Views of family physicians about survivorship care plans to provide breast cancer follow-up care: exploration of results from a randomized controlled trial

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ABSTRACT

Background  The U.S. Institute of Medicine recommends that cancer patients receive survivorship care plans, but evaluations to date have found little evidence of the effectiveness of such plans. We conducted a qualitative follow-on study to a randomized controlled trial (RCT) to understand the experiences of family physicians using survivorship care plans to support the follow-up of breast cancer patients.

Methods  A subset of family physicians whose patients were enrolled in the parent RCT in Ontario and Nova Scotia were eligible for this study. In interviews, the physicians discussed survivorship care plans (intervention) or usual discharge letters (control), and their confidence in providing follow-up cancer care.

Results  Of 123 eligible family physicians, 18 (10 intervention, 8 control) were interviewed. In general, physicians receiving a survivorship care plan found only the 1-page care record to be useful. Physicians who received only a discharge letter had variable views about the letter’s usefulness; several indicated that it lacked information about potential cancer- or treatment-related problems. Most physicians were comfortable providing care 3–5 years after diagnosis, but desired timely and informative communication with oncologists.

Conclusions  Although family physicians did not find extensive survivorship care plans useful, discharge letters might not be sufficiently comprehensive for follow-up breast cancer care. Effective strategies for two-way communication between family physicians and oncologists are still lacking.

Key Words  Family practice, survivorship care plans, breast cancer

INTRODUCTION

The safety of follow-up breast cancer care delivered exclusively by family physicians (FPs) has been established in two randomized trials. Family physicians have expressed comfort with taking on more responsibility for cancer survivors, but they desire additional tools such as patient-specific standardized letters and guidelines for follow-up care, expedited routes for re-referral, and expedited access to investigations for suspected recurrence.

The report From Cancer Patient to Cancer Survivor: Lost in Transition from the U.S. Institute of Medicine called for health care practitioners to provide patients with a survivorship care plan (SCP) or a comprehensive care summary and follow-up plan that is effectively explained. Cancer SCPs have been endorsed as the “new way of doing business” once primary treatment is complete and are regarded as powerful tools for coordination of care at the end of adjuvant cancer treatment. As a personalized strategy for both cancer follow-up and surveillance, the goal of care plans is to provide a summary of the specific characteristics of the cancer (that is, type, stage, nodal status) and a summary of treatment modalities received by the patient. The National Cancer Survivorship Initiative in the
United Kingdom is implementing treatment summaries as a strategy to improve communication between specialists and primary care practitioners in several communities. The American College of Surgeons Commission on Cancer has recommended that cancer patients receive a scp upon completion of active treatment.

Since the publication of the Lost in Transition report, the body of literature on various aspects of scps has been growing, but rigorous evaluations of scp effectiveness are limited. Several studies have focused on what scps should entail10-13, their rationale and strategies for their implementation14,15, or obstacles to their completion16-20. Other studies have described the perspectives of patients about, and patient and health care provider support for or satisfaction with, scps.

More recently, two randomized controlled trials (rcts) evaluated the effectiveness of a scp for breast cancer patients. The results indicated that, with the exception of cancer worry, a scp delivered within a personal visit is no more effective than either a discharge visit with an oncologist21 or a 24-page publication from the U.S. National Cancer Institute22 on a wide range of patient-reported outcomes33.

To date, descriptions of the experiences of rps in actually using discharge documents from oncologists, especially within the context of a randomized trial, have been limited. We conducted a follow-on study of our previous rct to gain a deeper and more nuanced understanding about the experiences and views of rps with respect to discharge documents (scps and usual discharge letters). The specific study objectives were to explore:

- the awareness, understanding, and experiences of rps with various components of the scp and oncologist discharge letters; and
- the views of rps toward their role in providing follow-up care after adjuvant cancer treatment.

METHODS

The descriptive qualitative design used for the present study is appropriate for exploring new research concepts or new dimensions of existing concepts when little information is available. The focus is on obtaining the views of participants on a particular issue (for example, scps for the follow-up of breast cancer patients) and includes the broader context (for example, practice setting, the relationship of the fp with oncologists) to understand a given phenomenon.

