ORIGINAL RESEARCH

Oncology and Primary Care Provider Views on Cancer Survivorship Care: Mind the Gap

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Context: **Coordination between oncology and primary care practices in cancer survivorship is lacking.**

Objective: **To identify cancer care coordination perceptions, knowledge, and practices in a sample of Oklahoma oncology care providers (ONCs) and primary care providers (PCPs) regarding post-treatment care of adult cancer survivors.**

Design: **Cross-sectional, statewide survey by mail/web link in 2014/5.**

Setting: **PCPs identified through a primary care research network, primary care organization membership lists; ONCs identified through www.Healthgrades.com.**

Participants: **Contacts who were clinically active and seeing cancer patients were eligible. The final sample size included 101 ONCs and 58 PCPs who reported actively seeing cancer patients.**

Measures: **Responses to predominately Likert scale or ranked-order questions derived from the Survey of Physician Attitudes Regarding the Care of Cancer Survivors.**

Analyses: **Chi square and t tests were performed to test bivariate associations between provider type and survey measures.**

Results: **Statistically significant differences ($P < .05$) between ONC and PCP perceptions were observed for several questions on communication between the 2 provider types, ONC perceptions of PCP ability to address survivorship care, and responsibilities for post-treatment care.**

Conclusions: **Highly discrepant perspectives between ONCs and PCPs regarding communications and responsibilities for survivorship care may lead to adverse health outcomes. Interventions aimed at improving care coordination for cancer survivors should define each provider group's responsibilities in survivorship care, and create structures and processes that foster clear channels of communication between ONC and PCP practices. (J Am Board Fam Med 2022;35:329–340.)**

Keywords: **Cancer, Cancer Survivors, Cross-Sectional Studies, Delivery of Health Care, Oklahoma, Primary Health Care, Quality Improvement, Survivorship**

Introduction

The need to improve health care delivery for those who have completed cancer treatment is accelerating. Roughly 17 million individuals in the United Sates (US) have been diagnosed with cancer, but this figure will rise to over more than 22 million individuals by 2030.[1] Cancer survivorship care, which typically focuses on the period of time after the completion of active cancer treatment, encompasses a range of complex health challenges. These include managing other chronic conditions (eg, heart disease, diabetes), monitoring for recurrent or new cancers, and addressing late effects of cancer treatment (eg, neuropathy, cardiomyopathy).[2,3] High-

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quality survivorship care also helps patients address challenging psychosocial issues caused by cancer and its treatment. Changes in relationships, employment status, and health insurance coverage can lead to increases in financial distress, anxiety and depression.[4–6] Despite the growing need for high-quality cancer survivorship care, many patients who have had cancer do not receive recommended follow-up services.[2,7,8]

The frequency of visits to oncology providers (ONCs) is associated positively with receipt of recommended follow-up testing for cancer survivors.[7] However, the majority of cancer survivors do not see ONCs regularly.[8] One study showed that by 5 years after the completion of treatment, visits to ONCs declined substantially, with only one third of cancer survivors continuing to seek care from their ONCs.[9] In contrast, nearly three quarters of these individuals continued to seek care from their primary care providers (PCPs). For a variety of chronic conditions including cancer, suboptimal care coordination and poor communication between specialists and PCPs results in fragmented care, increased costs and potentially avoidable morbidity and mortality.[10–12] The quality of cancer survivorship care depends on how well ONCs and PCPs are able to coordinate clinical services and communicate with each other, and with their mutual patients.[13,14]

Carefully implemented care coordination interventions focusing on chronic conditions, such as diabetes, for which clinical management falls within the scope of primary care practice have been shown to improve health outcomes.[15,16] Similarly, greater coordination of care between ONCs and PCPs improves the quality of and patient satisfaction with follow-up care.[17–19] Effective communication between specialists and PCPs is a fundamental aspect of these care coordination interventions. Yet, communication between ONCs and PCPs is poorly understood. Multiple models aiming to enhance ONC-PCP coordination and communication for survivorship care have been described, including primary care-based, shared-care and specialist-based models.[20–22] Despite this attention, evidence that systematic ONC-PCP care coordination and communication occurs regularly for cancer survivors is lacking.[23,24] Even primary care practices that have achieved patient-centered medical home status lack processes for delivering and coordinating cancer survivorship care.[23]

Cancer survivorship programs that capitalize on the fact that most cancer survivors continue to be seen in primary care even as they gravitate away from oncology care need to be developed and evaluated. Research, however, remains limited on how ONCs and PCPs perceive their roles in delivering care to cancer survivors,[25] how well they communicate with each other, and how the follow-up needs of cancer survivors should be integrated into primary care.[26] As a first step in building and implementing an efficacious survivorship care program, our team sought to gain a better understanding of the perspectives of both ONCs and PCPs regarding survivorship care. We investigated these issues in Oklahoma, which among all the states has the fourth worst cancer mortality rate,[27] and the third and fifth lowest supplies of specialist and primary care physicians, respectively.[28] A statewide survey was conducted to gather ONC and PCP perspectives on their communications regarding survivorship care, and to explore ONC and PCP views on their roles in the management of survivorship care for patients.

Methods

Sample and Participants

We conducted a cross-sectional, statewide survey by mail/web link in 2014/5 of oncology care providers (ONCs) and primary care providers (PCPs) to examine the perspectives of these 2 groups on treating patients who have completed the active phase of cancer treatment (ie, cancer survivors). We sought to draw, insofar as possible, a representative sample of ONCs and PCPs in Oklahoma who treat cancer survivors. However, no definitive membership lists of ONCs or PCPs were available, so the sampling frame included identification of ONCs through www.Healthgrades.com, mailing lists from state oncology organizations, and mailing lists of other, predominately surgical, specialist organizations whose members often treat cancer patients (eg, urologists). For PCPs, the sample was drawn by sending initial surveys by mail to addresses documented on professional membership lists of state primary care organizations (eg, Oklahoma Academy of Family Physicians) and via the listserv of a statewide practice based research network. All contacts were invited to participate if they were ONCs or PCPS and clinically active in seeing patients who had cancer or had been treated for it.

Because nurse practitioners, physician assistants and registered nurses ae often involved in cancer survivorship care, these individuals as well as physicians were allowed to respond. The sample of ONCs included medical oncologists, gynecological oncologists, surgical oncologists (including the disciplines of otolaryngology, thoracic surgery, gastrointestinal surgery, and urology), and radiation oncologists. Respondents had the option of returning surveys by postage prepaid mailing envelopes or by completing an online version of the instrument. The final sample included 58 PCPs and 101 ONCs who met these criteria. The study was approved by the University of Oklahoma Health Sciences Center Institutional Review Board.

Measures

Survey

Participants were asked to respond to predominately Likert scale or ranked order questions derived from the National Cancer Institute/American Cancer Society Survey of Physician Attitudes Regarding the Care of Cancer Survivors (SPARCCS). The SPARCCS survey can be downloaded at http://healthservices.cancer.gov; detailed methods have been published elsewhere.[29]

SPARCCS was selected as the basis for the present PCP and ONC surveys because its questions permit comparisons by provider type of the perceived roles, knowledge, and practices of these 2 key provider groups with regard to follow-up cancer survivorship care, which involves surveillance for cancer progression or recurrence, identification of second cancers, and managing the medical and psychosocial late effects of cancer or its treatment. Online Appendices 1 (ONC) and 2 (PCP) present full surveys used in the current study.

Comparisons between ONCs and PCPs were made in the following thematic areas: 1) provider and practice characteristics (eg, years in practice, use of electronic data systems, practice-level capacity for change); 2) provision of cancer care coordination services (eg, communication between ONCs and PCPs regarding various aspects of patient care); 3) perceived confidence and skill of PCPs in providing cancer survivorship care (eg, skill in ordering appropriate cancer follow-up tests and detecting recurrences or late effects of cancer treatment); 4) preferred role in cancer survivorship care (frequency take responsibility for screening for other new cancer, detecting recurrences, etc.) and 5) preferred practice model for cancer survivor ship care (eg, care led by ONCs, PCPs, specialized survivorship clinics, or shared care).

