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ORIGINAL ARTICLE

Breast cancer survivor's perspectives on the role different providers play in follow-up care

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Abstract

Importance Significant variation in the number and types of oncologists that provide breast cancer follow-up exists. However, there is limited understanding regarding breast cancer survivors' preferences for who provides their follow-up. Our objective was to explore breast cancer survivors' perspectives on the goals of breast cancer follow-up, the preferred role for primary care providers, and the perceived roles of different types of oncologists during follow-up.

Methods A convenience sample of stage 0–III breast cancer survivors was identified and in-depth one-on-one interviews conducted. Data were analyzed using inductive content analysis.

Results Survivors cited a strong preference for oncology-based follow-up within the first 5 years after diagnosis, driven by their need for reassurance that cancer had not recurred. Survivors also thought that their primary care provider needed to be involved. Survivors assumed that oncology follow-up was directed by a standard protocol that included streamlining the follow-up team. Survivors recognized that patients with more complex cancers or challenging treatment courses may require more intensive follow-up and deviate from the standard protocol. Most survivors were comfortable deferring decisions regarding who participated in follow-up to the oncology team.

Conclusions Most patients think a streamlined approach to oncology-based breast cancer follow-up already occurs, driven by a standard protocol. The use of a standard protocol to provide guidance for which types of oncology providers should participate in breast cancer follow-up will streamline care and represents a significant opportunity to reduce unnecessary variation. This approach is especially critical given patients' strong preferences for oncology-based follow-up.

Keywords Breast cancer · Providers · Follow-up care · Survivorship · Surveillance

Introduction

More than three million breast cancer survivors currently live in the USA [1], and each requires follow-up to evaluate for new primary cancers, cancer recurrence, and treatment side effects. Current clinical practice guidelines from the American Society of Clinical Oncology and the National Comprehensive Cancer Network recommend frequent follow-up within the first 5 years after diagnosis [2–4]. Per guidelines, these visits should be performed by a "physician experienced in the surveillance of patients with cancer and in breast examination" [2] or "members of the treatment team" [3]. This guidance is quite broad, and allows for the delivery of follow-up by both primary care and oncology specialists. However, barriers to primary care provider (PCP) participation in breast cancer follow-up exist [5–11], and oncology providers (medical and radiation oncologists along with

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surgeons) currently provide most breast cancer follow-up in the USA [12–17]. There is significant variation in the number and types of oncologists that provide follow-up for a given patient, and this variation is strongly associated with the frequency of follow-up visits [12–14, 16]. Some of this variation reflects oncologists tailoring of follow-up recommendations based on patients' risk of recurrence or treatment side effects [18, 19]. Oncologists also have differing perceptions of their individual roles and responsibilities for breast cancer follow-up. Further, some oncologists cite breast cancer survivor's preference as one reason they continue to participate in ongoing follow-up [19]. In current clinical practice, each oncology provider independently makes the decision whether to actively participate in follow-up or defer care to others. The lack of clear guidance regarding who should provide follow-up is one source of variation, which creates potential for both redundancy (overuse) and gaps (underuse) in follow-up care.

Given that oncologists cite survivor preferences as a driver of their recommended follow-up care, the preferences of breast cancer survivors represent another potential source of variation. Little is currently understood about breast cancer survivors' preferences for who provides their follow-up care within the first 5 years after diagnosis. Most breast cancer patients prefer to play an active role in treatment decision-making [20–24], and it seems plausible that this applies to decisions about breast cancer follow-up as well. Prior studies suggest that breast cancer survivors have a strong preference for oncology-based follow-up [25–29] and highly value the relationship with their oncology team [16]. However, we have little insight into how patients conceptualize the follow-up roles of the different oncology providers that comprised their treatment team. In addition to increasing our general understanding of how follow-up is currently being delivered, understanding patients' perspectives regarding the role that different providers (both oncologists and PCPs) play in follow-up is critical to ensuring that any new recommendations designed to improve the quality and efficiency of breast cancer follow-up would be acceptable to survivors, and thus translatable into practice change. Therefore, the objective of this study was to explore breast cancer survivors' perspectives on the goals of follow-up within the first 5 years of diagnosis, the preferred role for PCPs, and the perceived roles and responsibilities of different types of oncologists during follow-up.

