Adopting patient-centred tools in cancer care: role of evidence and other factors

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ABSTRACT

Background  Randomized controlled trials (RCTs) provide limited evidence to support the use of survivorship care plans (SCPs), but they provide strong evidence for patient decision aids (PTDAs). Despite that evidence, the uptake of PTDAs has been limited, but SCPs are being endorsed and implemented in many cancer programs across Canada. The objective of the present study was to illuminate the decision-making processes involved in the adoption of SCPs and PTDAs.

Methods  Informed by the principles of grounded theory, in-depth semi-structured interviews were conducted with clinicians, managers, and administrators who work in cancer care programs across Canada (n = 21). Data were collected and analyzed concurrently, using a constant comparative analysis approach. Data collection ended when theoretical saturation was reached.

Results  For these types of patient-centred tools, participants noted that high-quality research evidence is often unnecessary for adoption decisions. Six key factors contribute to adoption or non-adoption decisions for SCPs and PTDAs:

- Alignment of research evidence with other evidence
- Perceived clinician benefit
- Endorsement by organizations and professional bodies
- Existence of local champions
- Adaptability to local contexts
- Ability to routinize and reach a large patient population

Conclusions  High-level evidence is not always the main consideration when adopting new tools into practice. And yet, understanding how clinicians and health system decision-makers decide whether and how to adopt new tools is important to optimizing the use of new tools and practices that are supported by research evidence.

Key Words  Adoption into practice, evidence, grounded theory, survivorship care plans, patient decision aids

BACKGROUND

In 2006, the U.S. Institute of Medicine recommended implementation of survivorship care plans (SCPs) for survivors in response to unmet needs and lack of care coordination after intensive cancer treatment1. A patient-centred tool, the SCP provides an individualized plan for ongoing care and ideally contains a summary of the patient’s cancer treatment, a follow-up plan and schedule, and resources tailored to the patient1. Many studies have examined the effectiveness of SCPs with respect to patient and health system outcomes. Systematic reviews of those studies have revealed limited evidence of benefit2,3, with most randomized controlled trials (RCTs) showing no effect on patient or health system outcomes such as patient distress, quality of life, satisfaction with care, and care coordination. Despite the lack of high-level evidence supporting SCP use, and the resource-intensive nature of the plans4,5, SCPs continue to be widely endorsed and implemented in cancer care6-9.

In contrast, researchers have shown that patient decision aids (PTDAs) are effective in the cancer care setting. A PDA is designed to improve communication between the health care provider and patient, and to promote active patient participation in weighing the costs and benefits of
treatment or screening\textsuperscript{10,11}. A Cochrane review of 115 studies found that \textit{ptdas} improve patient knowledge, promote active participation in decision-making, and, when probabilities are included, improve the accuracy of risk perception while also reducing decisional conflict and resulting in decisions that are more compatible with patient values\textsuperscript{11}. Another Cochrane review (23 studies) on the use of \textit{ptdas} in cancer care screening and treatment reported findings similar to those for the use of \textit{ptdas} in general\textsuperscript{12}. The latter review also revealed that \textit{ptdas} might reduce the overuse of some interventions or treatments, while promoting underused interventions that can be beneficial (for example, colon cancer screening). Another systematic review of 34 RCTs examining cancer-related \textit{ptdas} found that \textit{ptdas} increase patient knowledge without increasing anxiety and even reduce anxiety about screening decisions\textsuperscript{10}.

Despite supporting evidence, \textit{ptdas} are not widely implemented in cancer care\textsuperscript{13}. Several barriers to \textit{ptda} implementation in general practice have been noted, including time constraints and context-specific barriers (including complexity of available information)\textsuperscript{14,15}. However, how clinicians and other decision-makers in cancer care (program managers and administrators, for instance) make decisions related to the adoption or non-adoption of patient-centred tools (for example, scp\textsuperscript{s} and \textit{ptdas}), particularly in light of the best available research evidence, is unclear. The objective of the present study was to illuminate the decision-making processes involved in the adoption of scp\textsuperscript{s} and \textit{ptdas}, including how research evidence is considered, how additional factors influence those decisions, and how the role of scientific evidence differs for the two tools.