Analyses

Frequency distributions were calculated for ONCs versus PCPs using the SAS software suite (v9.4; Cary, NC). Chi square testing with a 2-tailed $P < .05$ was performed to assess associations between provider type and survey measures. The small sample size limited the ability to adjust for potentially meaningful provider- or practice-level factors.

Results

Regarding provider characteristics, PCPs were significantly more likely than ONCs to have spent more years in practice ($P = .03$) and worked in a rural location ($P = .05$) (Table 1). In addition, PCPs reported higher weekly patient volume ($P = .03$) than ONCs. Regarding practice characteristics, no statistically significant differences between ONCs and PCPs were observed for most measures, such as use of electronic billing systems or electronic health records. However, the difference between ONCs and PCPs in referral processes approached statistical significance, indicating that ONCs may be less likely than PCPs to have defined referral processes or dedicated personnel responsible for referrals ($P = .06$). In contrast, PCPs were significantly less likely than ONCs to report having defined care coordination processes or dedicated personnel responsible for care coordination ($P = .04$). The ONC-PCP difference in perceived practice change capacity was not statistically significant, with only about approximately 1 quarter of both ONCs and PCPs working in practices characterized as welcoming change.

Table 2 shows statistically significant ONC-PCP differences for several aspects of cancer care coordination. ONCs were more likely than PCPS to report they communicate routinely with other providers about who will follow the patient for cancer ($P < .001$) and who will handle cancer patients' other medical issues ($P = .03$). The proportion of ONCs who reported sending comprehensive cancer treatment summaries to PCPs was much higher than the proportion of PCPs reporting having received such summaries from ONCs ($P < .001$). In addition, a higher proportion of ONCs reported providing information to PCPs in a timely manner

Table 1. Oncology Provider (ONC) and Primary Care Provider (PCP) Characteristics

Selected Characteristics	ONC (n = 101)	PCP (n = 58)	p-Value
Provider Discipline (%)			0.29
Physician	73.8	82.4	
Other Provider type (ARNP, PA, or RN)	26.2	17.6	
Years in practice (%)			**0.03**
<10	24.7	12	
10 to 19	18.2	40	
20 to 29	27.3	18	
30 or more	29.9	30	
Practice location (%)			**0.05**
Urban	65.9	45.1	
Suburban	18.3	23.5	
Rural	15.9	31.4	
Number of patients seen per week			**0.03**
25 or fewer	30.0	11.8	
26 to 50	23.8	21.6	
51 to 75	23.8	19.6	
76 to 100	15.0	23.5	
101 or more-	7.4	23.5	
Practice size			
Solo practice	13.4	7.8	0.21
2 to 5 clinicians	28.1	31.4	
5 to 10 clinicians	23.2	11.8	
>10 clinicians	35.3	49.0	
Practice has electronic billing system (% yes)	57.4	53.7	0.66
Practice has electronic health record (% yes)	67.8	57.3	0.14
Practice has secure messaging (% yes)	47.8	47.6	1.0
Practice has patient registry/tracking available (% yes)	35.7	26.8	0.22
Practice Referral Processes (%)			
No specific system (handled case-by-case)	43.6	21.6	0.06
Protocols and tracking system	10.2	13.7	
Comprehensive, health system-wide referral system	15.4	15.7	
All of the above + dedicated personnel	30.8	49.0	
Practice care coordination processes (%)			
No specific system (handled case-by-case)	28.6	35.3	**0.04**
Organized communication approach (e.g., messaging)	24.7	37.3	
Communication approach and dedicated personnel	27.3	7.8	
Comprehensive, health system-wide care coordination	19.4	19.6	
Perceived organizational/practice change capacity (%)			
Practice has not tried to implement changes or improvements in care processes	3.7	0	0.32
It has been very difficult to implement changes	7.4	11.8	
It has been challenging, but possible to implement changes	24.7	35.3	
Several changes/improvements have been implemented successfully	37.0	25.5	
The organization welcomes change and has a process to implement care improvements	27.2	27.5	

Abbreviations: ARNP, advanced registered nurse practitioner; PA, physician assistant; RN, registered nurses.

than PCPs reported receiving timely information from ONCs ($P < .001$). ONCs were more likely than PCPs to report they help patients with recurrent cancer make treatment decisions ($P < .001$) and have discussions with patients about future care and surveillance ($P < .001$). In addition, ONCs were much more likely than PCPs to report that they understand the division of care responsibilities between ONCs and PCPs ($P < .001$). The proportion of ONCs who reported sending information to PCPs that cancer had recurred was much higher than the proportion of

Table 2. Provision of Cancer Care Coordination Services by Oncology Providers (ONCs) and Primary Care Providers (PCPs)

	ONC	PCP	p-Value
How often do you routinely communicate with patient's other provider(s) about which provider(s) will. . .			
. . .follow the patient for cancer? (%)			**<0.001**
Never	6.1	10.9	
Rarely	3.7	41.8	
Sometimes	17.1	20.0	
Often	36.6	18.2	
Always/Almost Always	36.6	9.1	
. . .handle patient's other medical issues? (%)			**0.028**
Never	7.2	12.7	
Rarely	15.7	29.1	
Sometimes	27.7	32.7	
Often	26.5	18.2	
Always/Almost Always	22.9	7.3	
How often do you. . .			
. . . send (ONC)/receive (PCP) a comprehensive summary including detailed cancer treatment information from the ONC? (%)			
Never	4.9	10.5	**<0.001**
Rarely	6.1	28.9	
Sometimes	23.2	26.3	
Often	23.2	28.9	
Always/Almost Always	35.4	5.3	
N/A	7.3	0.0	
. . .provide (ONC)/receive (PCP) information from the oncologist in a timely manner? (%)			
Never	1.2	7.9	**<0.001**
Rarely	1.2	18.4	
Sometimes	13.6	34.2	
Often	32.1	34.2	
Always/Almost Always	46.9	7.9	
N/A	4.9	0.0	
. . .experience difficulties transferring patient care responsibilities between you and the PCP/ONC? (%)			
Never	3.7	2.0	0.603
Rarely	21.0	22.0	
Sometimes	42.0	32.0	
Often	18.5	24.0	
Always/Almost Always	9.9	18.0	
N/A	4.9	2.0	
. . .assist patients with recurrent cancer in making decisions about whether and how their cancer should be treated? (%)			
Never	2.4	8.0	<0.001
Rarely	4.9	20.0	
Sometimes	6.1	38.0	
Often	29.3	28.0	
Always/Almost Always	54.9	6.0	
N/A	2.4	0.0	
. . .have a specific discussion with the patient regarding recommendations for future care and surveillance? (%)			
Never	1.2	6.0	**<0.001**
Rarely	1.2	26.0	
Sometimes	7.4	28.0	
Often	21.0	34.0	
Always/Almost Always	64.2	6.0	
N/A	4.9	0	

Continued

Table 2. Continued

	ONC	PCP	p-Value
. . .clearly understand the division of care responsibilities between you and the ONC/PCP team? (%)			
Never	1.2	16.2	**<0.001**
Rarely	8.6	27.0	
Sometimes	28.4	37.8	
Often	28.4	16.2	
Always/Almost Always	32.1	2.7	
N/A	1.2	0	
. . .provide (ONCs)/receive (PCPs) information that cancer has recurred? (%)			
Never	1.3	8.3	**<0.001**
Rarely	7.5	22.9	
Sometimes	11.3	31.3	
Often	17.5	31.3	
Always/Almost Always	56.3	6.3	
N/A	6.3	0	

PCPs who reported receiving information regarding recurrence ($P < .001$). Among ONCs, 27.1% indicated they "often, almost always, or always" provided patients with written follow-up care plans summarizing past treatments and recommendations for future care and surveillance (data not shown). Among PCPs, only 2.7% reported that they "often, almost always, or always" received an explicit follow-up care plan from the ONC with recommendations for future care and surveillance (data not shown).

