n = 31$; 35%) were in rural practices. See Table 1 for details on demographic characteristics.

Perceived Usefulness of the Re-Engineered SCP

As shown in Fig. 1 an overwhelming majority selected either "strongly agree" or "agree" for the questions, "Survivorship Care Plans like this would be useful to me" and "I would like to receive Survivorship Care Plans like this." Respectively, 92.6% and 90.3% of survey

Table 1 Respondent characteristics

Characteristics	%
Primary care eligibility ($n = 111$)	
Currently practice or employed in a primary care setting	86.5
Previously practiced or was employed in a primary care setting	10.8
Neither of the above	3.6
Professional degree ($n = 90$)	
Physician (e.g., MD, DO, MD/PhD)	53.3
Advanced practice providers (e.g., NP, PA)	18.9
Other (e.g., RN, MA, PT, OT)	27.8
Training ($n = 107$)	
Family practice	71
Internal medicine	11.2
Pediatrics	6.5
Obstetrics	2.8
Other	9.3
Gender ($n = 90$)	
Female	66.7
Male	32.2
I prefer not to answer	1.1
Rurality of practice location ($n = 89$)	
More than 50,000 people	62.9
50,000 people or less	34.9
I do not know	2.2

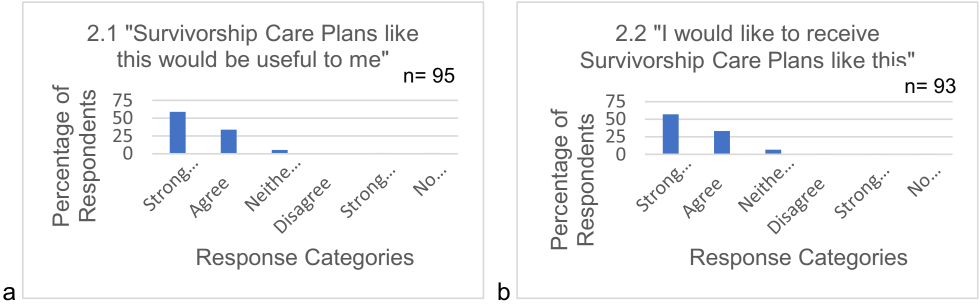

Fig. 1 Thoughts about usefulness in reference to the Survivorship Care Plan

respondents agreed with these statements regarding the *re-engineered SCP*. As shown in Fig. 2a–c, most respondents agreed that the *re-engineered SCP* was relevant, easy to understand, and that content was in the appropriate order. Most also agreed that the *re-engineered SCP* included the information they wanted to know about cancer patient's survivorship care and that it would help provide better care for patients with cancer (Fig. 2d–e). No significant differences in responses were found due to professional degree, training, rurality, and gender on exploratory analyses.

Free Text Comments for SCP Improvement

Categories identified throughout the survey's free text responses included suggestions on SCP length, EHR integration, additions, and individualization as well as the overall process of SCP use (see Supplemental Material 2). One survey respondent explained "I do think the entire document is quite long, which makes it difficult to reference quickly in a clinical setting." However, this respondent also noted, "it's also got some very important information in it, and I'm not sure what areas I would recommend shortening." Other respondents