**METHODS**

Guided by the principles of grounded theory\textsuperscript{16}, we used semi-structured interviews in a qualitative study investigating the adoption of two patient-centred (nontherapeutic) tools in the context of cancer care. Ethics approval to conduct the study was granted by the Nova Scotia Health Authority Research Ethics Board. Informed consent, including authorization to audiotape interviews and use anonymized quotes, was obtained in writing from each participant.

**Participants**

Clinicians, managers, and administrators in cancer care programs from across Canada were recruited to participate in the study. The research team began by purposefully identifying potential participants within cancer programs across Canada where scp\textsuperscript{s} and \textit{ptdas} are endorsed or used (that is, purposive sampling). Maximum variation was also used to ensure variation with respect to profession (medical, radiation, and surgical oncologists; primary care providers; nurses; managers; administrators) and jurisdiction (province). Given infrequent use of \textit{ptdas}, participants were asked to identify individuals within their programs or organizations who might be willing to speak about \textit{ptda} use or non-use (that is, snowball sampling, a purposeful nonprobability sampling technique). As data collection and analyses ensued, theoretical sampling was used as needed.

One investigator (RU) made the initial approach to all potential participants by e-mail or telephone. Individuals who failed to respond were approached again after 1 week. If the participant responded in the affirmative, the other investigator (AG) followed up to discuss the nature and purpose of the study and to arrange a time to conduct the informed consent discussion and interview.

**Data Collection**

Interviews, conducted by one investigator (AG), were used to gain insight into participant experiences with scp\textsuperscript{s} and \textit{ptdas}—particularly their decision-making about whether to use those tools in their practice or program, and the role of research evidence in the decisions. Patton\textsuperscript{17} and Rubin and Rubin\textsuperscript{18} both provided practical guidance for the interview design and the questions (Table 1), which were drafted based on the research objectives. Two pilot interviews were conducted, audiotaped, transcribed verbatim, and discussed by the investigators to ensure that all topics of interest were explored. The interview script was refined through the pilot interviews.

All interviews were audiotaped and transcribed verbatim, with the transcripts being verified by listening to the audiotapes. The audiotapes and transcripts were supplemented with field notes. After each interview, the questions and responses were reviewed to determine whether the issues had been covered in sufficient depth; if not, the questions were revised before the next interview\textsuperscript{18}.

**Data Analysis**

Data were collected and analyzed concurrently, allowing emergent concepts and categories to be incorporated and explored in subsequent interviews. An inductive grounded approach using constant comparative analysis was applied\textsuperscript{16,18–20}. Data from the pilot interviews were included in the complete data set, with the permission of the pilot participants. Data collection continued until data saturation was reached (that is, the point at which no new substantive information emerged to contribute to the explanation)\textsuperscript{16}.

Data from the first 10 interviews were coded and analyzed independently by both investigators. An electronic codebook was developed to guide the coding scheme and subsequent categorization of data. The remaining 11 interviews were coded and analyzed by one investigator (AG) because consistency in coding had been apparent after the first 10 interviews. Open and axial coding of interview transcripts occurred simultaneously (consistent with constant comparative analysis). Open coding involved reading the transcribed interviews and field notes line-by-line in their entirety to identify ideas and concepts, and then grouping concepts to form categories and subcategories. Axial coding involved making connections between the code categories and subcategories, leading to the identification of larger categories based on content similarity. The final stage of analysis involved the detailed development and integration of the categories. Qualitative analysis was performed manually, and qualitative software [Weft qda (Alex Fenton, http://www.pressure.to/qda/)] was used to assist in data management and to enable comparison and synthesis of codes. The two investigators met regularly to review the coded data and emerging categories, to assess for theoretical saturation, to confirm categories, and to discuss the organization of categories into a coherent.
TABLE I  Draft interview guide