Table 3 presents findings regarding confidence and perceived skill in the provision of cancer survivorship care among ONCs and PCPs. Compared with PCPs, ONCs reported higher confidence in ordering appropriate surveillance testing to detect recurrent cancer ($P < .001$) and detecting physical adverse effects of cancer or cancer treatment ($P < .001$). The ONC-PCP difference for confidence in addressing psychosocial outcomes of cancer or its treatment was nearly significant ($P = .052$), with ONCs reporting greater confidence in this realm. Table 2 also presents findings from the 3 survey questions on the perceived role of PCPs in survivorship care. Compared with PCPs, ONCs were much more likely to disagree with these statements, which included: PCPs have the skills needed to initiate appropriate screening or diagnostic work-up ($P < .001$), PCPs should have primary responsibility for cancer-related follow-up ($P = .02$), and PCPs are better able than ONCs to provide psychosocial support ($P < .001$).

Table 4 shows that ONCs were less likely than PCPs to report that they screen patients for other new types of primary cancers ($P < .001$) and evaluate patients for adverse psychological effects of cancer or its treatment ($P = .016$). However, ONCs were more likely than PCPs to report that they evaluate patients for recurrence of cancer ($P < .001$) and for long-term and late physical adverse effects of cancer and cancer treatment ($P < .001$).

Figure 1 shows the discrepancy between ONCs and PCPs on their ranking of 4 approaches to survivorship care for patients with early-stage cancer. The first choice among ONCs was an ONC-led survivorship care model, but this was the second choice among PCPs. In contrast the first choice among PCPs was an ONC-PCP shared care model, but this was the third choice of ONCs. The second choice of ONCs, specialized survivorship care clinics, was the fourth (last) choice among PCPs.

Discussion

Our findings parallel other reports documenting poor communication and lack of care coordination between specialist physicians and PCPs.[10,11,30–32] We observed a discrepancy in which most ONCs reported that they provided information on survivorship care to PCPs, yet few PCPs reported receipt of this information. Furthermore, most ONCs felt that PCPs do not possess the skills to conduct follow-up cancer surveillance or provide

Table 3. Confidence and Perceived Skill in the Provision of Cancer Survivorship Care by Oncology Providers (ONCs) and Primary Care Providers (PCPs)

	ONC	PCP	p-Value
Amount of confidence in knowledge of cancer-related follow-up care for survivors:			
Order appropriate surveillance testing to detect recurrent cancer (%)			
Not at all confident	1.2	25.5	**<0.001**
Somewhat confident	20.9	49.1	
Very confident	77.9	23.6	
Don't know	0.0	1.8	
Detect long-term and late physical adverse effects of cancer and cancer treatment (%)			
Not at all confident	2.3	25.5	**<0.001**
Somewhat confident	30.2	58.2	
Very confident	67.4	16.4	
Don't know	0.0	0.0	
Address adverse psychosocial outcomes of cancer or its treatment (%)			
Not at all confident	2.3	12.7	0.052
Somewhat confident	50.0	43.6	
Very confident	47.7	43.6	
Don't know	0.0	0.0	
To what extent do you agree/disagree with statements regarding patients who have completed active cancer treatment?			
PCPs have the skills needed to provide follow-up care related to the effects of cancer or its treatment for survivors (%)			
Strongly disagree	22.6	2.4	**<0.001**
Somewhat disagree	41.7	7.3	
Neither Agree nor disagree	9.5	34.1	
Somewhat agree	19.0	34.1	
Strongly agree	7.1	22.0	
PCPs have the skills needed to initiate appropriate screening or diagnostic work- up to detect recurrent cancer (%)			
Strongly disagree	29.4	1.9	**<0.001**
Somewhat disagree	40.0	14.8	
Neither Agree nor disagree	7.1	24.1	
Somewhat agree	15.3	35.2	
Strongly agree	8.2	24.1	
PCPs should have primary responsibility for cancer-related follow-up for survivors (%)			
Strongly disagree	40.0	12.5	**0.002**
Somewhat disagree	42.4	37.5	
Neither Agree nor disagree	4.7	17.5	
Somewhat agree	10.6	25.0	
Strongly agree	2.4	7.5	
PCPs are better able than ONCs to provide psychosocial support for survivors (%)			
Strongly disagree	36.5	5.6	**<0.001**
Somewhat disagree	30.6	9.3	
Neither Agree nor disagree	18.8	24.1	
Somewhat agree	10.6	27.8	
Strongly agree	3.5	33.3	

psychosocial support for patients who have had cancer. In addition, most ONCs preferred that survivorship care be conducted by ONCs or by specialized survivorship care clinics, whereas PCPs tended to prefer a shared-care approach to survivorship care.

This lack of engagement between ONCs and PCPs is concerning given that the majority of cancer survivors do not see ONCs regularly,[8,33] and visits to ONCs decline substantially by 5 years after the completion of cancer treatment.[9] In contrast, most cancer survivors continue to visit their PCPs,

Table 4. Oncology Provider (ONC) and Primary Care Provider (PCP) Perceived Role in Cancer Survivorship Care

	ONC	PCP	p-Value
For patients who have completed cancer treatment, how often take responsibility for…			
…screening for other new primary cancers (%)			
Never	10.8	2.6	**<0.001**
Rarely	20.5	0	
Sometimes	22.9	5.1	
Often	15.7	30.8	
Almost/Almost Always	22.9	61.5	
N/A	7.2	0.0	
…evaluating patients for recurrence of cancer (%)			
Never	2.4	2.0	**<0.001**
Rarely	6.0	7.8	
Sometimes	2.4	31.4	
Often	13.3	45.1	
Almost/Almost Always	67.5	13.7	
N/A	8.4	0.0	
…evaluating patients for adverse psychological effects of cancer or its treatment (%)			
Never	6.0	0	**0.016**
Rarely	13.3	0	
Sometimes	27.7	33.3	
Often	24.1	46.2	
Almost/Almost Always	20.5	17.9	
N/A	8.4	2.6	
…evaluating patients for long-term and late physical adverse effects of cancer and cancer (%)			
Never	3.7	0	**<0.001**
Rarely	6.2	12.0	
Sometimes	12.3	38.0	
Often	32.1	38.0	
Almost/Almost Always	37.0	12.0	
N/A	8.6	0.0	

and PCPs frequently address patient survivorship care needs.[9,34] The deficits in ONC-PCP coordination observed by us and others[29,35] can impede desirable outcomes by delaying follow-up testing and by missing opportunities to identify late effects of treatments.[36–38]

The quality of cancer survivorship care hinges on how well ONCs and PCPs can bridge these differences. In recognition of the need to improve ONC-PCP coordination, the Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition* highlighted coordination between ONCs and PCPs as 1 of 4 key components of survivorship care.[2] Although this seminal report illuminated the issue of poor ONC-PCP care coordination, it provided little evidence-based guidance on how ONCs and PCPS could improve their interactions to optimize survivorship care delivery. One major barrier to achieving effective ONC-PCP care coordination is that ONCs and PCPs in the United States typically work within separate health care systems.[39] Moreover, our findings reveal that only about approximately one quarter of ONCs and PCPs reported working in practices welcoming change. Given these organizational barriers, it is unsurprising that relatively little attention has been paid to developing and testing interventions to improve survivorship care, and that many of these attempts have faltered.

For example, standalone survivorship care plans (SCPs) have been developed to improve communication from ONCs,[40,41] so have become a standard of care.[42,43] Yet, SCPs alone have not been shown unequivocally to improve outcomes,[44–46] and many oncology practices nay not have the time or resources that are required to complete these forms. Modifying electronic health record (EHR) systems to improve ONC-PCP communication could also help, but can be difficult given the incompatibilities of EHR software products and the inability of health information exchanges that link EHRs to provide granular data on cancer survivorship.

