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Survivorship care plans: are randomized controlled trials assessing outcomes that are relevant to stakeholders?

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Abstract

Purpose The purpose of this study was to compare outcomes assessed in extant randomized controlled trials (RCTs) to outcomes that stakeholders expect from survivorship care plans (SCPs). To facilitate the transition from active treatment to follow-up care for the 15.5 million US cancer survivors, many organizations require SCP use. However, results of several RCTs of SCPs' effectiveness have been null, possibly because they have evaluated outcomes on which SCPs should be expected to have limited influence. Stakeholders (e.g., survivors, oncologists) may expect outcomes that differ from RCTs' outcomes.

Methods We identified RCTs' outcomes using a PubMed literature review. We identified outcomes that stakeholders expect from SCPs using semistructured interviews with stakeholders in three healthcare systems in the USA and Canada. Finally, we mapped RCTs' outcomes onto stakeholder-identified outcomes.

Results RCT outcomes did not fully address outcomes that stakeholders expected from SCPs, and RCTs assessed outcomes that stakeholders did not expect from SCPs. RCTs often assessed outcomes only from survivors' perspectives.

Conclusions RCTs of SCPs' effectiveness have not assessed outcomes that stakeholders expect. To better understand SCPs' effectiveness, future RCTs should assess outcomes of SCP use that are relevant from the perspective of multiple stakeholders.

Implications for Cancer Survivors SCPs' effectiveness may be optimized when used with an eye toward outcomes that stakeholders expect from SCPs. For survivors, this means using SCPs as a map to guide them with respect to what kind of follow-up care they should seek, when they should seek it, and from whom they should seek it.

Keywords Survivorship care plans · Stakeholders · Outcomes · Randomized controlled trials

Introduction

The more than 15.5 million cancer survivors in the USA are at risk for long-term and late effects of cancer and its treatment (e.g., organ toxicity, compromised reproductive function, fear of recurrence and new cancers) [1]. These effects can be identified and addressed through coordinated care from follow-up care providers (e.g., primary care providers [PCPs], oncologists); however, coordination of survivors' care is often poor, at times resulting in the duplication or omission of recommended services [2–5], poor health outcomes [4, 6–9], and significant costs to survivors and the healthcare system [10]. To improve care and outcomes for survivors, many organizations (e.g., the Commission on Cancer, the largest US cancer program accrediting organization) recommend or require cancer care providers to develop and deliver survivorship care plans (SCPs) to survivors and their follow-up care providers [10–13]. SCPs are written documents that ideally include

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treatment summary information (e.g., diagnosis, stage, treatments), plans for follow-up care (e.g., surveillance, preventive services), and recommended division of responsibilities among follow-up care providers.

Observational studies have found that survivors and PCPs benefit from SCPs [14]; however, to date, eight randomized controlled trials (RCTs) of SCPs' effectiveness have reported mixed results [15–28]. Some RCT results may be null because they have evaluated outcomes on which SCPs should be expected to have limited influence. For example, SCPs may be unlikely to improve health-related quality of life (HRQOL) because HRQOL is determined by a complex set of clinical, demographic, and social determinants [29]. Stakeholders (e.g., survivors, oncologists) may expect more practically relevant outcomes than those assessed in RCTs. The US National Cancer Institute (NCI) has called for research to produce clearer evidence of SCPs' effectiveness (PA-12-275, PA-16-012). A key component of such evidence involves the outcomes that stakeholders expect from SCP use. The objectives of this study were to (1) understand the outcomes that diverse stakeholders expect from SCP use and (2) compare them to outcomes assessed in extant RCTs. If stakeholders expect outcomes that differ from those assessed in extant RCTs, clearer evidence of SCPs' effectiveness may be achieved by assessing the outcomes identified in this study. Further, SCPs' effectiveness may be optimized when practitioners use SCPs with an eye toward outcomes that stakeholders expect from SCPs.

Methods

Study design

We identified outcomes assessed in extant RCTs, identified outcomes that stakeholders expect from SCPs, and mapped RCT outcomes onto stakeholder-identified outcomes.

Identifying RCTs of SCPs' effectiveness

We began with a literature review in PubMed using the search terms in Appendix 1 through February 2017. We then hand-searched PubMed results to identify RCTs. Finally, three members of the research team reviewed articles to identify outcomes assessed in each RCT and the instruments used to assess them. When instruments were not included in publications, we used citations to identify the instruments.

Identifying outcomes that stakeholders expect from SCPs

We identified outcomes that stakeholders expect from SCPs via semistructured stakeholder interviews.

Recruitment

The North Carolina Cancer Hospital (NCCH), part of the University of North Carolina Healthcare System, is a tertiary academic NCI-designated comprehensive cancer center. Kaiser Permanente Southern California (KPSC) is an integrated healthcare system providing comprehensive care to over four million members. The Program of Care for Cancer, Nova Scotia Health Authority (NSHA), oversees all cancer services in the province of Nova Scotia, serving a population of approximately 940,000. We used snowball (NCCH, KPSC) and purposive (NSHA) sampling approaches to recruit interview participants with a stake in SCP use (see Table 1 for interview participants and their stake in SCP use). The Institutional Review Board at the University of North Carolina at Chapel Hill exempted the study from human subjects review. The Research Ethics Board at NSHA and the Institutional Review Board at KPSC approved the study.

At NCCH and KPSC, we recruited administrative and provider stakeholders through clinical co-investigators. These stakeholders participated in initial interviews and were then asked to recommend other stakeholders. Survivors whom clinical co-investigators identified in turn identified their caregivers. At NSHA, one research team member directly contacted potential administrative and provider participants based on her knowledge of their role, practice, and/or involvement in SCPs for breast cancer survivors. Survivors and caregivers were recruited through distribution of study information/posters in clinics.