| Interview aims |
|----------------|
| 1. Illuminate the processes involved in adoption decisions. |
| 2. Explore the role of scientific evidence in these decisions. |
| 3. Identify factors other than research evidence that impact decisions. |

| General |
|----------------|
| 1. When you make decisions about using a new tool or technology in your practice [or program], what are the main types of evidence that you consider? **Probes:** research evidence, clinical experience, local data, patients’ needs and preferences |
| In general, when considering these different types of evidence, is there a hierarchy that you consider? Does one have more importance than another? |
| 2. Are there times when you find it difficult to apply research evidence into practice? |

| Survivorship care plans |
|-------------------------|
| 1. Let’s talk about survivorship care plans. Do you use SCPs in your practice? [or Are SCPs used in this centre/program?] |
| If yes to 1: |
| 2. Take me back to when you began using [or when your program adopted] SCPs. |
| ■ How did you hear about them? |
| ■ What was your early impression? |
| 3. What is your understanding of SCPs? **Probes:** research evidence, clinical experience, local data supporting/not supporting use, patient needs and preferences |
| 4. How do you view the quality and strength of the research evidence supporting SCPs? |
| 5. What other things played a role in your decision to provide SCPs to patients? How so? **Probes:** Ease of use, trusted colleagues, standard of care, use elsewhere, recommendations or endorsements of cancer organizations or professional bodies |
| 6. For clinicians only: |
| ■ How do you decide when to use them in practice? |
| ■ Do you use them with all patients or only select patients? Why/why not? |
| 7. What are some benefits of SCPs that you see in your practice [or program]? |
| ■ What drawbacks do you see? |
| 8. How do SCPs compare with what you did before [or with what happened here before]? |
| If no to #1: |
| 9. What is your understanding of SCPs? **Probes:** research evidence, clinical experience, local data supporting/not supporting use, patient needs and preferences |
| 10. How do you view the quality and strength of the research evidence supporting SCPs? |
| 11. Would you consider using them? Why/why not? |
| 12. Why do you believe SCPs are not used here? |

| Patient decision aids |
|-----------------------|
| 1. Let’s talk about patient decision aids (DA). Do you use DAs in your practice? [or Are DAs used in this centre/program?] |
| If yes to 1: |
| 2. Take me back to when you began using [or when your program adopted] DAs. |
| ■ How did you hear about them? |
| ■ Which specifically do you use? |
| ■ What was your early impression? |
| 3. What is your understanding of DAs? **Probes:** research evidence, clinical experience, local data supporting/not supporting use, patient needs and preferences |
| 4. How do you view the quality and strength of the research evidence supporting DAs? |
| 5. What other things played a role in your decision to use DAs? How so? **Probes:** Ease of use, trusted colleagues, standard of care, use elsewhere, recommendations or endorsements of external bodies |
| 6. How do you decide when to use them? |
| ■ Do you use them with all patients or only select patients? Why/why not? |
| 7. What are some benefits of DAs that you see in your practice [or program]? |
| ■ What drawbacks do you see? |
| 8. How do DAs compare with what you did before [or with what happened here before]? |
| If no to #1: |
| 9. What is your understanding of DAs? **Probes:** research evidence, clinical experience, local data supporting/not supporting use, patient needs and preferences |
| 10. How do you view the quality and strength of the research evidence supporting DAs? |
| 11. Would you consider using them? Why/why not? |
| 12. Why do you believe DAs are not used here? |

| Closing |
|----------------|
| 1. Are there any other issues related to use of SCPs or DAs you would like to comment on? If so, what are they? |
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exploration. Those iterative processes continued until both investigators were satisfied that the final categories and organizations adequately reflected the findings. Throughout the analysis, any disagreement between the investigators was resolved through discussion and, when needed, a re-examination of transcripts and coded data.

A number of steps were taken to optimize rigor, including field notes during interviews, detailed documentation of methodologic and analytic decisions, and ongoing review and questioning of data coding, analytic decisions, and resultant categories by the two investigators. In addition, direct quotes were used to ensure participant perspectives were represented as accurately as possible.