Participants in the study were rps with a breast cancer patient who had previously participated in a rct. In the parent rct, 408 women (408 rps) were enrolled through 9 tertiary cancer centres in four provinces (British Columbia, Nova Scotia, Ontario, and Quebec). Patients were transferred back to their fp for exclusive follow-up care. All patients received a discharge visit with their oncologist. In addition, patients in the intervention group received a scp within the context of an educational visit with a nurse.

The scp was developed with input from oncologists, fps, and patients to identify barriers and supports to transition from oncologist to routine follow-up in primary care. The plan included a 1-page Record of Care, a patient version of the Canadian follow-up care guidelines, a summary table of the guideline, and a resource kit on supportive care resources based on patients’ needs. The fps of intervention patients received a copy of the patient’s scp, a full and a 2-page “user friendly” version of Canadian guidelines35, and a reminder checklist. The fps of patients in the control group received a discharge letter from the oncologist according to each centre’s usual practice.

Sampling

Of the 9 cancer centres in the parent rct, 4 centres were approached (3 in Ontario and 1 in Nova Scotia) to participate; 1 Ontario centre declined. Because of budget constraints, we did not approach cancer centres in British Columbia or Quebec. After ethics board approval, the names and contact details of fps, together with the names of their patients who participated in the rct, were received from the 3 participating cancer centres. We used maximum variation purposive sampling40 to create a diverse sample of physicians with respect to sex, years in practice, cancer centre, and province. Of the 123 eligible physicians, 61 (50%) did not respond to faxed invitations, 14 (11%) responded but refused, and 18 (15%) were interviewed. The remaining 30 (24%) did not receive additional follow-up because data saturation was achieved (see the Analysis subsection).

Recruitment

A mailed invitation letter was sent to each fp’s office. A modified Dillman method was used for follow-up. The fps provided written informed consent before their interview.

Data Collection

A semistructured interview guide was developed for the study, pilot-tested, and revised. Questions focused on the approach of the fps to breast cancer follow-up care, their views of the discharge information received, their use of the information in clinical practice, their views of the patient’s transition to their care, and the role of fps in breast cancer follow-up care. Telephone interviews (approximately 30 minutes) were conducted by an experienced research associate (MHM). Each fp was asked to obtain their patient’s chart before the interview and to have it available for review. Interviews were audiorecorded and transcribed verbatim. Interviews were held approximately 3–4 years after the fps had first received the scp or discharge letter and after outcomes for the parent rct had been collected.

Analysis

The researchers were unaware of the intervention or control status of each fp’s patient until discharge documents were described during the interviews. Transcripts were independently analyzed using the constant comparative method by two experienced researchers (MAO, MHM) using the NVivo 9 software application (QSR International, Doncaster, Australia). Coding disagreements were minor and were resolved through discussion. Codes and categories were constantly compared to determine interrelationships. Saturation of the data was achieved when no new variations of a theme or category were found. In the present study, saturation occurred after 16 interviews; another 2 interviews were conducted to ensure that no new themes were identified.
Rigour
We used a systematic and transparent approach for data collection and analysis that included using a data management software program to create and maintain an audit trail of coded transcripts, interview notes, and memos, and holding periodic meetings of the entire multidisciplinary research team. To mitigate any undue influence from the personal characteristics or views of the researchers over the research process, each FP’s perspective was carefully elicited during the interviews. In addition, all instances of both positive and negative views expressed by the FPs of follow-up cancer care and of SCPs and discharge letters were documented. The analytic process and emerging themes were reviewed by the entire research team.

RESULTS

Demographics
Table I sets out the demographic details of the study physicians. The 18 FPs interviewed included 12 women and 6 men (median age: 51 years). The FPs had been in practice for a median of 20.5 years (range: 3.5–49 years). Of the 18 physicians, 14 (78%) practiced in community settings. We examined two characteristics (sex and number of years since medical school graduation) of participating and non-participating FPs. There were 12 (of 18, 67%) and 56 (of 105, 53%) female FPs in the participating and non-participating groups respectively. The average number of years since medical school graduation was 24 years (range: 6–50 years) and 30 years (range: 6–63 years) in the participating and nonparticipating groups respectively.