Instrument

We developed interview guides (Appendix 2) iteratively with input from the study team. We tailored guides to stakeholders' roles and elicited information regarding the outcomes that they expected and/or desired from SCPs.

Procedure

We conducted individual, semistructured interviews in person (in a private setting at the clinic location or a researcher's office) or over the telephone after obtaining informed consent from stakeholders. Each interview lasted 30–45 min and was conducted by the site principal investigator or research associate. We audio-recorded and transcribed all interviews verbatim.

Analysis

Four study team members used inductive analysis to identify outcomes that stakeholders expect from SCP use (hereafter "stakeholder-identified outcomes"). We developed a codebook based on emerging data (Appendix 3) to guide and

Table 1 Interview participants and their stake in SCP use

Potential participant	Stake	Number interviewed at KPSC	Number interviewed at NSHA	Number interviewed at NCCH
Survivors	Intended SCP recipients	1	2	2
Caregivers (e.g., partners)	Intended SCP recipients		1	1
Primary care provider	Intended SCP recipients	1	1	1
Survivorship coordinator	Develop SCP implementation processes	3		1
Medical oncologists	Refer survivors for SCPs	3[a]	2	1
Oncology nurse practitioners	Develop and/or deliver SCPs			2[a]
Oncology nurses	Develop and/or deliver SCPs		2	1
Administrators	Compelled to comply with SCP use requirements or local initiatives	3[a]	2	2[a]
	Total	8	10	9

SCP survivorship care plan, *KPSC* Kaiser Permanente Southern California, *NSHA* Nova Scotia Health Authority, *NCCH* North Carolina Cancer Hospital

[a] Dual role

document coding using the constant comparative method [30–32]. All coders collaboratively coded three interview transcripts, resolving discrepancies until consistency in coding was achieved. Two study team members then independently coded the remaining interview transcripts to identify salient themes related to expected outcomes of SCP use. We used qualitative analysis software (ATLAS.ti at NCCH and KPSC; NVivo at NSHA) to organize and manage the data. We had regular research team meetings to review, discuss, and confirm findings. Finally, we organized findings into service outcomes (i.e., services provided and stakeholders' perceptions of services provided [33]; e.g., efficiency, effectiveness) and patient outcomes (i.e., clinical outcomes; e.g., satisfaction, function) [34].

Mapping of RCT instruments onto stakeholder-identified outcomes

First, we disaggregated the RCT outcomes by stakeholder group and outcome type (service; patient). Next, one study team member mapped stakeholder-identified outcomes onto RCT outcomes. Finally, the larger research team, including three survivorship experts and one patient-reported outcomes expert, discussed and iterated mapping until we reached consensus.

Results

Outcomes assessed in RCTs

We identified 14 manuscripts reporting results from eight RCTs (Table 2). Service outcomes included information provision and helpfulness [18, 20, 21, 23–25]; communication, continuity, and coordination [15, 16, 20, 21, 24–26]; knowledge of disease and follow-up [15, 16, 19, 22]; treatment satisfaction [15, 16, 18–23]; provider adherence to guidelines [22, 24]; and cost-effectiveness of SCPs [17].

Patient outcomes include cancer-related distress [15, 16, 19, 27], health-related quality of life [15–17, 19–23, 25, 26], psychological distress (not necessarily attributable to cancer) [15, 16, 19, 22, 26], survivor adherence to recommended care [16, 25], health literacy [19], and knowledge and/or self-efficacy related to survivorship [26, 27].

Most RCTs assessed outcomes in survivors; only three studies assessed outcomes among cancer care providers or PCPs [24, 27, 28], and none assessed outcomes among caregivers.

Outcomes that stakeholders expect from SCPs

We interviewed 27 stakeholders in eight groups across three sites (Table 1). Table 3 displays the stakeholder-identified outcomes with illustrative quotes by outcome type (service; patient) and stakeholder group.

Service outcomes

Enhancing communication and role clarity Members of all stakeholder groups valued SCPs for their potential to facilitate communication among providers, survivors, and caregivers. Stakeholders also reported that SCPs might help formalize relationships between cancer care providers and PCPs, clarifying the roles of each in follow-up care. One participant commented, "I think from the specialist perspective, it's the comfort of being able to say, 'okay, I've done my piece, everybody knows what they need to do, I can let go of this without worrying that something is going to happen and not get followed up.'"

Meeting providers' educational and informational needs Providers described SCPs as a clear resource for describing

Table 2 Outcomes assessed in extant randomized controlled trials (RCT) of survivorship care plan (SCP) use[a,c]