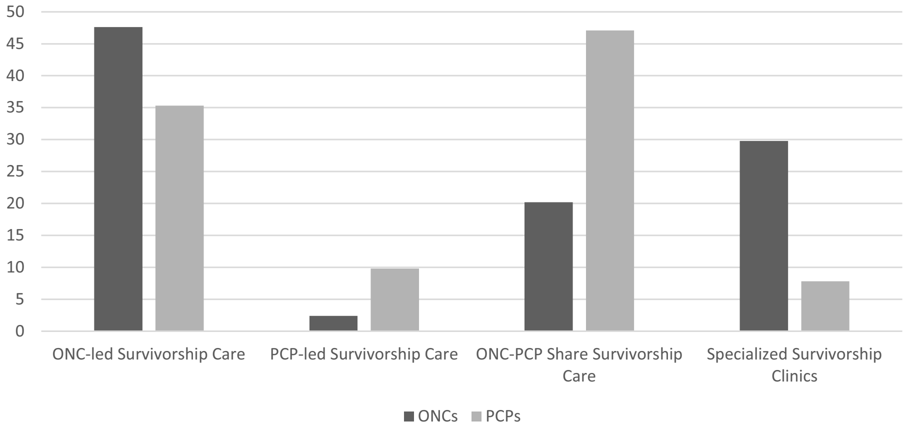
Another key barrier to improving survivorship care coordination is that ONCs and PCPs disagree fundamentally on how care for cancer survivors should be delivered. In our study, ONCs favored oncologist-led clinics followed by specialized survivorship care clinics. In contrast, nearly half of PCPs favored a shared-care model in which PCPs and ONCs jointly manage survivorship. Specialized clinics were PCPs least favored option. A similar discordance between ONCs and PCPs in preferred survivorship care delivery models has been observed by others.[35] In addition, many ONCs in our and other studies express skepticism that PCPs have the skills needed to initiate appropriate screening or diagnostic work-up for cancer survivors.[35,47] Given these differences, it is unsurprising that the quality of follow-up survivorship care has been shown to be suboptimal,[48] and that many survivorship outcomes are overlooked by the health care system.[8,49]

Because ONCs and PCPs largely operate in separate spheres both in terms of how their clinics are organized and how they think about their roles in cancer survivorship care, we believe research is needed to develop and test interventions that can bridge these differences. Given that the growing number of cancer survivors will further strain ONC workforce supply and given that most cancer survivors stop seeing ONCs by 5 years post-treatment, we feel interventions to improve survivorship care coordination should not create new "carve out" services that would further compartmentalize the delivery of survivorship care. Instead, a major goal would be to help PCPs to know what to watch for and when to refer back to the cancer specialists.

One straightforward intervention that seems feasible would be to ensure that direct, structured personal communication between ONC and PCP practices occurs regularly. Ideally, this communication would be led by individuals with clinical judgment, such as nurse care coordinators, as many PCP practices already have nurses on staff who could take on this role. Such a point person could reach out periodically to counterparts at ONC practices to gather, organize and transmit clinically actionable information on survivorship care to PCPs. The point person could also contact patients to screen for psychological and financial distress and other patient concerns. One advantage is that activities nested within in primary care could be accomplished whether or not the oncology site regularly completes SCPs or provides specialized survivorship care services. A similar approach has been implemented and evaluated for rural preventive services.[50] This mode of communication was nearly unanimously viewed as helpful by PCPs, which provides justification for developing and testing a similar approach for cancer survivorship care.

Another potential solution that has gained attention is to risk-stratify patients into survivorship care pathways based on the complexity of their ongoing needs and the types of providers their personalized pathway requires.[51] This approach has been implemented successfully in England and Northern Ireland,[52,53] which have single-payer systems.

Figure 1. Preferred Approach to Survivorship Care for Patients with Early-Stage Cancer. Abbreviations: ONCs, oncology care providers; PCPs, primary care providers.



Implementation and evaluation of personalized, risk-stratified survivorship care across a variety of US health care settings merits attention, especially as value-based care gains traction. In particular, its application might be most feasible for early-stage, relatively common cancers having a good prognosis, as recent research shows promise in delivering survivorship care within the primary care setting to women with early-stage breast cancer.[54] In addition, implementation and evaluation of interprofessional training in the use of a risk-stratified approach to cancer survivorship care is warranted, given that many primary care providers express a need to gain skills in this area.[29,5557,55,56,57]

Our findings are subject to limitations. The survey was conducted in Oklahoma, which is a highly rural state with a disproportionate cancer burden and a low supply of ONCs and PCPs. Finding cost-effective solutions to cancer care coordination that can work in Oklahoma may not generalize to all geographic locations but may have important implications for locations with similar profiles. Because the small sample size precluded comparison of rural-urban differences in provider views about survivorship care needs, additional research would be needed to examine this issue. In addition, we lacked a definitive sampling frame for identifying ONCs and PCPs, although used a variety of sampling strategies to try to contact as many of these providers statewide as possible.

The sample included physicians, advanced practice nurses, and physician assistants. Experiences, perceptions and beliefs about cancer survivorship care could vary among these provider groups, but the small sample size limited our ability to explore this issue. It is possible that providers who have recently treated patients with cancer may have greater recall of whether information was communicated between oncology and primary care than their counterparts who have not recently seen these patients. In addition, oncology-primary care communications for patients who are critically ill may be recalled more vividly than for those who have milder illness. Moreover, instances in which communication between oncology and primary care was suboptimal may have a greater impact on recall than instances in which this information was communicated smoothly. Prospective data collection could help confirm or refute whether recall bias affects findings, but a prospective design was outside the scope of this small pilot study.

Although our sample size was small, our findings were strikingly similar to those reported by others.[29,35] Because our survey was anonymous, ONC and PCP responses could not be linked. The data are now several years old, but the issue of the lack of coordination between oncology and primary care remains relevant.[51] Finally, this report does not summarize companion qualitative research we are conducting (manuscript under review) that provides a richer understanding from ONCs, PCPs and patients on how to configure interventions to improve survivorship care. Importantly, this qualitative study will add patient perspectives on how and where they want to receive survivorship care.

Conclusion

ONCs and PCPs have widely divergent perspectives on cancer survivorship care, but both groups have vital roles in providing health care for patients who have been treated for cancer. We found that many PCPs indicated an interest in a shared-care approach to survivorship care. This is important because many patients stop seeing ONCs regularly for survivorship care and these numbers are likely to increase as the number of cancer survivors in the US grows. Effective interventions to improve ONC-PCP communications are needed, as are interventions to clarify provider roles in survivorship care. Poor patient outcomes that could be reversed through improved survivorship care will persist unless improvements in PCP-ONC care coordination are made.

Preliminary data from this study were presented at the 2015 North American Primary Care Research Group (NAPCRG) Annual Meeting; October 26, 2015; Cancun, Mexico.

To see this article online, please go to: http://jabfm.org/content/35/2/329.full.

References

1. American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2019–2021. American Cancer Society. Published 2019.
2. Hewitt M, Greenfield S, Stovall E. *From cancer patient to cancer survivor: lost in transition. Committee on Cancer Survivorship, Improving Care and Quality of Life.* Washington, DC:: National Cancer Policy Board, Institute of Medicine, and National Research Council, The National Academies Press; 2006.
3. Hawkes AL, Lynch BM, Owen N, Aitken JF. Lifestyle factors associated concurrently and

prospectively with co-morbid cardiovascular disease in a population-based cohort of colorectal cancer survivors. Eur J Cancer 2011;47: 267–76.