Views of FPs About SCPs
Although the SCP consisted of several components (including a reminder checklist for follow-up care, full and “user friendly” versions of guidelines, and the patient’s version), the 10 FPs saw only the 1-page Record of Care as useful. They indicated that the rest of the package did not contain much new information, and 2 physicians described the information as basic knowledge. Several physicians noted that the recommended follow-up was “stuff I’d do anyway” in the context of an annual physical examination.

One-Page Record of Care
The FPs said that having all adjuvant treatment information, including chemotherapy and radiation therapy, on 1 page was helpful. Otherwise, they described having to review several consultation notes to find the information they needed:

So it was really useful to receive everything that she had done on one piece of paper—because we often just receive the consult letters, either from the oncologist, or the surgeon. Sometimes, they’ll summarize what happened with the type of cancer... and what they’ve had to date, or sometimes they don’t... When you’re flipping through [consult letters], sometimes it’s not helpful; you have to go through more than one.

Reminder Checklist
Many physicians kept an electronic medical record (EMR) and used reminders to recall patients rather than a paper reminder checklist. A one participant explained,

I would actually never use this form [SCP reminder checklist] now.... I would actually put the reminder in my electronic medical record to recall the patient every three months to come in for her breast exam.
However, one physician who did not use an EMR liked the reminder checklist as a means to prevent the patient being lost to follow-up. For her, having the checklist available was reassuring to me that the patient is getting care as recommended by the guidelines, and [the checklist] makes it quite clear that this patient needs to come in for these assessments. I don’t have any recall program to send out reminders.... So, [the patient] and I are both looking at the same schedule.... It’s very helpful to keep from being lost to follow-up.

**Guidelines (Full and User-Friendly Versions)**

For most physicians, the full version of guidelines for care was not helpful because it was too long, could not be easily input into the EMR, or contained information that was already known:

I think if it were more succinct, it would be easier for the family doctor.... There [are] so many different things that can be going on with patients.... If you could imagine getting a sixteen-page handout for many patients, that would be pretty much impossible to follow. So it would be nice to get something that was a bit more of a summary.

Most of [the guidelines] are pretty intuitive. I can’t say there were any wonderfully “aha” moments reading them over. And really, there’s not all that much to do, really. It’s clinical exam and a mammogram.

Only half the physicians (5 of 10) recalled receiving the user-friendly version of the guideline.

**Views of Oncologist Discharge Letters**

Based on descriptions given by the 8 FPs who received them, the content of the discharge letters varied. Some letters contained detailed recommendations for follow-up care; others simply noted the transfer of care to the FP. Physicians described variable satisfaction with this documentation. For example, one participant referred to his 3-page discharge letter as a “fabulous consult” and did not desire any additional documentation. Other FPs were not satisfied with the documentation from the oncologist: “So, he says, ‘Okay. You go ahead and just follow her.... She’s yours now.’”

Another FP said that the discharge letter did not have enough information on possible medication side effects and directions on “what to look out for.” This physician also felt that the direction around history-taking and physical examination for breast cancer survivors was not sufficiently specific.

**Location of Discharge Information in the Medical Record**

For several physicians in both groups, the documents were difficult to locate within the patient’s medical record. Most FPs of patients in the intervention group (8 of 10) located the Record of Care, but none of the FPs recalled receiving (or could find) the patient version of the SCP. Like the physicians who had received the SCP, several physicians who received the usual discharge letter had trouble locating that letter in the medical record.

**Views of FPs about Providing Breast Cancer Follow-Up Care**

Four themes emerged from the FP discussions of their role in providing breast cancer follow-up care. The FPs perceived that

- they are well-suited to provide follow-up care.
- providing recommended care is straightforward.
- patients are partners in care.
- communication with oncologists is variable and often inefficient.