Outcome	Stakeholder	Findings
Service outcomes		
Information provision and helpfulness	Survivor	No differences [18, 20, 21]
		Patients in the SCP arm reported to have received more information about treatment (*M* 57, SD 20 vs *M* 4, SD 24; $P = 0.03$), other services (*M* 35, SD 22 vs *M* 25, SD 22; $P = 0.03$), and different places of care (*M* 27, SD 25 vs *M* 23, SD 26; $P = 0.04$) [20].
		Disease-related internet use was found to moderate the intervention effect of helpfulness of information ($P = 0.01$) [23].
		In intention-to-treat analysis, patients in the SCP care arm reported lower reception of information about other services at 6 ($B - 10.9$, $P < 0.05$) and 24 months ($B - 11.2$, $P < 0.05$) [21].
		In a subset analysis within the intervention group only (at baseline), Latinas more likely than non-Latinas to agree SCP provided more info than provider (96.0 vs 72.0%; $P = 0.002$), provided new info not previously found on own (97.3 vs 68.0%; $P = 0.001$), and improved communication with doctors (97.1 vs 73.7%; $P = 0.005$) [25].
	PCP	No differences [24]
Interpersonal communication, continuity, and coordination	Survivor	No differences [16, 21, 25, 26]
		Fifteen usual care patients and 16 intervention patients had an oncologist visit after transfer to PCP; for reasons related to recurrence or other reasons, 5 control and 9 intervention patients were not transferred to PCP for follow-up [15][b].
		Pragmatic cluster-randomized trial for endometrial cancer, 12 hospitals in the Netherlands were randomized to “SCP care” or “usual care.” Overall, patients who received SCP reported more cancer-related contact with primary care physicians: intention to treat (*M* 3.4, SD 2.0, vs *M* 2.6, SD 2.4; $P = 0.002$) and per protocol (*M* 4.4, SD 2.4 vs *M* 3.9, SD 2.1; $P = 0.003$) [20].
	PCP	PCPs in SCP care arm had more contact with a medical specialist than PCPs in the usual care arm (ITT 43 vs 26%; $P = 0.01$; PP 47 vs 32%; $P = 0.04$) [24].
Knowledge of disease and follow-up	Survivor	Results not reported [16, 19]
		No differences [22]
		Over 12 months, more patients in the intervention than in the control arm correctly identified PCP as primarily responsible for follow-up (98.7 vs 89.1%; difference, 9.6%; $P < 0.005$) [15].
Treatment satisfaction	Survivor	No differences [15, 16, 18–22]
		Internet use was not found to be a moderator of the intervention effect of satisfaction with care [23].
Provider adherence to guidelines	Survivor	No differences [22]
		Physician implementation of recommended care items (which were identified at baseline) was higher for the intervention group in comparison to the control group (60.8 ± 32.6, Med 66.7, IQR 50–85.7 vs 48.6 ± 29.1, Med 50, IQR 25.8–66.7; unadjusted $P = 0.005$) [25].
Cost-effectiveness of SCP	N/A	Resource use and utility data for 408 patients with breast cancer enrolled in the RCT of Grunfeld et al. [15] comparing an SCP with standard care were used. Total QALYs were equivalent across arms (1.42 for usual care vs 1.41 for SCP). The probability that SCP was cost-effective was 0.26 at a threshold value of a QALY of $50,000. A variety of sensitivity analyses did not change conclusions [17].
Patient outcomes		
Cancer-related distress	Survivor	No differences [16, 19, 27]
Health-related quality of life	Survivor	No differences [16, 19, 22, 25]

Table 2 (continued)

Outcome	Stakeholder	Findings
		Resource use and utility data for 408 patients with breast cancer enrolled in RCT comparing an SCP with standard care were used. Modest differences between arms for changes from baseline utility scores over each time period, with a slight decrease from baseline utility scores for SCP arm in second year [17].
		In overall ITT analysis, patients in the SCP care arm reported experiencing more symptoms (M 3.3, SD 2.0 vs M 2.6, SD 1.6; $P = 0.03$) and more concern about illness (M 4.4, SD 2.3 vs M 3.9, SD 2.1; $P = 0.03$) and were affected more emotionally (M 4.0, SD 2.2 vs M 3.7, SD 2.2; $P = 0.046$). In overall PP analysis, SCP arm patients also experienced more symptoms (M 3.4, SD 2.0 vs M 2.6, SD 1.6; $P = 0.02$) and were more concerned about their illness (M 4.4, SD 2.4 vs M 3.9, SD 2.1; $P = 0.03$) [20].
		The intervention SCP group versus usual care has significantly higher change in mental health (improvement on SF-36 MH scale) and self-reported health (F-statistic (3, 71), 3.63; $P = 0.017$) for breast cancer survivors from baseline to 3 months follow-up and significantly lower social role limitations (F(3, 70), 3.82; $P = 0.014$) for breast cancer at baseline [26].
		Disease-related internet use moderated the intervention effect of how well patients understood their illness ($P = 0.04$) [23].
		In ITT analysis, SCP arm patients overall reported lower belief that treatment would cure the illness, overall (− 1.0, $P < 0.01$), after diagnosis (− 0.8, $P < 0.05$), after 6 months (− 0.9, $P < 0.05$), and after 12 months (− 1.4, $P < 0.01$), but not after 24 months [21].
Psychological distress (not necessarily attributable to cancer)	Survivor	No differences [16, 19, 22, 25]
		Significant decrease in PHQ-9 scores from baseline to follow-up for the intervention group, but not for the control group (M 5.94, SD 4.92 to M 4.13, SD 4.05; t-statistic (36) 3.21, η^2 0.23) [26].
Patient adherence to recommended care	Survivor	No differences [16, 25]
Health literacy	Survivor	No differences [19]
Knowledge and/or self-efficacy related to survivorship	Survivor	No differences [25–27]
		Difference between arms at baseline: needing local healthcare in the patient-initiated SCP arm ($P = 0.03$). Patient-initiated arm also reported unmet needs in managing health together with the medical team. Provider-initiated arm had improvement on family/partner needing information (mean change 0.5; $P = 0.04$), handling topic of cancer in social/work situations (mean change 0.8; $P = 0.03$), and exploring spiritual beliefs (mean change 0.6; $P = 0.04$) [27].