RESULTS

Of 41 people contacted, 21 clinicians, managers, and administrators (12 men, 9 women) from 7 Canadian provinces participated in the study. Three people declined to participate, and fifteen failed to respond to either the initial e-mail message or follow-up contact attempts. An additional 2 people agreed to participate, but were not scheduled for an interview before theoretical saturation was reached and data collection was completed. Of the 21 participants, 16 were clinicians (including surgical, medical, and radiation oncologists; urologists; a primary care physician; and cancer care nurses); the remaining 5 had administrative or managerial roles. The greatest proportion of interviews (86%) were conducted over the telephone. No repeat interviews occurred.

Overall, most participants used or supported use of scps, despite incomplete or limited knowledge of the evidence base. Several were aware of the first null Canadian-based rct, but had limited or no knowledge of subsequent rctts in the literature. Few participants regularly used pt das, but almost all were aware of the high-quality evidence base supporting pdas use. For those types of nontherapeutic interventions, participants noted that high-quality research evidence (that is, coming from rctss) is often unnecessary for adoption decisions, with the belief that the intervention is an intuitively good idea having weighed heavily in decision-making. As one participant said, “I think [scps are] one of those things that intuitively make sense, and I don’t necessarily think we need a ton of evidence to really sway my decision” (P11).

Six key factors found to influence adoption or non-adoption decisions concerning scps and pt das (Figure 1) are described in the subsections that follow. Table II provides additional illustrative quotes about each factor.

Alignment of Research Evidence with Other Evidence

The data revealed that the research evidence for scps is not well-aligned with clinical experience, patient preferences, and local evaluation data, which demonstrate largely positive patient and provider experiences. Participants also noted value in scps that might be difficult to assess using traditional rct outcomes, as highlighted by one participant:

“I think it is pretty clear that having a very clear roadmap, particularly for the surveillance testing, is very much appreciated. And again, I think there is great symbolic value for patients to feel like this communication has happened. Hopefully, it is also effective for care. But I think the symbolic value of knowing that has happened, and the message of respect and of, you know, taking the family doctor’s role and responsibility seriously by providing good-quality information. I think that sends the right signal around collaborative care, too. So I would just separate the kind of the instrumental value of the information provided about what scans are needed when, with the message it gives: that this handoff is important to us, and you are important to us, patient and family doc. And I think there is value in that.”

— P3

Importantly, an scp also addresses an expressed need for a change in how cancer patients are being discharged. By adopting scps, participants felt that patients who were “feeling they were in a void” (P12) are given a tool that enables self-advocacy and self-management.

As a result of overwhelmingly positive experiences and the high face validity of scps, the high-quality research evidence seemed to lose credibility with many participants. One participant described that lack of credibility:

“Obviously there has been one large Canadian randomized control study which essentially was reported as a negative study. I think that you have to understand what was negative in that study was the primary outcome, where basically patients were asked about their experience of transition a year after transition. You should ask yourself the

FIGURE 1 Key factors influencing adoption or non-adoption decisions with respect to survivorship care plans and patient decision aids.
TABLE II  Additional illustrative quotes from participants about the six key factors for adoption or non-adoption decisions with respect to survivorship care plans (SCPs) and patient decision aids (PDAs)