**FPs Are Well-Suited to Provide Follow-Up Care**

Overall, most physicians (n = 15) felt that FPs are well-suited to provide breast cancer follow-up care. Several FPs indicated that the unique philosophical approach to health and illness as a whole offered by FPs well suited them to provide comprehensive care, as seen here, where the FP would like to help patients to move away from the medical model and really [focus] more on lifestyle and quality of life and healthy living. I don’t think oncologists are specifically trained in that, whereas we are.

Another FP supported that view for the patient and their family members:

My feeling is that [follow-up care] has to be embedded back into primary care, and the primary care practitioner needs to be supported to be able to pick it up and then support it.... I think [FPs] play a central role in it. They would play a central role, also, for the family members, who are part of that practice, which doesn’t often get captured when it’s just an individual that is being followed.

A number of physicians also raised the issue of resource allocation as a reason that follow-up care should be provided by the FP:

I’d rather have the oncologist treating the people quickly who have new breast cancer than having [those patients] wait because they’re so busy following people out from breast cancer for eight or nine years. It just makes more sense for resource allocation for family doctors to follow up.

A preference for follow-up care to be provided in a cancer centre or breast clinic was expressed by 3 physicians; however, 2 conceded that, because of limited specialist resources, it made sense to shift follow-up to the FP once the patient was far enough away from their diagnosis and “really routine follow-up” began. Most physicians indicated comfort with providing care 3–5 years after diagnosis:

Ideally, I would say that [follow-up care should take place with] the specialist. Whether that’s...
feasible in our system is a whole other question.... Five, ten years down the road, do they really need to go every year to a specialist? Probably not.... I think when they're far enough out from it and ... you're just doing really routine follow-up, ... there's certainly no concern with that.

Providing Recommended Care Is Straightforward

When asked about what follow-up would typically entail for a patient who is several years post diagnosis of breast cancer, most physicians noted that it would typically consist of an annual breast exam and a mammogram. For many, providing that care was seen as straightforward:

Honesty, if all [the specialists] are doing is clinical breast exam and ordering mammograms, there's really no reason why I can't do that. Really and truly.

Most physicians indicated that they felt comfortable managing care for patients on hormonal therapy, but a few said that they would have benefited from additional information about switching from tamoxifen to an aromatase inhibitor:

A lot of times now, they're on five years of tamoxifen and then they get switched over to five years of [letrozole], although now the situation's changing yet once again. So, for people coming on medications, it might be useful to know ... the things that you need to be aware of.

An EMR system with automated patient reminders was seen as advantageous in providing follow-up care.

Patients As Partners in Care

Several physicians indicated that the patient is an active partner or leader in follow-up care. Physicians and patients were seen as a “mutual reminder system.” In cases in which FPs felt that they had this sort of collaborative relationship with the patient, a role in follow-up care was welcomed:

I consider patients to be a collaborative partner, and so, it really is about them, and I see myself as guiding their care. So the first thing is “Do you know what kind of cancer you had? Do you know what you were given? Do you know the effects of it?” So usually they'll see me reviewing the discharge summary and checking with them.

A number of physicians encouraged patients to take more ownership of their health and incorporated strategies to facilitate self-management in their practices:

I can tell you that the way that things are moving forward is really helping patients to take more ownership over their health.... We're rolling out some of the Stanford Chronic Disease patient education modules where patients learn to manage their own health.

Most physicians felt that women with a history of breast cancer were likely to be more vigilant in ensuring that their follow-up was completed on schedule:

The difference with [breast cancer survivors is that] ... they present regularly, [so] you're more likely to get it [a mammogram] done.... Because of their anxiety, they're more likely to follow through.

Communication with Oncologists During Follow-Up Is Variable and Often Inefficient

Effective communication between FPs and oncologists varied across the 3 sites. In Nova Scotia, participants viewed communication with oncologists favourably and felt comfortable “picking up the phone” to ask questions:

I can say that my experience in that regard is very favourable.... There's not much of a delay, and sometimes, even just picking up the phone and saying to the individual oncologist, “This is my concern.”