[a] An expanded version of this table with details regarding instruments, measures, and study information is available as Electronic supplementary material

[b] Grunfeld et al. and Boekhout et al. [15, 16] report results of the same trial at 12 and 24 months, respectively. Results are reported separately only if there was a difference; otherwise, the findings of Boekhout et al. [16] can be assumed to contain the findings of Grunfeld et al. [15]

[c] Nicolaije et al. [28] not included for lack of service and patient-level outcomes

Table 3 Stakeholders' expected outcomes from survivorship care plan (SCP) use

	Stakeholder	Expected outcomes	Illustrative quote(s)
Service outcomes			
Enhancing communication and role clarity	Survivor	Facilitate communication with PCP, caregiver(s), and other survivors	I think everyone should have a copy of this [SCP]...Everyone should pull it up [because]…I come to the doctor and I give them some information [but] I omit a lot of information because I just don't think of it at that precise moment…so if they were to browse this then they might catch, "Oh, this might be a symptom of a... delayed side effect for the treatment that she had." (survivor)
	Caregiver	Facilitate communication with survivor, PCP, and other caregivers	We were fortunate…we talked a lot about this stuff. I met people through the whole process who didn't do that. The spouses or… sometimes…siblings, whatever… didn't communicate with each other. And [the SCP] would be a really good instrument to do that...to say, "well, this is kind of where we're at" and kind of you'd have your own team meetings under…[your] own roof. (caregiver)
	PCP	Facilitate communication with cancer care providers	I mean I don't think it has to be that formal. I mean I think there... I think just…either a message encounter or... or a phone call [from Oncology]…something like that just to alert us to the fact that…I mean like we do when we discharge from the...hospital. I mean you get a... you get an alert that, "Hey, this person was in the hospital and they're being discharged"…then I know I've got to go look at the discharge summary and that they're [going to] have an appointment to meet… coming up. I don't think it has to be kind of a sit down with the patient and the oncologist and the primary [care provider]... I think that would be kind of unrealistic…but a similar thing could happen in a virtual…environment. (PCP) …we kind of speak to…our value of being integrated, and so I think if we take advantage of the electronic medical record…[the potential for] communication between the patient and the specialist and…the primary care provider so that everybody knows kind of we are all on the same page…that's kind of why we are here…what we do. (PCP) [A SCP] should provide family docs, they are the primary people, a plan. Because that's really what they want. When they are seeking any kind of specialist, they just want a plan in place to know what they need to do. And then who to call … so that if something was to happen, they know what to do, who to go to, kind of thing. (Cancer care provider)
		Facilitate communication with patient and caregivers	I think the fact that the [SCP] document is there…if it says…there may be risks…10, 15, 20 years out…it allows us to…have that conversation, to keep that on… the radar…"Hey, good news but…we still have to be…concerned about these [long term effects]"…there is a lot of value to… keep that communication open and make everybody aware… these are the issues that we have to be concerned about. (PCP)
		Define roles and responsibilities in follow-up care	…so I mean [the SCP] is nice to have…it gives us some kind of a roadmap (PCP) …in the oncology world…there's this point where…[the oncologists] can't necessarily follow all these [survivors] indefinitely…And in our [primary care] world…if we don't feel comfortable with kind of what we're looking for [that's a concern] (PCP) I mean I've had patients come back to me and say, "Well, the family doctor says that's not up to him" or "he's not sure what the follow-up care is.' So patients are feeling then not very secure. 'Who's following me? My family doctor says he's not even sure.' You know? (cancer patient navigator)
	Cancer care provider	Facilitate communication with PCPs	

Table 3 (continued)

	Stakeholder	Expected outcomes	Illustrative quote(s)
			…much of [what is in the SCP] is written for their primary care physician because often the patient, in my experience, they go through the primary care" and say, "I'm here for a breast exam," and they go, "Oh, don't you know that doesn't help?"…That is the truth. I can't tell you how many patients come back like that, and I tell the patients, "Take this to the primary care and say, 'My oncologist, my cancer specialist, told me this is what I need.'" They're more apt to pick up a phone and call me rather than sending you away. (cancer care provider)
		Define roles and responsibilities of all participants in follow-up care	I think [a SCP] empowers patients to what their role is…[what] they need to do and who they can educate…some primary care physicians have told me, "My, your patients are really educated." Not just me, like oncology patients. "They really know about their cancer." And that's the whole idea of them being empowered to question. (cancer care provider)
Meeting providers' educational and informational needs	PCP	Contain current surveillance and follow-up care guidelines to ensure appropriate use of testing and services	PCPs, who have 15-minute visits, have to spend their evening hours having to sift through records we don't understand, seeing all of these chemotherapeutics that maybe we learned about in medical school, but now they're all changing, and putting together our own version of the SCP when we can, and if we're not, patients aren't getting good…appropriate care or treatment. (PCP)
		Describe the "who, what, when" of follow-up care	…it gives [family doctors]….a guide… Yes, they do get that very detailed note from [the oncologist] stating…your patient is now discharged, this is our recommendations for follow-up. But by also patients presenting with their care plans, they can also show the family doc I'm due for my blood work, it's 3 months, and so forth…not all physicians are aware of what the follow up care is. (PCP) From a [PCP] perspective, to be able to pick up a plan of care to say, 'okay, so this is [Patient X], this is what she had, this is what she didn't have, this is what she knows she's responsible for, this is when she's going to call me, this is the treatment plan that I need to be sure I'm following, and here's when I need to transition back to the acute care setting.' (cancer program administrator)
	Cancer care provider	Contain current surveillance and follow-up care guidelines to ensure follow-up care providers' appropriate use of tests and services	…honestly, when I write...when I started writing those long-term follow-ups, it was because of that because I felt like, oh, my goodness. Look at...I got several patients back [from primary care]. They had gotten, you know, inappropriate testing based on the level of their cancer. (cancer care provider)
		Describe the "who, what, when" of follow-up care for follow-up care providers, survivors, and caregivers	I think as far as physicians, and I'm talking family doctors, it gives them a guide of what their patient requires. … By also patients presenting with their care plans, they can also show the family doc I'm due for my blood work, it's 3 months, and so forth. Because not all physicians are aware of what the follow up care is. (cancer care provider)
		Resource to address aspects of health beyond cancer-related concerns and care	…people [don't] fully appreciate…the concept of survivorship…in medicine…you always have to be evaluating and fixing something. In survivorship, you're not really doing that…it's more health promotion, health maintenance, and just…a global perspective of the patient…what really [is] the point of curing the breast cancer… only…to stick around for a miserable existence or to die an early death of some other cause… (cancer care provider)
Mitigating provider anxiety	PCP	Reduce anxiety of transition by providing a clear roadmap of ongoing responsibilities and expectations	I would think from a provider perspective, [an SCP] would give the primary care physician that kind of peace of mind of knowing what [tests and procedures are] next. (cancer program administrator)
	Cancer care provider		