| Factor Tool                                                                 | Quotations                                                                                                                                 |
|-----------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|
| **Alignment of research evidence with other evidence**                      |                                                                                                                                          |
| SCP [We gave] post-transition questionnaires to patients—like, within 4 weeks of being transitioned to primary care—asking them about their experience. And it was overwhelmingly positive feedback. | — P4                                                                                                                                     |
| What has helped us in [our province] is patient experience and patient feedback. So we do patient satisfaction surveys and stuff, and we have had positive feedback from patients, which kind of helps drive us locally. | — P9                                                                                                                                     |
| PtDA And I’ve seen [PDAs] used ... and the physicians actually don’t ... they completely abdicate their responsibility in terms of helping people make decisions then. They just say, “Well, go watch this video, and come tell us if you want surgery. And if you don’t, we’ll send you to radiation.” And it’s a tragic abdication of our role. | — P16                                                                                                                                    |
| You know, patients are educated. And they want numbers, and they want to know what their options are, and they want to know what you think about their options. I think [decision aids] provided some more impetus to help meet that goal. | — P5                                                                                                                                     |
| **Perceived clinician benefit**                                             |                                                                                                                                          |
| SCP A sense that here was a perfect kind of intervention that would both support those patients and, you know, their close family, and also give family docs tools they would appreciate and enable them to do a better job. | — P3                                                                                                                                     |
| If it’s going to the family doctor as well, then everyone has all the information. So they’re all on the same page. It’s also nice that everyone then knows what the plan is going forward. | — P20                                                                                                                                    |
| PtDA Personally I never really felt that they were that helpful. They did not really enhance what we were doing. | — P4                                                                                                                                     |
| Part of it is that physicians think that they’re doing a good job of shared decision-making and don’t think that they need a decision aid. I don’t think that that’s true, but I think that that’s the perception of physicians. | — P18                                                                                                                                    |
| **Endorsement by organizations and professional bodies**                    |                                                                                                                                          |
| SCP It was [the Canadian Partnership Against Cancer] grant that kind of highlighted the fact that there was something that I guess was being recommended in the Canadian environment. | — P3                                                                                                                                     |
| PtDA Well, I think it would be easier for the average physician to use decision aids if they were promoted by their respective organizations. | — P6                                                                                                                                     |
| **Existence of local champions**                                            |                                                                                                                                          |
| SCP We actually have got a fair [number] of clinical champions that support [SCPs], so—and in all honesty—they all think [SCPs are] important. They all agree with doing formal care plans and key processes at transitions of care. | — P9                                                                                                                                     |
| PtDA A new physician came onboard that was quite passionate about [PDAs] and very much supported it. So a physician champion helped. | — P14                                                                                                                                    |
| **Adaptability to local contexts**                                         |                                                                                                                                          |
| SCP Just listening at a conference last year.... Certainly [ours] is probably a more Cadillac service.... So we certainly have a very resource-intensive program here. | — P14                                                                                                                                    |
| PtDA I think one of the things with a decision aid is that the data used to populate the decision aid doesn’t necessarily apply. So with prostate cancer, outcomes can be very different from surgeon to surgeon. So patients in the decision aid have the average patient outcome for the average surgeon sort of thing. But you know, [there are] different approaches, there’s laparoscopic and open, and individual surgeons have individually different outcomes. And so, at least the ones that we use, I would say they’re not as granular probably as they could be or should be. And that’s just I think a reality. I don’t know that there’s really any good way around that. But that’s one of the limitations, I would say, is that patients are possibly making a decision based on data that isn’t entirely applicable to them. | — P13                                                                                                                                    |
| **Ability to routinize and reach a large patient population**              |                                                                                                                                          |
| SCP I mean our care plan, we developed them for ... different disease sites. Patients I transition in my practice, I use a care plan. And for now we are doing it with everyone. | — P4                                                                                                                                     |
| Where we are at with our [number of] disease sites and all patients get a care plan in those disease sites. | — P5                                                                                                                                     |
| PtDA So I used decision aids personally ... not on every patient, but, you know, in some instances. | — P2                                                                                                                                     |
| You know, [a PtDA] doesn’t actually help patients if it’s not a good one. Because I’ve seen, you know, a number of different ones. And there are some that are generic decision aids. I’m sure you’ve seen all these. And they’re really not that useful for me personally because I feel like I do take the time to counsel patients. So I’d say it’s a good idea, but it has to be actually applicable to that patient’s situation. | — P13                                                                                                                                    |
question “How in any way could that be tied to a care plan that was sent to the family physician a year previously?” That is a lot of time to have experiences to report on, [and] so I am not surprised that that was negative. No one really asked the family physician if the care plan was of any use. Nobody really looked to see if people getting care plans had more consistent adherence to surveillance. Those are very important outcomes.