4. Armes J, Crowe M, Colbourne L, et al. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. J Clin Oncol 2009;27:6172–9.
5. Aaronson NK, Mattioli V, Minton O, et al. Beyond treatment - Psychosocial and behavioural issues in cancer survivorship research and practice. EJC Suppl 2014;12:54–64.
6. Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial Hardships Experienced by Cancer Survivors: A Systematic Review. J Natl Cancer Inst 2017;109.
7. Keating NL, Landrum MB, Guadagnoli E, Winer EP, Ayanian JZ. Factors related to underuse of surveillance mammography among breast cancer survivors. JCO 2006;24:85–94.
8. Snyder CF, Earle CC, Herbert RJ, Neville BA, Blackford AL, Frick KD. Preventive care for colorectal cancer survivors: a 5-year longitudinal study. JCO 2008;26:1073–9.
9. Pollack LA, Adamache W, Ryerson AB, Eheman CR, Richardson LC. Care of long-term cancer survivors: physicians seen by Medicare enrollees surviving longer than 5 years. Cancer 2009;115: 5284–95.
10. McGlynn EA, Asch SM, Adams J, et al. The quality of health care delivered to adults in the United States. N Engl J Med 2003;348:2635–45.
11. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press; 2001.
12. Forster AJ, Murff HJ, Peterson JF, Gandhi TK, Bates DW. The incidence and severity of adverse events affecting patients after discharge from the hospital. Ann Intern Med 2003;138:161–7.
13. Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. J Clin Oncol 2006;24:5112–6.
14. Grunfeld E. Looking beyond survival: how are we looking at survivorship? J Clin Oncol 2006;24: 5166–9.
15. Renders CM, Valk GD, de Sonnaville JJ, et al. Quality of care for patients with Type 2 diabetes mellitus–a long-term comparison of two quality improvement programmes in the Netherlands. Diabet Med 2003;20:846–52.
16. Peikes D, Chen A, Schore J, Brown R. Effects of care coordination on hospitalization, quality of care, and health care expenditures among Medicare beneficiaries: 15 randomized trials. JAMA 2009; 301:603–18.
17. Cheung WY, Neville BA, Cameron DB, Cook EF, Earle CC. Comparisons of patient and physician expectations for cancer survivorship care. J Clin Oncol 2009;27:2489–95.
18. Grunfeld E, Levine MN, Julian JA, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. JCO 2006;24: 848–55.
19. Nekhlyudov L, Latosinsky S. The interface of primary and oncology specialty care: from symptoms to diagnosis. J Natl Cancer Inst Monogr 2010; 2010:11–7.
20. Madarnas Y, Joy AA, Verma S, Sehdev S, Lam W, Sideris L. Models of care for early-stage breast cancer in Canada. Curr Oncol 2011;18 Suppl 1: S10–19.
21. Oeffinger KC, McCabe MS. Models for delivering survivorship care. J Clin Oncol 2006;24: 5117–24.
22. Cohen HJ. A model for the shared care of elderly patients with cancer. J Am Geriatr Soc 2009;57 Suppl 2:S300–302.
23. Rubinstein EB, Miller WL, Hudson SV, et al. Cancer Survivorship Care in Advanced Primary Care Practices: A Qualitative Study of Challenges and Opportunities. JAMA Intern Med 2017;177: 1726–32.
24. Tsui J, Hudson SV, Rubinstein EB, et al. A mixed-methods analysis of the capacity of the Patient-Centered Medical Home to implement care coordination services for cancer survivors. Transl Behav Med 2018;8:319–27.
25. Lawrence RA, McLoone JK, Wakefield CE, Cohn RJ. Primary Care Physicians' Perspectives of Their Role in Cancer Care: A Systematic Review. J Gen Intern Med 2016;31:1222–36.
26. Nekhlyudov L, O'Malley DM, Hudson SV. Integrating primary care providers in the care of cancer survivors: gaps in evidence and future opportunities. Lancet Oncol 2017;18:e30–e38.
27. CDC/National Center for Health Statistics. Cancer Mortality by State. https://www.cdc.gov/nchs/pressroom/sosmap/cancer_mortality/cancer.htm. Accessed July 25, 2020.
28. Association of American Medical Colleges. State Physician Workforce Data Report; Oklahoma Physician Workforce Profile. https://www.aamc.org/system/files/2019-12/state-physician-Oklahoma-2019%5B1%5D.pdf. Accessed July 25, 2020.
29. Potosky AL, Han PK, Rowland J, et al. Differences between primary care physicians' and oncologists' knowledge, attitudes and practices regarding the care of cancer survivors. J Gen Intern Med 2011;26:1403–10.
30. Forrest CB, Glade GB, Baker AE, Bocian A, von Schrader S, Starfield B. Coordination of specialty referrals and physician satisfaction with referral care. Arch Pediatr Adolesc Med 2000;154:499–506.

31. Kripalani S, LeFevre F, Phillips CO, Williams MV, Basaviah P, Baker DW. Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. JAMA 2007;297:831–41.
32. Bodenheimer T. Coordinating care–a perilous journey through the health care system. N Engl J Med 2008;358:1064–71.
33. Keating NL, Landrum MB, Guadagnoli E, Winer EP, Ayanian JZ. Surveillance testing among survivors of early-stage breast cancer. JCO 2007;25:1074–81.
34. Snyder CF, Frick KD, Herbert RJ, et al. Comorbid condition care quality in cancer survivors: role of primary care and specialty providers and care coordination. J Cancer Surviv 2015;9:641–9.
35. Cheung WY, Aziz N, Noone AM, et al. Physician preferences and attitudes regarding different models of cancer survivorship care: a comparison of primary care providers and oncologists. J Cancer Surviv 2013;7:343–54.
36. Halpern MT, Viswanathan M, Evans TS, Birken SA, Basch E, Mayer DK. Models of Cancer Survivorship Care: Overview and Summary of Current Evidence. J Oncol Pract 2015;11:e19-27–e27.
37. Dossett LA, Hudson JN, Morris AM, et al. The primary care provider (PCP)-cancer specialist relationship: A systematic review and mixed-methods metasynthesis. CA Cancer J Clin 2017;67:156–69.
38. Jefford M, Baravelli C, Dudgeon P, et al. Tailored chemotherapy information faxed to general practitioners improves confidence in managing adverse effects and satisfaction with shared care: results from a randomized controlled trial. JCO 2008;26: 2272–7.
39. Prouty CD, Mazor KM, Greene SM, et al. Providers' perceptions of communication breakdowns in cancer care. J Gen Intern Med 2014;29: 1122–30.
40. Jacobs LA, Palmer SC, Schwartz LA, et al. Adult cancer survivorship: evolution, research, and planning care. CA Cancer J Clin 2009;59:391–410.
41. Ganz PA. Survivorship: adult cancer survivors. Prim Care 2009;36:721–41.
42. McCabe MS, Bhatia S, Oeffinger KC, et al. American Society of Clinical Oncology statement: achieving high-quality cancer survivorship care. J Clin Oncol 2013;31:631–40.
43. American College of Surgeons Commission on Cancer. *Cancer Program Standards 2012: Ensuring Patient-Centered Care*. Chicago, IL 2011.
44. Mayer DK, Birken SA, Check DK, Chen RC. Summing it up: an integrative review of studies of cancer survivorship care plans (2006-2013). Cancer 2015;121:978–96.
45. Blanch-Hartigan D, Forsythe LP, Alfano CM, et al. Provision and discussion of survivorship care plans among cancer survivors: results of a nationally representative survey of oncologists and primary care physicians. JCO 2014;32:1578–85.
46. Brennan ME, Gormally JF, Butow P, Boyle FM, Spillane AJ. Survivorship care plans in cancer: a systematic review of care plan outcomes. Br J Cancer 2014;111:1899–908.
47. Kantsiper M, McDonald EL, Geller G, Shockney L, Snyder C, Wolff AC. Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers. J Gen Intern Med 2009;24 Suppl 2:S459–466.
48. Arora NK, Reeve BB, Hays RD, Clauser SB, Oakley-Girvan I. Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. JCO 2011;29:1280–9.
49. Snyder CF, Earle CC, Herbert RJ, Neville BA, Blackford AL, Frick KD. Trends in follow-up and preventive care for colorectal cancer survivors. J Gen Intern Med 2008;23:254–9.
50. Nagykaldi ZJ, Scheid D, Zhao D, Mishra B, Greever-Rice T. An Innovative Community-based Model for Improving Preventive Care in Rural Counties. J Am Board Fam Med 2017;30:583–91.
51. Mayer DK, Alfano CM. Personalized Risk-Stratified Cancer Follow-Up Care: Its Potential for Healthier Survivors, Happier Clinicians, and Lower Costs. J Natl Cancer Inst 2019;111:442–8.
52. Richards M, Corner J, Maher J. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. Br J Cancer 2011;105:S1–S4.
53. Jefford M, Rowland J, Grunfeld E, Richards M, Maher J, Glaser A. Implementing improved post-treatmentat care for cancer survivors in England, with reflections from Australia, Canada and the USA. Br J Cancer 2013;108:14–20.
54. Wallner LP, Abrahamse P, Gargaro JG, et al. Improving the delivery of team-based survivorship care after primary breast cancer treatment through a multi-level intervention: a pilot randomized controlled trial. Breast Cancer Res Treat 2021;189:81–92. Aug.
55. Geramita EM, Parker IR, Brufsky JW, Diergaarde B, van Londen GJ. Primary Care Providers' Knowledge, Attitudes, Beliefs, and Practices Regarding Their Preparedness to Provide Cancer Survivorship Care. J Cancer Educ 2020;35:1219–26.Dec.
56. McDonough AL, Rabin J, Horick N, et al. Practice, Preferences, and Practical Tips From Primary Care Physicians to Improve the Care of Cancer Survivors. J Oncol Pract 2019;15:e600–e606.
57. Virgo KS, Lerro CC, Klabunde CN, Earle C, Ganz PA. Barriers to breast and colorectal cancer survivorship care: Perceptions of primary care physicians and medical oncologists in the United States. J Clin Oncol 2013;31:2322–36.