In the large urban Ontario centre, contact between oncologists and FPs appeared to be much more limited. Several FPs described having difficulty speaking to an oncologist directly and would instead re-refer the patient to the oncologist when questions arose:

Right now, in order to get an answer to what needs to be done in regard to breast cancer concerns, it requires a consultation, which means that we have to refer the patient back, the patient has to wait around until the consultation occurs.... A letter comes back to me that would take at a minimum three months. Often longer. It's highly inefficient. If I could pick up the phone and call [the name of institution] breast cancer team physician line and say, “Listen, I have a quick question. What should I do? Or do you need to see the patient?” I think it would save everybody a ton of time.

In the smaller urban Ontario centre, FPs indicated that they were generally satisfied with how they communicated with oncologists:

It's not that hard to phone the [cancer centre] and speak to one of the oncologists.

Basically [I will] fax over a letter. That's probably the most efficient way ... but then it's again dependent on how good that doctor is in responding to that. Some physicians are really good... Then [there are] other physicians.... You just don't hear back from them.

Across all sites, FPs welcomed clear direction from oncologists regarding expectations for follow-up care, including recommendations for screening, frequency of follow-up, and a list of potential problems related to the type of cancer or treatment to “watch out for.” Most, but not all, FPs said that they receive some type of documentation
from the specialist at the time of discharge back to them, usually recommending yearly mammograms.

No physician anticipated or had experienced difficulty returning a patient to specialist care if a recurrence was suspected.

**Suggestions from FPs for Improving Follow-Up Care**

**Simple, EMR-Friendly Documents**
The FPs desired short, simple, EMR-compatible documents pertaining to follow-up care that could be easily scanned and searched. The 1-page Record of Care was mentioned as an example of a user-friendly document. In addition, FPs suggested that discharge letters could include a statement that FPs input reminders into the EMR system at specified times. Guidelines for recommended care could be provided by means of a Web address.

**Improving Ongoing Communication with Oncologists**
The FPs expressed a desire for efficient ongoing communication with oncologists. Several FPs thought that e-mail would be an efficient way to communicate. Others wanted a contact person to be available to answer questions as they arose. One FP explained that she would feel comfortable if there was ... a number you call when you have a question. Which doesn’t mean you would necessarily speak to the specialist at that exact moment, but just knowing that they’re going to get that message, it’s going to be addressed quickly ... that would be great.

**DISCUSSION**

Our study examined the views of FPs whose patients with breast cancer had been treated at 3 cancer centres in two Canadian provinces about SCPs and discharge letters for those patients. The study is unique in that the patients of the FPs had participated in a larger RCT. Consequently, the study offers perspectives based on the actual experiences of FPs who had received a SCP or only a discharge letter rather than a hypothetical view of how such documents could be used. All FPs were providing exclusive follow-up care to the breast cancer patient who had participated in the RCT. All FPs had multiple opportunities to review or consult the documentation after it had been sent to them.

Physicians who received the SCP found it to be of limited value beyond the 1-page Record of Care. Physicians who received only the discharge letter from the oncologist had variable views on its content, but wanted more detailed information about treatments received and potential late effects. Those findings suggest that the SCP was not an effective tool for FPs, which accords with the results of the parent RCT, which found no differences in patient-reported outcomes between patients who received a SCP and those who did not.

Our findings differ from those of Shalom et al., who examined the experiences of primary care physicians (internists) with SCPs (73% of the SCPs were related to breast cancer). Those authors found that physicians were more confident in providing care for cancer survivors after reading the SCP than that the physicians valued the comprehensive SCP format. Approximately half indicated that they had changed their practice as a result of the SCP. Our study, in the context of a rigorous evaluation, raises questions about the key components of discharge information needed by FPs. In our study, only the Record of Care component of the SCP was seen as useful by most physicians. In a survey of 587 primary care physicians, Smith et al. similarly found that a diagnosis and treatment synopsis was identified as the most useful information to be included in a discharge summary.

The views of the FPs in our study also differ in some respects from those reported by Kantisper et al. Those authors asked primary care providers (as well as oncologists and breast cancer patients) for their views about providing follow-up care if a SCP created by the oncologist were to be available at the end of adjuvant treatment. Some primary care providers were interested in having tools such as written SCPs, but they also indicated that the oncologist should stay involved with the patient. A possible explanation for the difference between our findings and those of Kantisper et al. is that we asked FPs about their actual experiences with SCPs for patients under their care; Kantisper et al. inquired about the hypothetical availability of SCPs and how such plans might affect the willingness of the providers to deliver future follow-up care.