— P4

Despite high face validity, some participants questioned the essential elements of an scp and how implementation of scps has affected real-world outcomes. Future research into those topics was cited as important, particularly given that scps are resource-intensive. For instance:

Where the research needs to go [is determining] what are the essential elements. What are the things, the contextual factors, that are unique to a given place you need to ... account for. I don’t think we know any of those kind of details.

— P1

With respect to ptdas, the data also revealed that the research evidence is not well-aligned with clinical experience. Indeed, many participants did not view ptdas as an effective tool. As one participant said, “They were cumbersome, [and] so in the end, we sort of stopped using them once the research studies were completed” (P4). However, a number of participants did see ptdas as being valuable for patients. For example, one participant said, “I think it helps people clinically when I use them. For people who are having a lot of anxiety, it does help them sort of have something to read about when they go home” (P16).

Perceived Clinician Benefit
Survivorship care plans were seen as addressing an important clinical need and were viewed as beneficial to clinicians themselves. In contrast, participants did not believe that ptdas addressed any particular clinical need or concern. Participants noted that scps facilitated an oncologist’s ability to transfer low-risk patients back to primary care upon completion of treatment. Many viewed that transfer process as important, given the projected rise in the number of cancer patients. Additionally, participants continually described scps as benefiting oncologists, primary care providers, and patients, with the concept of a secure handoff between oncology and primary care emerging often: “The care plan is just kind of a tool. It is really about a bigger mandate to improve our relationship and communication [with] primary care” (P4).

With respect to ptdas, participants recognized the benefits for patients, and yet the data revealed that most did not view ptdas as having a substantive personal benefit. For instance, ptdas were not perceived to streamline conversations or to provide assistance to the clinician in terms of communicating risks or treatment alternatives. That view was exemplified by one participant:

I might choose not to adopt a decision aid even if there is evidence that it is helpful. If I just felt like ... the way I was having the discussion with my patients already was serving the purpose equally well, if not better, than with the decision aid.

— P10

Endorsement by Organizations and Professional Bodies
The endorsement of respected organizations (professional associations, provincial cancer agencies, and national cancer care or control bodies, for instance) was key in scp adoption by strengthening the support by individuals and organizations for scps and providing resources to implement scps. One participant exemplified that stance:

I heard about [scps] through the Canadian Partnership Against Cancer, I suppose. Well, I heard about them through Livestrong in the States, but there was a cpac-sponsored grant, I think in 2009 or so. Basically, a request for proposals for implementation of care plans in Canadian cancer settings. So that was kind of a funding opportunity that got me into reading more about them.

— P3

Because scps have been endorsed by professional organizations, several participants believed scps must be supported by rct-level evidence. Conversely, participants were unaware of any professional body endorsing ptdas, but felt that similar endorsements would increase their use:

If some cancer agency or [the Canadian Partnership Against Cancer] said, “[ptdas] are really important, you should use them” or if they became an accreditation thing for the hospital, suddenly they would be everywhere, I am sure. And that would probably help, but lacking that as sort of a personal project, it seems like a good idea, but so do lots of things we don’t do.

— P11

Existence of Local Champions
Local respected colleagues who were knowledgeable about scps or ptdas and championed their use were highly influential in shaping the attitudes of clinicians about those tools and convincing them to use them. Although participants reported using (or supporting) ptdas much less than scps, settings in which ptdas were adopted were those in which local champions existed. In the case of ptdas, local champions increased awareness of the tools, but also provided support and resources to help increase their use. Related to ptdas, one participant said, “I think you need to have people buy into [ptdas] and be champions of [them] or [they] will not be successful” (P14).

Adaptability to Local Contexts
Participants perceived scps to be easier than ptdas to adapt to local contexts. Indeed, the data demonstrated that scps implemented across Canada are variable in regard to content, format, and mode of delivery, having been adapted to local needs, contexts, and resources. One participant,
for example, compared scps in the local setting to scps in other settings:

The care plans [here] are fairly labour-intensive, human resource-intensive, to develop very accurate [ones]. Where I’ve heard [that in] other places, they just have a family physician and a nurse, and discharge the people with just a very basic letter back to their [general practitioner].
— P14

Participants recognized that such adaptation is limited in ptdas, which are tools developed for specific patient management decisions.