Table 3 (continued)

	Stakeholder	Expected outcomes	Illustrative quote(s)
		Reduce anxiety of transitioning patient to nonspecialist care by ensuring follow-up care providers are sufficiently educated on role and responsibilities	Oncologists don't want to transfer their patients because they don't trust that the doctor will know how to take care of them. Well, make sure that they know and make sure that they have access to you if they're not sure. (cancer program administrator)
Facilitating efficient discharge to primary care and promoting equitable and appropriate follow-up care	Organization/system (from the perspective of multiple stakeholders)	Facilitate efficient discharge to primary care	One of the things that I've been interested in in a while is discharge back to GPs and so on, right? I think [a SCP] helps facilitate that because again I think it helps patients feel like, ok, I sort of know what needs to happen. (cancer program administrator)
		Reduce unnecessary return to oncology care post-discharge	If I had cancer, if I had this—"returning cancer signs to watch for"—that would make me feel a little bit better knowing what I should be looking for [in follow-up]. (survivor)
		Reduce burden on oncologists	Part of what has spurred this has been that cancer programs are recognizing they need to start discharging patients, that they don't have the capacity to continue to see patients 10 years after they've ended treatment. (cancer program administrator) Like, if I were to keep all those patients … If you were to keep every single one of those early stage patients that you'd otherwise discharge, it would be huge numbers. … So it's impossibility in our system, and probably in the rest of the universal type setting. (cancer care provider)
		Reduce under- and overutilization	I think that there are a group of survivors who are probably over-monitored at the moment, and a larger group that are perhaps under-monitored. So I think that that would be useful in terms of standards. So … I think [with a SCP] the appropriate things would be getting done at the appropriate time. (PCP)
		Maximize efficiency and save money over time	It should save money in the long run. In the window of when they're looking at it, they probably don't see it. It has to be a perspective kind of thing after years going back and looking back and going okay, how much did that save? (cancer care provider)
		Provide equity in care (NSHA only)	…making sure that we're giving standardized, appropriate information...everybody's getting the same message, patients are being treated the same. (cancer program administrator)
Patient outcomes			
Meeting educational and informational needs	Survivor	Permanent, reliable resource for information	…I put [the SCP] away and…that makes me feel like I still have control because if I want to review what's happening then I can pull it out and then I can go and ask questions, but it's there. It's that information that I would need to ask my question, it's already there and it's not going to change. (survivor)
		Describe the "who, what, when" of follow-up care	One of the biggest gaps [patients] identify is at the end of treatment: "Now what? What is my follow-up?" I think if they had the survivorship care plan, they would be able to…take charge, be their advocate…It gives the patient control. I find it gives them that sense of control that they know now what is it that they require for follow-up. (cancer care provider)
		Provide health-promoting information, including diet and exercise	It is about my health and wanting to live a long time. I had triple negative cancer… there was nothing to give me as a follow-up. I thought, "okay, what can I do then?" I've been doing everything I can possibly do…I'm doing yoga and meditation. And none of that was told to me to do…I mean the research supports it, that a lot of this stuff can be prevented by our lifestyle choices. So…why not encourage somebody? (survivor)

Table 3 (continued)