Appendix 1 - Oncology Survey

Dear Provider:

We invite you to participate in this research study on care coordination for cancer patients who have completed their active treatment. Your input will help to identify oncology care providers' needs regarding the provision of care for this group and how we might provide optimal care to this important, growing population.

You are being asked to participate in this study because you may be providing care to cancer patients. The information you provide will be useful for planning and implementing an intervention to facilitate the care coordination between primary care and oncology for patients completing active treatment.

If you agree to participate, you will fill out a questionnaire that asks a series of questions about your experiences caring for this patient population. This survey should take about 10 minutes. You can refuse to answer any of the questions. Your completion of the survey and returning it to the investigators indicates your consent to participate in this study.

There is no benefit or risk to you for participating in this study. In order to keep your answers confidential, your name will not appear on the survey and you will not be identifiable by name in any reports or publications; however, we cannot guarantee absolute confidentiality.

We would like to offer all participants the opportunity to be entered into a drawing for a new iPad. Information about how to enter is provided on the last page.

We would also like to be able to contact you for a follow up interview, if you so choose. More details are provided on the last page.

Taking part in this survey is voluntary. You may choose not to take part. If you choose to participate, complete the survey and return it in the self-addressed stamped envelope.

If you have questions about this study, please contact the Principal Investigator, Dr. Kathleen Dwyer at (405) 271-1491 ext. 49223. For questions about your rights as a research subject, contact the OUHSC Director of the Human Research Participant Protection Program at (405) 271-2045.

Do you see cancer patients in your practice?

☐ Yes, please continue ☐ No, Please stop and return the survey.

IMPORTANT TERMINOLOGY FOR THIS SURVEY

For the purpose of this study, "**cancer survivors**" are defined as individuals in your practice who have completed active treatment(s) for cancer.

The term "**late effects**" refers to those adverse outcomes of cancer or its treatment that do not occur during treatment but become manifest months to years after active cancer treatment is over.

The term "**long-term effects**" refers to adverse outcomes of cancer or its treatment that begin during active cancer treatment and persist (remain chronic) even after cancer treatment is over.

(*continued*)

Please answer the following questions regardless of the actual number of cancer survivor patients that you treat in your practice.

1. How confident do you feel about your knowledge of the following aspects of cancer-related follow-up care for…

(MARK ONE BOX IN EACH ROW)

	Not at all confident	Somewhat confident	Very confident	Don't know
a. Appropriate surveillance testing to detect recurrent cancer	☐	☐	☐	☐
b. Long-term and late physical adverse effects of cancer and cancer treatment	☐	☐	☐	☐
c. The potential adverse psychosocial outcomes of cancer or its treatment	☐	☐	☐	☐

2. To what extent do you agree or disagree with the following statements regarding patients who have already completed active treatment for cancer?

(MARK ONE BOX IN EACH ROW)

	Strongly disagree	Somewhat disagree	Neither disagree nor agree	Somewhat agree	Strongly agree
a. Primary Care Providers (PCPs) have the skills necessary to provide follow-up care related to the effects of cancer or its treatment for survivors of cancer	☐	☐	☐	☐	☐
b. PCPs have the skills necessary to initiate appropriate screening or diagnostic work-up to detect recurrent cancer, for survivors of cancer	☐	☐	☐	☐	☐
c. PCPs should have primary responsibility for providing cancer-related follow-up care for survivors of cancer	☐	☐	☐	☐	☐
d. PCPs are better able than Oncologists to provide psychosocial support for survivors of cancer	☐	☐	☐	☐	☐

(*continued*)

3. Thinking about how you deliver cancer-related follow up care for cancer survivors, how often do you:

(MARK ONE BOX IN EACH ROW)

	Never	Rarely	Sometimes	Often	Always/ Almost Always	N/A
a. Provide a comprehensive summary including detailed cancer treatment information, recommendations for future care and surveillance to the patient's PCP	☐	☐	☐	☐	☐	☐
b. Assist patients with recurrent cancer in making decisions about whether and how their cancer should be treated	☐	☐	☐	☐	☐	☐
c. Receive a summary of the patient's past non-cancer medical history from the patient's PCP	☐	☐	☐	☐	☐	☐
d. Provide information to the PCP in a timely manner	☐	☐	☐	☐	☐	☐
e. Experience difficulties transferring patient care responsibilities between you and the PCP	☐	☐	☐	☐	☐	☐
f. Provide the patient with a written follow-up care plan summarizing their past treatment and recommendations for future care and surveillance	☐	☐	☐	☐	☐	☐
g. Have a specific discussion with the patient regarding recommendations for future care and surveillance	☐	☐	☐	☐	☐	☐
h. Clearly understand the division of care responsibilities between you and primary care providers	☐	☐	☐	☐	☐	☐
i. Provide information to the patients' PCP that cancer has recurred	☐	☐	☐	☐	☐	☐
j. Communicate with PCPs about patients' advanced directives	☐	☐	☐	☐	☐	☐

(*continued*)

After completion of active treatment for cancer, patients may require various types of care from different providers, including primary care and oncology specialists.

4. In patients who have completed their cancer treatment, how often do you take primary responsibility for the following?

(MARK ONE BOX IN EACH ROW)

	Never	Rarely	Sometimes	Often	Always/ Almost Always	N/A
a. Screening for other new primary cancers	☐	☐	☐	☐	☐	☐
b. Evaluating patients for recurrence of cancer	☐	☐	☐	☐	☐	☐
c. Evaluating patients for adverse psychological effects of cancer or its treatment	☐	☐	☐	☐	☐	☐
d. Evaluating patients for long-term and late physical adverse effects of cancer and cancer treatment	☐	☐	☐	☐	☐	☐

5. Thinking about patients who have recently completed active treatment for early stage cancer, how often do you routinely...