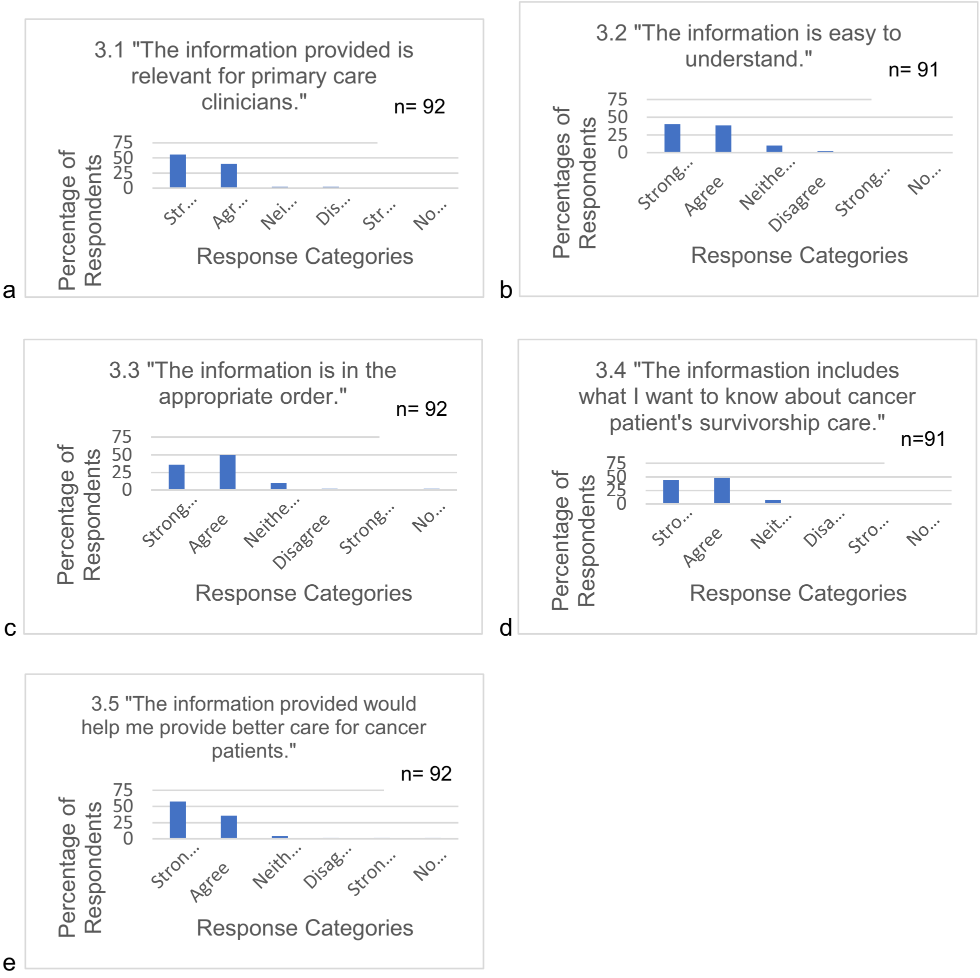

Fig. 2 Response to "Looking at the sample Survivorship Care Plan, please indicate how much you agree or disagree with the following statements"

indicated desires for a "bulleted list" or summary section at the beginning of the document and for the SCP to be found within the "problem list" or a "specific area in [EHR]." Notably, there were also a series of comments regarding advanced directives or end of life care and a need for further survivorship education. Additionally, although this study assessed a single SCP for provision to both survivors and clinicians, one survey respondent requested that instead, "there needs to be separate Survivorship Care Plans for a patient and for a patent's primary physician." Overall, similar response categories were identified by respondents with varying professional degrees.

Discussion

SCPs are currently recommended with a high-face validity [15, 16, 24], as a tool for facilitating communication, collaboration, and coordinated shared survivorship cancer care between oncology and primary care [15, 16]. While SCPs were originally designed for a patient end-user, recent SCP research has focused primary care to explore potentially impactful ways of improving SCP use [14–16, 19, 25]. The concept of creating documents that incorporate a clinician-centered approach as opposed to patient-centered might be met with some doubt or resistance. Yet, the two approaches are not mutually exclusive. By focusing on the needs of primary care clinicians, the overall aim is to improve communication and, ultimately, coordinated care delivery for cancer survivors. Clinician-centered research that supports communication and collaboration can improve patient-centered care by facilitating care coordination across varying populations. Therefore, efficiently sharing care between oncologists and primary care becomes vital; structured communication to facilitate collaboration and care coordination seems an obvious solution. However, prior studies with primary care clinicians have indicated the need for a tailored, user-centered to better support primary care needs [12, 14–16, 26, 27] along with the need for survivorship care plans to include more actionable information and responsibility delegation to treat survivors [27], the ability to track ongoing care needs and EHR compatibility [15]. To improve care coordination and delivery, our study sought to address some of these concerns directly through a user-centered assessment approach.

In this research, we focused on primary-care networks with significant rural practices, as our research has suggested that rural survivors may struggle more to bridge communication, and care coordination divides across healthcare systems and thus, might benefit more [28]. In response, our Collaborative undertook re-engineering the EHR-based templates for existing UW SCPs—informed by primary care preferences in a multi-phase project. The first two phases of the project re-engineered the SCP template through the use of primary care interviews and a rigorous iterative re-design process. Subsequently, the Collaborative conducted follow-up surveys of primary care clinicians (physicians, APPs, and other healthcare professionals) on the perceived usefulness and satisfaction of this *re-engineered SCP*. The results presented here illustrate that the majority of primary care respondents were satisfied with the *re-engineered SCP* in regard to both layout and content. Overall, both rural and non-rural primary care clinicians reported high rates of perceived usefulness and desires to receive the *re-engineered SCP*. On further exploratory analysis, there was no difference between rural and non-rural primary care clinicians' survey responses. However, the results revealed continued room for improvement.