	Stakeholder	Expected outcomes	Illustrative quote(s)
	Caregiver	Describe the "who, what, when" of follow-up care	But that time afterwards…we kind of found ourselves quite lost and kind of faced with a lot of the stuff that we had been through. And to have a little direction of where we were going would have been helpful. (caregiver)
Mitigating fear and anxiety	Survivor	Reduce fear of abandonment by oncologist	You've gone through this whole process, which is obviously very, very traumatic and very worrisome, and then there's nothing afterwards. You know, you walk out the door and they're on to the next person…You're by yourself, you don't really know what's going on. There's a lot of anxiety. There's a lot of…wondering…for me anyway…to have somebody to…talk about the next steps, or for somebody to lay out a plan, or…this is what it could look like…would be very helpful. (survivor) But it is hard for [patients]...you know, previously, you've [as the oncologist] ordered all the mammograms, and now they're going away and they're relying on a doctor that has not taken a role for that, so they feel that...umbilical cord breaking and the other party is not there. So, you equip them with something that validates that that's what they need, so they can take it to their primary care. (Cancer care provider)
		Reduce fear of death and/or recurrence	I think that it would reduce both patient and primary care provider anxiety…that the patients would understand that yes, there does have to be surveillance but that there is sort of a system approach. That it's not random, that it is not incumbent upon the survivor to sort of be constantly monitoring and that kind of thing. (PCP)
	Caregiver	Reduce fear of abandonment by an oncologist	Helping to keep that patient in the right frame of mind. We can't do it all the time, but if they had something…to [better] understand that we're not just patting them on the head and saying, "Bye-bye, go on," to let them know that, yes, we are still a part of their lives. We will be here for whatever is needed. "We will see you X number of months out and then a year out, and..." I think it's really important for women... these women and their families…the families will call, too, and say, "Well, what's going to be happening next? What do we do from here?" (cancer patient navigator)
		Reduce fear of recurrence of loved one's cancer	Fear and anxiety really have a huge impact on that stuff. So I think having an actual plan, being able to monitor kind of where you are after all the treatment stuff, and how am I progressing and how am I doing rather than just a visit with the oncologist and their half hour deal. (caregiver)
Improving capacity for self-management; sense of control	Survivor	Shift locus of control to survivor and caregiver(s)	I understand that no one has...I cannot always control everything that happens in my body. I believe I can do something to help. And for me a survivorship care plan helps me feel that I have some control because I have some information…I spoke to both oncologists about long-term effects, and they mentioned a couple like perhaps I would [be at risk for]…second cancers… (survivor)
	Caregiver	Provide benefit for caregivers and family members	I think this might help, having an after-care plan. Again, I know it sounds a little selfish but my perspective from where I sit…there was times that not knowing what you were going through, whether it's not sleeping properly, feeling moody, feeling out-of-sorts, doing things out-of-character, and not knowing why…I think part of an after-care plan, from a spouse or a child [perspective], I think would be a health benefit. I think it's a benefit, I've seen caregivers get ill because of it. And both physically and psychologically. (caregiver)

what kind of follow-up care survivors should receive as well as when and from whom they should receive it. Stakeholders reported that SCPs gave clear surveillance and follow-up care guidelines to PCPs, whose knowledge of cancer and its sequelae may be limited. For cancer care providers, who largely focus on treatment, SCPs offered information about aspects of health beyond cancer, giving them a more “global perspective of the patient.”

Mitigating provider anxiety We conceptualize provider anxiety as closely tied to other service outcomes because of its influence on providers’ ability and willingness to provide services. A cancer care provider stated, “Oncologists don’t want to transfer their patients because they don’t trust that the [follow-up care] doctor will know how to take care of them.” Cancer care providers saw SCPs as a road map for moving forward and reassuring survivors that they were “not just… saying, ‘bye bye, go on,’” thus reducing cancer care providers’ anxiety and allowing them to transition survivors to nonspecialist care. PCPs also reported feeling “peace of mind knowing what’s next” with SCPs.

Facilitating efficient discharge to primary care; promoting equitable and appropriate follow-up care By strengthening communication among providers, stakeholders hoped that SCPs might facilitate post-treatment discharge to primary care. Several cancer care providers reported that cancer survivors often return to oncology soon after post-treatment discharge because PCPs were unclear about their role and current recommendations for follow-up care. Stakeholders reported that improving the discharge process to primary care might reduce oncologist burden, mitigate over- and underutilization of tests and services, and “save money in the long run” by maximizing efficiency. One cancer care provider said, “…you would assume that if the patient, primary care physician and acute care physicians and team are clear, that you’d have appropriate transfer, testing, appointments.” Finally, some stakeholders at NSHA (but not KPSC or NCCH) noted that SCPs might promote equity in care by ensuring that “everybody’s getting the same message, [and] patients are being treated the same.”

Patient outcomes

Meeting educational and informational needs Survivors described SCPs as a permanent, reliable source of information for them, their caregivers, and providers in the face of provider turnover and contradictory information. Survivors highlighted many informational needs that SCPs could meet, often describing them as a map that can guide them with respect to what kind of follow-up care they should seek, when they should seek it, and from whom they should seek it. An oncologist reported that survivors in her care are “…satisfied that there is...a roadmap for them…there’s such a satisfaction in the fact that ‘I know about what my cancer was [and] what I was treated [with]—I got all that information…for the rest of my life…’” Survivors also reported that SCPs containing lifestyle recommendations (e.g., diet, exercise) could promote holistic health long after treatment. Of note, several cancer care stakeholders reported not expecting SCPs to single-handedly address all of survivors’ educational and informational needs, stressing the importance of ongoing provider-survivor communication.

Mitigating fear and anxiety Survivors and caregivers discussed the potential for SCPs to alleviate anxieties associated with a survivor’s transition from treatment to follow-up care. For example, fear of recurrence and fear of abandonment by cancer care providers were frequently mentioned as major sources of anxiety for survivors and caregivers. This domain was closely related to other outcome domains: by enhancing communication and role clarity, meeting educational needs, and building capacity for survivor self-management, SCPs were expected to mitigate survivor and caregiver anxiety.

Improving survivor capacity for self-management; sense of control Stakeholders repeatedly described healthcare delivery systems as uncoordinated, thus limiting their capacity for self-management and sense of control. In this context, stakeholders credited SCPs with the potential to empower survivors to engage with their providers and manage their own health, thus shifting control toward survivors and caregivers. A cancer care provider echoed this, saying that having an SCP “gives patients more control over their cancer journey.” One survivor elaborated, “…I put [the SCP] away and…that makes me feel like I still have control because if I want to review what’s happening then I can pull it out and then I can go and ask questions…It’s that information that I would need to ask my question, it’s already there...”