(MARK ONE BOX IN EACH ROW)	Never	Rarely	Sometimes	Often	Always/ Almost Always
a. Discuss with your patient which provider will follow them for their cancer?	☐	☐	☐	☐	☐
b. Discuss with your patient which provider will handle any other medical issues?	☐	☐	☐	☐	☐
c. Communicate with your patients' other provider[s] about which provider will follow them for their cancer?	☐	☐	☐	☐	☐
d. Communicate with your patients' other provider[s] about which provider will handle other medical issues?	☐	☐	☐	☐	☐

(continued)

6. **For how long do you believe oncologists should continue regular follow-up visits to evaluate the health of survivors <u>who have completed active treatment for their cancer</u>, assuming they have no evident disease or treatment complications?**

☐☐ years OR ☐ Indefinitely

7. **In your practice, how often do you encounter the following problems when caring for <u>cancer survivors</u> who have completed active treatment <u>5 or more years ago</u>?**

How often is this a problem?

(MARK ONE BOX IN EACH ROW)

	Never	Rarely	Some-times	Often	Always/ Almost/ Always	N/A
a. I am uncertain about which provider (oncology specialist or PCP) is providing patients' general preventive health care	☐	☐	☐	☐	☐	☐
b. Patients contact the PCP for problems that should be treated by me	☐	☐	☐	☐	☐	☐
c. Patients contact me for problems that should be treated by the PCP	☐	☐	☐	☐	☐	☐
d. I am concerned about duplicated care by the PCP and oncology specialist	☐	☐	☐	☐	☐	☐
e. I am concerned about missed care by the PCP and oncology specialist	☐	☐	☐	☐	☐	☐
f. Patients request more aggressive cancer surveillance testing than what I would recommend	☐	☐	☐	☐	☐	☐
g. I don't have adequate knowledge or training to manage my patient's non-cancer related problems	☐	☐	☐	☐	☐	☐
h. Other (Please specify below)	☐	☐	☐	☐	☐	☐

____

☐ **I am not able to respond to the items above because I do not follow cancer survivors beyond 5 years post-active phase of treatment.**

(*continued*)

Several alternative models have been proposed for providing follow-up care for cancer survivors. These models differ in terms of their strengths and limitations.

8. Assuming that adequate resources were available to implement any of the care delivery models below, which model do you <u>most prefer</u> to ensure the best possible outcomes for patients who have completed active treatment for early-stage cancer?

(Please select the top 2 options you would prefer, and rank them from 1 to 2, where
1 = the MOST-PREFERRED OPTION and 2 = the SECOND MOST-PREFERRED OPTION)

RANK

☐ Primary Care Providers have primary responsibility for cancer-related follow-up care and refer to other providers as needed.

☐ Oncologists have primary responsibility for cancer-related follow-up care and refer to other providers as needed.

☐ Oncologists and Primary Care Providers share responsibility for cancer-related follow-up care.

☐ Cancer survivors are cared for in specialized clinics led by providers who focus exclusively on cancer survivor care.

9. How does your office handle referrals?

☐ No specific system (handled case-by-case)

☐ Protocols and tracking system in place

☐ Comprehensive, health system-wide (centralized) referral system in place

☐ All of the above + dedicated personnel for referrals are in place

10. What is the current level of care-coordination in your practice?

☐ No specific system (handled case-by-case)

☐ Organized communication approach in place (e.g., messaging)

☐ Communication approach and dedicated personnel for care-coordination are in place

☐ Comprehensive, health system-wide (centralized) care coordination approach in place

(*continued*)

11. What types of electronic resources are available in your practice?

(CHECK ALL THAT APPLY)

☐ Electronic billing system
☐ Electronic Health Record [EHR]/Electronic Medical Record [EMR]
☐ Secure messaging
☐ Patient registry/tracking capabilities
☐ EHR interconnectivity to health information exchange (HIE)

For the next set of questions, if you practice at more than one site, please think about the site where you see most of your cancer patients.

12. What type of provider license do you currently hold?

☐ MD
☐ DO
☐ APRN/NP
☐ PA
☐ RN
☐ Other [please specify]: ______________________________

13. How many years have you been a clinician?

Years:__________

14. What is your primary specialty (i.e., the one specialty in which you spend most of your time)?

☐ Medical Oncology
☐ Gynecological Oncology
☐ Hematology/Oncology
☐ Other [Please specify]: ____
☐ Surgical Oncology
☐ Radiation Oncology

(*continued*)

15. During a typical week, approximately how many patients do you see in your oncology practice location?

(MARK ONE BOX)

☐ 25 or fewer

☐ 26-50

☐ 51-75

☐ 76-100

☐ 101-125

☐ 126 or more

16. During a typical week, how many patients have a cancer diagnosis? _______________

17. What is the type of your practice?

(SELECT BEST RESPONSE)

☐ Single provider

☐ Small provider group

☐ Hospital/health system

☐ Tribal clinic

☐ Government/public health (e.g., Federally Qualified Health Center)

☐ University/residency

☐ Other [please specify]: ________________________________

18. What is the geographical location of your practice?

(SELECT BEST RESPONSE)

☐ Urban

☐ Sub-urban

☐ Rural (small town)

☐ Rural (remote)

(*continued*)

19. What is your practice's size?

(SELECT BEST RESPONSE)

☐ Solo practice
☐ Small practice (2-5 clinicians)
☐ Medium size practice (5-10 clinicians)
☐ Large practice (over 10 clinicians)

20. How would you characterize your organization's change capacity?

(SELECT BEST RESPONSE)

☐ Practice has not even tried to implement changes or improvements in care processes
☐ It has been very difficult to implement changes in the practice
☐ It has been challenging, but possible to implement changes in the practice
☐ Several changes/improvements have been implemented successfully
☐ The organization welcomes change (has a "quality improvement culture") and has a process to implement care improvements (e.g., quality improvement committee)

Are there any additional thoughts, issues or needs you wish to share? Please feel free to write in the space below as we welcome your feedback.

Thank you very much. We greatly appreciate your participation.

Appendix 2 - PCP Survey

Dear Primary Care Provider:

We invite you to participate in this research study on care coordination for cancer patients who have completed their active treatment. Your input will help to identify primary care providers' needs regarding the provision of care for this group and how we might provide optimal care to this important, growing population.

You are being asked to participate in this study because you are a primary care provider in the State of Oklahoma. The information you provide will be useful for planning and implementing an intervention to facilitate the care coordination between primary care and oncology for patients completing active treatment.

If you agree to participate, you will fill out a questionnaire that asks a series of questions about your experiences caring for this patient population. This survey should take about 10 minutes. You can refuse to answer any of the questions. Your completion of the survey and returning it to the investigators indicates your consent to participate in this study.

There is no benefit or risk to you for participating in this study. In order to keep your answers confidential, your name will not appear on the survey and you will not be identifiable by name in any reports or publications; however, we cannot guarantee absolute confidentiality.

We would like to offer all participants the opportunity to be entered into a drawing for a new iPad. Information about how to enter is provided on the last page. We would also like to be able to contact you for a follow up interview, if you so choose. More details are provided on the last page.

Taking part in this survey is voluntary. You may choose not to take part. If you choose to participate, complete the survey and return it in the self-addressed stamped envelope.

You may have received this survey via another distribution list. If you have already completed the survey, please disregard this message – and accept our thanks for participating.

If you have questions about this study, please contact the Principal Investigator, Dr. Kathleen Dwyer at (405) 271-2428 ext. 49223. For questions about your rights as a research subject, contact the OUHSC Director of the Human Research Participant Protection Program at (405) 271-2045.

Are you currently practicing primary care of adults in a community setting?

☐ Yes, please continue ☐ No, Please stop and return the survey.

Do you see cancer patients in your primary care practice?

☐ Yes, please continue ☐ No, Please stop and return the survey.

IMPORTANT TERMINOLOGY FOR THIS SURVEY

For the purpose of this study, "**cancer survivors**" are defined as individuals in your practice who have completed active treatment(s) for cancer.

The term "**late effects**" refers to those adverse outcomes of cancer or its treatment that do not occur during treatment but become manifest months to years after active cancer treatment is over.

The term "**long-term effects**" refers to adverse outcomes of cancer or its treatment that begin during active cancer treatment and persist (remain chronic) even after cancer treatment is over.