A consistent finding of our study was that FPs of intervention and control patients alike perceived that providing follow-up breast cancer care (viewed by many FPs mainly as ordering annual mammograms and conducting yearly breast examinations) is not difficult. Yet that perceived lack of difficulty did not necessarily mean that patients received all aspects of recommended care. At 24 months’ follow-up, Boekhout et al. found that 41% of control and 44% of intervention patients had received 3 or more clinical examinations, and that 68% of control and 69% of intervention patients had received 2 or more breast imaging tests. Guidelines for follow-up after breast cancer also include recommendations for psychosocial support, sexual functioning treatment, and other aspects of care. In the present study, FPs seldom described initiating conversations about psychosocial issues, but said that they would refer patients for support if needed.

Most FPs were comfortable in providing care for patients who were 3–5 years post diagnosis. That observation is consistent with the findings of Del Giudice et al., who reported that FPs were willing to assume exclusive care for breast cancer patients an average of 2.8 years after completion of active treatment. Smith et al. also found that primary care physicians reported confidence in screening for breast cancer recurrence. In contrast, Blanch-Hartigan et al. reported that primary care physicians in the United States preferred either shared responsibility for survivorship care or that another physician provide such care.

We found that all FPs in our study emphasized the importance of timely communication with the oncologist to facilitate the FP’s own provision of effective follow-up care. Despite strong desires for timely communication with oncologists, the communication experiences of FPs...
were markedly variable across the 3 sites. In Nova Scotia, physicians described effective communication strategies such as telephone conversations in the context of smaller communities in which the FPs and the oncologists knew one another. In contrast, in the large urban centre in Ontario, FPs expressed dissatisfaction and frustration with frequent “telephone tag” or with telephone calls being ignored. In the smaller Ontario city, physicians agreed that a personal relationship was important to ongoing communication. They talked about “being known” and going out of their way to get to know the oncologist.

Our study has limitations. We spoke to FPs approximately 3–4 years after they had first received a SCP or discharge letter. We did not interview the FPs any earlier because of concerns of potential co-intervention or contamination during the follow-up period when data in the parent RCT were being collected. It is possible that the physicians did not recall their first impressions of the discharge material. However, they had multiple opportunities to review the SCP or discharge letter, because all patients continued to require follow-up care. A strength of the study was that, rather than rely on their recollections, participants reviewed the discharge documents during the interview.

Our study focused on SCPs for breast cancer in a context in which the FP was providing exclusive follow-up care. We cannot comment about the usefulness of SCPs for other types of cancer or for patients with specific needs or in other contexts. Although Jefford et al. and others have suggested that outcomes such as self-efficacy or unmet needs might be appropriate for detecting the benefits of SCPs, the present study cannot confirm or refute such suggestions because they exceed the scope of the work and are the subject of further research.

We investigated the perspectives of 18 FPs whose patient with breast cancer was treated at 1 of 3 cancer centres. Compared with nonparticipating FPs, the participating FPs were more likely to be women and to have been in practice for an average of 6 years less. It is not possible to know with certainty if their views would be generalizable to other FPs whose patients participated in the parent RCT and agreed to be discharged to their FP, or to FPs in general. However, we purposefully sampled the FPs whose patients were treated at 3 cancer centres in two provinces to obtain a range of perspectives, and informational saturation was reached in the analysis.

**CONCLUSIONS**

Although extensive SCPs were not seen as useful by FPs providing follow-up breast cancer care, the usual discharge letters provided by oncologists could be improved. The FPs preferred

- a standardized, concise discharge letter with sufficient information, including oncologist contact information; and
- a Record of Care.

Although SCPs are recommended as part of follow-up care, uncertainty remains about the format that would be effective for FPs. The FPs were comfortable providing follow-up care for breast cancer patients 3–5 years post diagnosis, but significant gaps remained in achieving more productive and less cumbersome strategies for communication between FPs and oncologists.

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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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