Comparison of outcomes assessed in RCTs and stakeholder-identified outcomes

Figure 1 displays overlap (and lack thereof) between outcomes assessed in RCTs and stakeholder-identified outcomes. RCTs assessed 20 service and 15 patient outcomes; stakeholders identified 19 service and 10 patient outcomes. Only three of eight RCTs assessed cancer care provider or PCP outcomes [23, 24, 27], and none assessed caregiver outcomes. In contrast, our interviews showed that stakeholders expected SCPs to influence the outcomes of survivors, caregivers, cancer care providers, PCPs, and organizations/systems.

Two of four stakeholder-identified service outcomes were assessed in RCTs: enhancing communication and role clarity, and facilitating efficient discharge and promoting equitable and appropriate follow-up care. The remaining two stakeholder-identified service outcomes were not assessed in

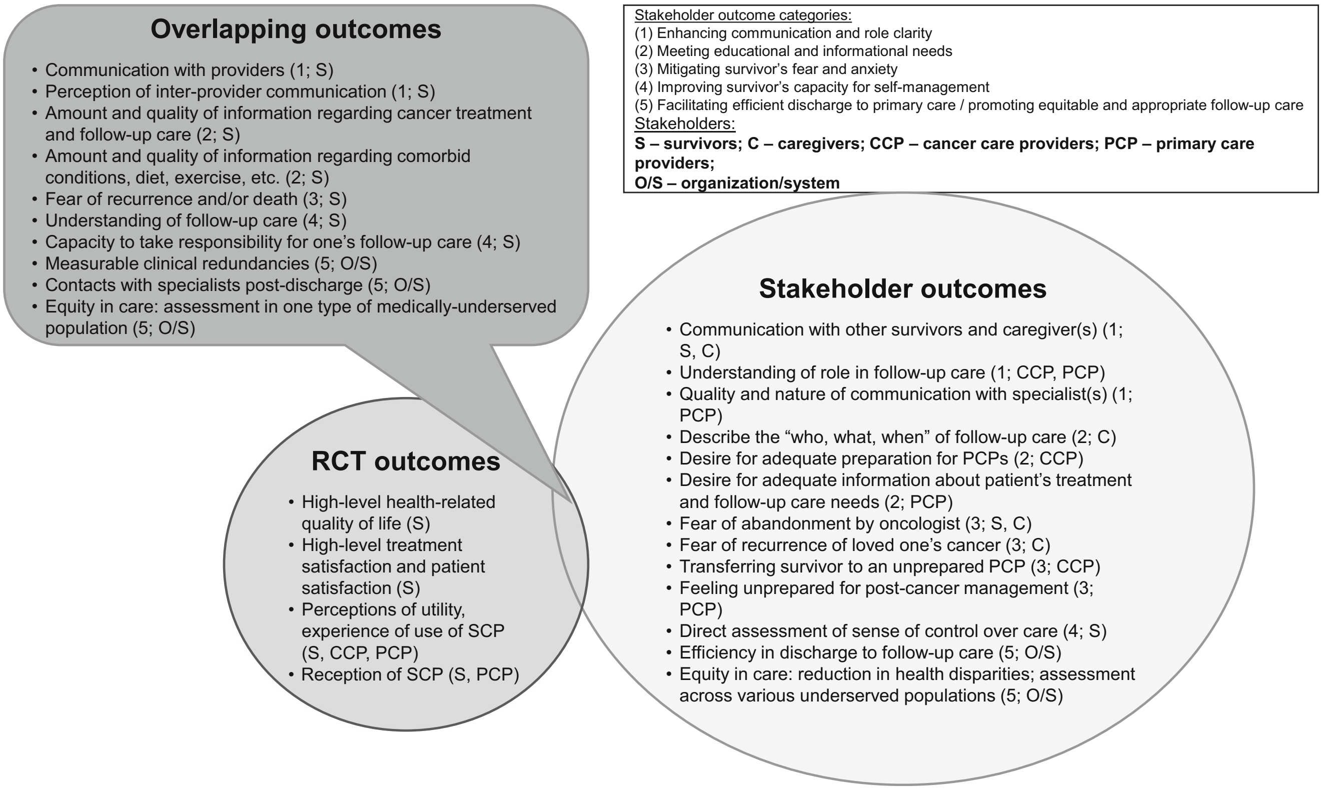

Fig. 1 Overlap between stakeholder-identified and randomized controlled trial outcomes. *S* survivors, *C* caregivers, *CCP* cancer care providers, *PCP* primary care providers, *O/S* organization/system, *RCT* randomized controlled trial. *Description*: Venn diagram comparing RCT outcomes to stakeholder outcomes; overlapping outcomes (middle section of Venn diagram) are described in a text bubble adjacent to the diagram circles. Key describes stakeholder outcome categories, numbered 1–5, and abbreviations for stakeholders referred to in the diagram

any RCT: mitigating provider anxiety and meeting providers' educational and information needs.

All three stakeholder-identified patient outcomes were assessed in RCTs: mitigating fear and anxiety, meeting educational and informational needs, and improving self-management capacity. However, RCTs did not fully capture the nuances of the stakeholder-identified patient outcomes. For example, Hershman et al. [19] and Smith et al. [27] assessed fears related to cancer (e.g., of recurrence and death), yet no RCT assessed stakeholder-identified patient outcomes of survivors' fear of abandonment by their cancer care provider or caregivers' fear of cancer recurrence in their loved one. Additionally, no RCT assessed stakeholder-identified patient outcomes of survivors' and caregivers' sense of control. RCTs assessed several outcomes that stakeholders did not report expecting from SCPs, including treatment satisfaction [15, 16, 18, 22] and HRQOL (e.g., mood and functionality) [15, 16, 19, 22, 25–27].