**Ability to Routinize and Reach a Large Patient Population**

The data also revealed that participants view scps as easier than ptdas to roll out and routinize for a larger population. For example, participants noted that scps can be used with most, if not all survivors, whereas ptdas are useful only in certain clinical situations and are not applicable to all patients and their individual circumstances. The ability to routinize broadly (compared with having to make specific decisions about a tool’s utility during each clinical encounter and with each individual patient) was viewed as important to adoption and ongoing use:

I think the issue is there are only so many [ptdas] that exist, and there are many, many decisions that patients have to make. We cannot provide a ds for every decision that somebody has to make, but we can provide the theoretical components.
— P5

**DISCUSSION**

In the present study, we examined the processes by which cancer care providers and teams make decisions about the adoption of patient-centred tools, specifically focusing on scps and ptdas. The findings indicate that high-quality research evidence was not weighed heavily in the decision to adopt either tool. In the context of evidence-informed decision-making, participants described their decisions as being influenced more by experiential knowledge and positive patient experiences than by research evidence. A number of participants did emphasize that, for patient-centred interventions, high face validity was sufficient and was often given more clout in adoption decisions. Other authors have found that, although some clinicians regard rcts evidence as the “gold standard,” others might rely more heavily on experiential than on research-based knowledge21,22. Beyond that assessment, six key factors were found to contribute to adoption or non-adoption decisions for scps and ptdas. Those six factors provide insights into how decisions are made to adopt new tools (and why a mismatch is sometimes observed between the scientific evidence and real-world decisions) and are thus important to consider when designing and planning implementation efforts in cancer care.

As was evident for scps, highly positive clinical and patient experiences with a tool can be quite influential in the adoption of that tool regardless of the evidence base. Another reason that scps were widely supported and adopted is that scps appear to serve multiple purposes. Unlike ptdas, which were perceived to serve mainly patients, scps were viewed as serving the purposes of patients, providers, and the system. For example, scps facilitate discharge of patients from resource-taxed oncology services with a secure handoff. The provider-centred outcomes that participants perceived are not often tested in clinical trials, but had credibility with individual participants26. That the participants perceived value in scps despite a lack of reported effectiveness might be as a result of rcts assessing outcomes that are too complex (for example, quality of life) or too distal to scp use. A recent study comparing rct-assessed outcomes with stakeholder-identified outcomes reported that stakeholders put more focus on service-related outcomes; rcts of scps more heavily assessed patient outcomes (for example, quality of life)23. The authors found that many of the rcts evaluating scps failed to capture the nuances of stakeholder-identified outcomes. Future research should assess more proximal and stakeholder-relevant outcomes to gain a more accurate picture of scp effectiveness. Inquiry into which components of scps are most useful or essential is also needed, particularly given evidence that primary care providers might only desire certain brief components24.

The importance of respected organizations and colleagues to the adoption of tools cannot be understated. In the present study, participants described the endorsement of scps by multiple professional organizations as key to scp adoption. Similarly, the most prevalent reason for scp adoption in the United States has been reported to be the organizational requirement to adhere to the accreditation standards set by the American College of Surgeon’s Commission on Cancer9. For example, a study looking at determinants of scp use by U.S. programs found that most participants in the study (78%) reported that scps were implemented because of requirements25. Although ptdas are supported by high-quality research evidence and perceived as valuable to patients in some institutions and programs, no participant could identify national or provincial organizations endorsing their use, and yet many felt that such endorsement would improve ptda uptake. In institutions in which ptdas have been readily adopted, local champions were instrumental in enabling that adoption. Like the findings in the present study, the literature suggests that one barrier to ptda uptake is an organization’s priorities and integration of the ptda into policy (or lack thereof), with ptda implementation occurring most often where facilitated by an opinion leader or champion26.