The end goal of the multi-phase project was to have a SCP that was rated as satisfactory by a majority of primary care clinicians surveyed; additional goals included eliciting preference differences between rural and non-rural primary care clinicians. That a majority would be satisfied was predicted given that previous literature's highlighted primary care preferences as including a front page including contact information of oncology providers, diagnosis including stage, surveillance plans and responsible providers, and potential long term/late effects, all of which were included in the *re-engineered SCP* [16]. While over 85% of survey respondents reported satisfaction with the SCP, about a third to one-half of those respondents remained in the "agreed" group versus "strongly agreed;" *this was consistent across both rural and non-rural clinicians.* This observation may indicate some level of reservation with the *re-engineered SCP*. The concerns and suggestions in the form of free text responses within our survey illustrate reservation with the *re-engineered SCP* and identified potential areas of improvement. For example, during the earlier interview phases of this project, primary care clinicians were asked about receiving a separate clinician-centered SCP. Interviewees were very clear that they did not want this, as these primary care interviewees felt that they would have to review two SCP documents. However, survey respondents proposed providing separate documents for patients and their primary care clinician. Primary care clinicians express concern about the current high workload needed to use the SCP document [15, 16]. The amount of work required to find information in an SCP document may not be sustainable in clinical practice, and adding a second end-user-specific document does not decrease the workload on oncologists for document creation nor the time primary care clinicians need to find essential information. Other survey respondents reiterated similar issues with workload associated with the document, expressing concerns regarding the current length of the *re-engineered SCP*. Yet, survey respondents also affirmed the importance of the current SCP content and did not identify any sections of the document to remove. This reluctance to remove SCP content was also apparent in the earlier phases of the project. Instead, clinicians repeatedly requested concise and easy-to-reference pieces of information, often in the form of summary sections or bullet lists at the beginning of the SCP. Interestingly, when primary care clinicians were interviewed in the earlier phases of the re-design, they were somewhat conflicted about such summaries. It may be that clinicians are actually asking for more support and actionable content in order to use SCPs in a primary care setting. This is supported by respondents who suggested more EHR functionality. Ultimately, our experience conducting the interviews with primary care clinicians during earlier project phases suggests the need to move beyond current SCPs that are primarily received as static, one-time documents pushed from oncology to primary care, and which do not facilitate return feedback. Further, the similar rates of perceived usefulness, regardless of demographics and clinical setting, suggest a generalizable desire to use the *re-engineered* SCP as potential tool for improving communication and care coordination.

Given limited literature on designing SCPs to support primary care, there are many strengths to this project. This includes the iterative SCP design and evaluation process accomplished during earlier phases of this project. Primary care interviews were conducted at multiple phases of the re-design, and the team repeatedly cooperated to evaluate advised changes to the original EHR-based template. This diverse team included primary care physicians and an engineer and oncologist who both had health IT and informatics expertise, as well as an EHR analyst to optimize the SCP template for primary care use. Our survey was delivered to clinicians widely distributed throughout the USA, thus increasing generalizability. By including demographic survey questions, we were able to explore possible differences in clinician satisfaction as well as the range of preferences. Our survey also over sampled primary care clinicians that provide care in disadvantaged rural settings. Ideally, this was intended to offer insight on any gaps or specific needs for this population where care coordination may be more challenging due to fragmentation across healthcare systems [9, 11, 12, 20]. However, as with any research based on clinician surveys, the study came with some predictable limitations. With only 111 survey respondents, the response remains low—the use of unfiltered listservs makes determining a response rate difficult. Response was likely hindered by the requirement of opening an additional link containing the *re-engineered SCP*. While including an original SCP in the survey for comparison with the *re-engineered SCP* was considered, the Collaborative ultimately decided to omit this comparison on the feedback of primary care clinicians due to the increased burden that this would place on respondents and because the methods used in the prior phases of the study better facilitated such comparison. Another limitation is the lack of consensus on capturing the rurality of the participating clinicians. The Census Bureau, US Department of Agriculture Economic Research Services, and Office of Management and Budget all agree on a definition of exclusion where, "'rural' encompasses all population, housing, and territory not included within an urban area," with urban areas defined as territory containing 50,000 or more people [23]. However, clinicians may not be able to estimate what percentage of their patients comes from such territories. We elected to ask about the size of the community where the clinician's practice was located, as this was believed to be a question that respondents could accurately answer. However, community size likely under-represents the rurality of the areas where survivors seen by those clinicians actually reside.

Various next steps might advance cancer survivorship communication, collaboration, and care coordination with primary care. One valuable and necessary step, not specifically addressed by this project, is lack of primary care training on survivorship [15]. Some of the free response categories also highlighted both desires and necessity for further survivorship care education for primary care clinicians. One difficultly primary care clinicians face is understanding which survivors will receive a SCP. In our study, multiple respondents called for additional information regarding DNRs, advance directives, and end of life care—topics that might not typically be included for survivors treated with curative intent. Without communication between oncologists and primary care on what is entailed in survivorship care, patients may continue to face disjointed care regardless of an improved SCP template. Moreover, this study has uncovered the need for more research investigating alternatives to SCP documents for delivering essential survivorship information to primary care clinicians in order to optimize care coordination.

In conclusion, even with a primary care-centered *re-engineered SCP*, there remain barriers that are unlikely to be overcome by simple alterations to the SCP document, which was viewed as a static document pushed from oncologists to primary care. This finding highlights the need for more research to optimize the delivery of the essential content for adequate cancer survivorship care. However, improving coordination, collaboration, and communication between oncologists and primary care may rely instead on alternate methods of supporting the overall clinical workload for both oncologists and primary care while delivering the same important content.

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Compliance with Ethical Standards

Conflict of Interest Tevaarwerk, Amye J reports an Epic Systems family member. The rest of the authors declare that they have no conflict of interest.

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