Discussion

In this study, we compared the outcomes that diverse stakeholders expect from SCPs to outcomes assessed in extant RCTs of SCPs' effectiveness. The premise of this study was that some RCTs' results may be null because they have evaluated outcomes that stakeholders may not expect from SCPs and on which SCPs might be expected to have limited influence (e.g., HRQOL). We found that many of the outcomes assessed in RCTs have not captured the nuances of stakeholder-identified outcomes. This finding may shed light on why some RCTs have found positive effects of SCPs only with respect to secondary outcomes, such as physician implementation of recommended care [25] and survivors' understanding of their providers' respective roles [15], which relate to stakeholder-identified outcomes. In contrast, outcomes for which RCT results were not statistically significant, such as satisfaction with care [20] and functional status, are not outcomes that stakeholders report expecting from SCPs.

RCTs assessed more patient outcomes than service outcomes, whereas stakeholders expected more service outcomes than patient outcomes. For example, stakeholders did not report expecting SCPs to influence HRQOL, an outcome frequently assessed in RCTs (6/8). This calls into question recent emphasis on HRQOL as a critical outcome [35]. In some cases, HRQOL may be too distal an outcome in RCTs of SCPs' effectiveness [36]. Stakeholders in this study identified more proximal outcomes (e.g., capacity for self-management, sense of control), which are consistent with themes identified in a study characterizing transitional readiness among survivors [37]. By assessing distal outcomes, RCTs may burden stakeholders by collecting data on outcomes not directly influenced by SCPs. Relatedly, HRQOL is a complex construct, and stakeholders may intuitively recognize that SCPs are unlikely to influence HRQOL independent of other interventions.

We also found that RCTs seldom assessed SCPs' outcomes from the perspective of diverse stakeholders (e.g., caregivers). For example, we found that stakeholders expect SCPs to mitigate providers' fears and meet their educational and informational needs, yet RCTs tended not to assess these outcomes from the perspective of providers. Our findings also suggest that stakeholders expect SCPs to promote efficiency and cost-savings in follow-up care for survivors, an organization-/system-level outcome seldom assessed in RCTs. Interestingly, these results were largely consistent across study sites. (A notable exception was the finding that stakeholders at NSHA but not KPSC or NCCH viewed SCPs as promoting equity in care, possibly reflecting a difference in ethos underlying Canada's national and the USA's employer-based health system.)

SCPs are intended to improve care and outcomes among survivors, but how they do so is unclear. Our study addresses calls for stakeholder engagement in research [38–41] on whether and how SCPs achieve their goal of improving care and outcomes among survivors, aligning with the efforts of the US Patient-Centered Outcomes Research Institute and Canadian Strategy for Patient-Oriented Research, which advocate for increased engagement of patients and other stakeholders throughout the research process [42, 43]. Some of this research has begun: the Canadian Partnership Against Cancer System Performance Initiative found that SCPs facilitated help-seeking among survivors; the extent to which help-seeking in turn improves care and outcomes should be assessed in future research [44].

Limitations of our study should be considered. We conducted the study with 27 stakeholders in three healthcare delivery settings, so results may not be generalizable beyond the stakeholders in these settings; however, each has features that may be generalizable. We included university-, institute-, and integrated health system-based cancer programs in the southwestern and southeastern USA and Canada. Further, the goal of qualitative research is depth, not breadth, of knowledge [45]. Stakeholder interviews may have been subject to social desirability bias. Stakeholders may have wanted to avoid sounding presumptuous about the outcomes that they expected from SCPs; however, we emphasized the importance of being forthright in the interest of sound research findings. Stakeholder interviews may also have been subject to selection bias: stakeholders who could speak to SCP use may have therefore believed that SCPs would yield greater outcomes; however, this would only make our findings more conservative. Further, some interview participants did not advocate SCP use, suggesting that selection bias was unlikely. Finally, some instruments that were used to assess outcomes were not publicly available, so RCTs may have assessed outcomes that we were unable to identify.

Despite these limitations, our study is among the first to assess the extent to which RCTs have addressed outcomes that stakeholders report expecting from an intervention [46]. In addition to the importance of evaluating interventions with respect to outcomes that are relevant to stakeholders, careful stewardship of limited research funding should compel us to design RCTs that assess stakeholder-identified outcomes. In comparing RCT outcomes to stakeholder-identified outcomes, our study makes a methodological contribution that may be applied to other interventions.

Conclusions

Overall, the outcomes that RCTs have assessed have been inconsistent with recommendations for key outcomes of SCP use. Scholars have emphasized proximal service outcomes at survivor, provider, and system levels (e.g., improved understanding, coordination, and communication) [36, 47]. Many RCTs addressed some dimensions of these outcomes; however, RCTs tended to assess patient outcomes more distal than recommendations suggest. Future RCTs should assess the outcomes that stakeholders identified in this study but have not been assessed in extant RCTs—largely service outcomes from diverse stakeholders' perspectives (see Fig. 1). We recognize the challenges associated with measuring the kinds of outcomes identified in this study and emphasized by survivorship experts. Indeed, assessing the many nuances of stakeholder-identified outcomes from each of their perspectives may be costly and infeasible. Nevertheless, if RCTs continue to assess outcomes that break with stakeholders' expectations and from a subset of stakeholders' perspectives, their results are likely to continue to be mixed which may in turn limit SCP implementation. Future work is needed to identify or develop valid and reliable measures of the stakeholder-identified outcomes identified in this study so that clearer evidence of SCPs' effectiveness may be achieved.

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Compliance with ethical standards

The Institutional Review Board at the University of North Carolina at Chapel Hill exempted the study from human subjects review. The Research Ethics Board at NSHA and the Institutional Review Board at KPSC approved the study.

Conflict of interest The authors declare that they have no conflicts of interest.

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