(*continued*)

In answering the next two items, think about your most recent cancer patient who recently completed active treatment for his/her cancer and provide your answers in that light.

What type of cancer did this patient have? ________________________________

1. How confident do you feel about your knowledge of the following aspects of cancer-related follow-up care for this cancer survivor?

(MARK ONE BOX IN EACH ROW)

	Not at all confident	Somewhat confident	Very confident	Don't know
a. Appropriate surveillance testing to detect recurrent cancer	☐	☐	☐	☐
b. Long-term and late physical adverse effects of cancer and cancer treatment	☐	☐	☐	☐
c. The potential adverse psychosocial outcomes of cancer or its treatment	☐	☐	☐	☐

2. How often do you routinely...

(MARK ONE BOX IN EACH ROW)

	Never	Rarely	Sometimes	Often	Always/ Almost Always
a. Communicate with your patient's other provider(s) about which provider will follow him/her for his/her cancer?	☐	☐	☐	☐	☐
b. Communicate with your patient's other provider(s) about which provider(s) will handle other medical issues?	☐	☐	☐	☐	☐

(*continued*)

Please answer the following questions regardless of the actual number of cancer survivor patients that you treat in your practice.

3. To what extent do you agree or disagree with the following statements regarding patients who have already completed active treatment for cancer?

(MARK ONE BOX IN EACH ROW)

	Strongly disagree	Somewhat disagree	Neither disagree nor agree	Somewhat agree	Strongly agree
a. Primary Care Providers (PCPs) have the skills necessary to provide follow-up care related to the effects of cancer or its treatment for survivors of cancer	☐	☐	☐	☐	☐
b. PCPs have the skills necessary to initiate appropriate screening or diagnostic work-up to detect recurrent cancer, for survivors of cancer	☐	☐	☐	☐	☐
c. PCPs should have primary responsibility for providing cancer-related follow-up care for survivors of cancer	☐	☐	☐	☐	☐
d. PCPs are better able than Oncologists to provide psychosocial support for survivors of cancer	☐	☐	☐	☐	☐

4. For how long do you believe oncologists should continue regular follow-up visits to evaluate the health of survivors <u>who have completed active treatment for their cancer</u>, assuming they have no evident disease or treatment complications?

☐☐ years OR ☐ Indefinitely

(*continued*)

5. In patients who have completed their cancer treatment, how often do you take primary responsibility for the following?

(MARK ONE BOX IN EACH ROW)	Never	Rarely	Sometimes	Often	Always/ Almost Always	N/A
a. Screen for other new primary cancers	☐	☐	☐	☐	☐	☐
b. Evaluate patients for recurrence of cancer	☐	☐	☐	☐	☐	☐
c. Evaluate patients for adverse psychological effects of cancer or its treatment	☐	☐	☐	☐	☐	☐
d. Evaluate patients for long-term and late physical adverse effects of cancer and cancer treatment	☐	☐	☐	☐	☐	☐

6. Thinking about how you deliver cancer-related follow up care for cancer survivors, how often do you:

(MARK ONE BOX IN EACH ROW)	Never	Rarely	Sometimes	Often	Always/ Almost Always	N/A
a. Receive a comprehensive summary including detailed cancer treatment information from the patient's oncology specialist	☐	☐	☐	☐	☐	☐
b. Assist patients with recurrent cancer in making decisions about whether and how their cancer should be treated	☐	☐	☐	☐	☐	☐
c. Receive information from the oncology specialist in a timely manner	☐	☐	☐	☐	☐	☐
d. Experience difficulties transferring patient care responsibilities between you and the oncology specialist	☐	☐	☐	☐	☐	☐
e. Receive an explicit follow-up care plan from the patient's oncologist, documenting recommendations for future care and surveillance	☐	☐	☐	☐	☐	☐
f. Have a specific discussion with the patient regarding recommendations for future care and surveillance	☐	☐	☐	☐	☐	☐
g. Clearly understand the division of care responsibilities between you and the oncology team	☐	☐	☐	☐	☐	☐
h. Receive information from the patient's oncologist that cancer has recurred	☐	☐	☐	☐	☐	☐
i. Engage in discussions with your cancer patients about advanced directives	☐	☐	☐	☐	☐	☐

(*continued*)

Several alternative models have been proposed for providing follow-up care for cancer survivors. These models differ in terms of their strengths and limitations.

7. Assuming that adequate resources were available to implement any of the care delivery models below, which model do you <u>most prefer</u> to ensure the best possible outcomes for patients who have completed active treatment for early-stage cancer?

Please select the top 2 options you would prefer, and rank them from 1 to 2, where
1 = the MOST-PREFERRED OPTION and
2 = the SECOND MOST-PREFERRED OPTION

RANK

☐ Primary Care Providers have primary responsibility for cancer-related follow-up care, and refer to other providers as needed.

☐ Oncologists have primary responsibility for cancer-related follow-up care, and refer to other providers as needed.

☐ Oncologists and Primary Care Providers share responsibility for cancer-related follow-up care.

☐ Cancer survivors are cared for in specialized clinics led by providers who focus exclusively on cancer survivor care.

8. How does your office handle referrals? (Select best response)

☐ No specific system (handled case-by-case)

☐ Protocols and tracking system in place

☐ Comprehensive, health system-wide (centralized) referral system in place

☐ All of the above + dedicated personnel for referrals are in place

9. What is the current level of care-coordination in your practice? (Select best response)

☐ No specific system (handled case-by-case)

☐ Organized communication approach in place (e.g., messaging)

☐ Communication approach and dedicated personnel for care-coordination are in place

☐ Comprehensive, health system-wide (centralized) care coordination approach in place

(*continued*)

10. What types of electronic resources are available in your practice?
(Check all that apply)

- ☐ Electronic billing system
- ☐ Electronic Health Record [EHR]/Electronic Medical Record [EMR]
- ☐ Secure messaging
- ☐ Patient registry/tracking capabilities
- ☐ EHR interconnectivity to health information exchange (HIE)

For the next set of questions, if you practice at more than one site, please think about the site where you see most of your cancer patients.

11. What type of provider license do you currently hold?

☐ MD	☐ RN
☐ DO	☐ Other (please specify): ______________________________
☐ APRN/NP	
☐ PA	

12. How many years have you been a clinician?

Years:_________

13. During a typical <u>week</u>, approximately how many patients do you see in your primary practice location? (MARK ONE BOX)

- ☐ 25 or fewer
- ☐ 26-50
- ☐ 51-75
- ☐ 76-100
- ☐ 101-125
- ☐ 126 or more

(*continued*)

14. During a typical week, how many patients have a cancer diagnosis? ________

15. What is the type of your practice? (Select best response)

- ☐ Single physician
- ☐ Small physician group
- ☐ Hospital/health system
- ☐ Tribal clinic
- ☐ Government/public health (e.g., Federally Qualified Health Center)
- ☐ University/residency
- ☐ Other (please specify): ____

16. What is the geographical location of your practice? (Select best response)

- ☐ Urban
- ☐ Suburban
- ☐ Rural (small town)
- ☐ Rural (remote)

17. What is your practice's size? (Select best response)

- ☐ Solo practice
- ☐ Small practice (2-5 clinicians)
- ☐ Medium size practice (5-10 clinicians)
- ☐ Large practice (over 10 clinicians)

(*continued*)

18. How would you characterize your organization's change capacity? (Select best response)

☐ Practice has not even tried to implement changes or improvements in care processes

☐ It has been very difficult to implement changes in the practice

☐ It has been challenging, but possible to implement changes in the practice

☐ Several changes/improvements have been implemented successfully

☐ The organization welcomes change (has a "quality improvement culture") and has a process to implement care improvements (e.g., quality improvement committee)

Are there any additional thoughts, issues or needs you wish to share? Please feel free to write in the space below as we welcome your feedback.

Thank you very much. We greatly appreciate your participation.