Interestingly, scps are supported despite not only limited evidence about effectiveness, but also about cost-effectiveness. For example, the first multisite rct of scp effectiveness, conducted at 9 sites across Canada, demonstrated that usual care was most cost-effective ($698 vs $765), with the total quality-adjusted life years being almost equivalent between the two arms4. In fact, creating an scp took 1–4 hours, a resource-intensive endeavour in what are increasingly resource-constrained settings4,27. Thus, scps
might be taking time away from other interventions that are equally or more beneficial. Given the tension between the influence of professional bodies in the adoption of new tools and constrained health care resources, how such bodies make endorsement decisions and what role high-quality research evidence assumes alongside other priority concerns and issues require further clarification or study.

Finally, it is essential to recognize the influence of various implementation considerations when understanding adoption decisions. For instance, data from the present study suggest the potential routinization of scps and ptadas for large populations and whether and how the tools could be adapted to each local setting were important to participants when deciding whether to adopt the tools. The successful adoption of scps was enabled by the fact that they can be modified to fit local settings and their use can be integrated into the post-treatment care of every patient (regardless of disease site or whether discharge to primary care occurs). Recent work in the United States has identified strategies for successfully implementing scps that should be considered by clinicians who decide to adopt and endorse those tools. Many participants viewed ptadas as too specific and thus difficult to implement and subsequently adapt to their clinical context. A reported barrier to ptada use is a perceived inappropriateness or complexity of ptadas for some groups of patients. The inability of ptadas to fit into pre-existing clinical care processes or general practice contexts (a commonly reported barrier to the implementation of many health care interventions) has also been reported. Despite those reported barriers, a recent systematic review that aimed to describe research efforts in cancer-related ptadas since shortly after the year 2000 found only two studies that investigated the effectiveness of strategies to implement decision aids in clinical practice. Research into this topic is clearly needed.

Our study findings have several implications for those who endorse or introduce new tools into clinical settings. Professional organizations and bodies have influence over whether teams and individual clinicians adopt new tools and interventions in practice. Delineating the evidence base of the tools that they endorse would assist individuals in making informed decisions concerning their use. Moreover, those who support and introduce evidence-informed tools have to be aware that the existence or provision of a tool does not mean that it will be used. Rather, they should understand both what targeted users expect from a particular tool and how they prefer to use it. A related understanding is how the tool’s core components are defined and operationalized (and thus how the tool could be adapted to fit local constraints and resources), which might be key to facilitating widespread adoption. Finally, identifying and obtaining the support of local champions can facilitate tool adoption and use.

The main limitation of our study is that the results might not be generalizable to adoption decisions related to patient-centred tools in all cancer care settings, especially settings outside of academic centres, given that most participants worked in academic or tertiary care centres. Even though the purpose of qualitative research is to obtain knowledge about processes, context, and causal mechanisms, and not to achieve generalizable results, the present study examined adoption decisions in 7 Canadian provinces and thus likely provides insights applicable to similar cancer care settings. In fact, participant views and experiences did not vary widely based on profession or geographic location, suggesting that the findings are applicable in a Canadian context and possibly in similar jurisdictions (for example, publicly funded health care systems).

CONCLUSIONS

Non-research sources of evidence, supportive organizations and colleagues, and implementation factors all influence decisions to adopt or not to adopt scps and ptadas. Misalignment of formal research evidence with clinical experience, patient preferences, and local data can lead to an apparent disconnect between “best practice” (as defined by science) and real-world practice. To help ensure that evidence-informed and cost-effective tools are being recommended and implemented, future research should take those important factors into account when developing and evaluating patient-centred tools. In particular, researchers should identify and include stakeholder-relevant outcomes in effectiveness trials and should delineate the core components that are likely critical to achieving beneficial outcomes with the tools. The latter knowledge can help to guide implementation and adaptation in local settings.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood Current Oncology’s policy on disclosing conflicts of interest, and we declare that we have none.

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