Methods

Recruitment

We conducted one-on-one in-depth interviews by telephone with breast cancer survivors across Wisconsin (March 2015–November 2015). Eligible patients were 18 years of age or older, had a history of stage 0–III breast cancer, and were disease free. Patients were within 5 years of finishing their cancer treatment and could still be receiving endocrine therapy or Her2neu-targeted therapy at the time of the interview. We excluded non-English speaking patients, men, and those lacking decision-making capacity.

To identify potential participants, we solicited recommendations from the oncologists who participated in our completed study on Wisconsin oncologists' perspectives on breast cancer follow-up [19]. Oncologists were asked to identify patients within their follow-up practice that they thought "would have a perspective on breast cancer follow-up that would be important for us to hear." Two recruitment methods were used based on preferences of the local site: (1) interested patients were provided contact information for the research team and asked to call, or (2) oncologists shared interested patient contact information with the research team, who then contacted them. The research coordinators (NS, JT) then screened interested patients for eligibility; basic demographics (age, type of treatment received, rural/urban residence, type of clinical practice where they receive care, residence) were also collected. We then used purposive sampling from within this convenience cohort to ensure diverse cohort that could be expected to have different perspectives within our final sample [30]. Each participant was offered a gift card equivalent to $25 for her time. This study was viewed as exempt by the University of Wisconsin Institutional Review Board.

Data collection

The semi-structured interview guide was developed based on a review of the literature and the findings of the completed study of oncologists [19]. Guide domains focused on (1) what the role of a PCP was in the patient's cancer follow-up, (2) patient's perspectives on why different types of oncology providers participated in follow-up, (3) what patients considered the roles of these different oncology providers to be, and (4) the potential negative aspects of cancer follow-up (see Appendix for guide). The interview guide contained questions along with sample probes to generate more in-depth responses or to clarify a response. In-depth, telephone interviews were conducted by a trained interviewer (N.S.). Participant accrual continued until data saturation was achieved (i.e., the point at which no new themes were encountered). This occurred after 13 patient interviews had been analyzed.

Data analysis

Interviews were audio recorded and transcribed verbatim. The resulting data were analyzed using an inductive approach to content analysis [31, 32]. Open coding was performed independently (J.T. and H.N.) on the first five transcripts to create a preliminary list of codes. The two investigators then reviewed each transcript together and refined the initial coding into a preliminary coding taxonomy. All transcripts were then reviewed independently by each investigator and coded using the newly defined coding taxonomy. The final transcript codes from each investigator were compared, and differences discussed and resolved through consensus. Concurrent interviewing and coding continued until the primary codes were saturated and the coding taxonomy was stable. In the next steps, codes were grouped into conceptual categories that best represented the data, and selective and axial coding was performed in order to examine particular relationships in the data. Mapping further delineated relationships between concepts [33]. Qualitative analysis software (NVIVO 10 software, QSR International) was used to organize the data.

Results

Thirteen interviews from breast cancer survivors from eight different oncology practices were completed (Table 1). At the time of the interview, four patients were following with medical oncology alone, three with both medical and radiation oncology, four with both medical and surgical oncology, and two with radiation oncology alone. The median length of the interviews was 47 min (range 28–83 min).

Figure 1 presents an overview of the key themes that are described in detail below.

Table 1 Characteristics of participants

	$N = 13$ patients
Median age	60 (43–80) years
Median months from diagnosis	40 (16–66) months
Academic (versus community) clinic	39%
Lumpectomy	69%
Received chemotherapy	46%
Received radiation	85%
Received endocrine therapy	77%
Current follow-up team	
Medical oncology alone	4/13
Radiation oncology alone	2/13
Medical + surgical oncology	4/13
Medical + radiation oncology	3/13

Survivor

Perceived reasons for follow-up

Anxiety about recurrence strongly influenced survivors' perceptions about the follow-up they received.

"I'm at the stage where, if I have any bit of pain or feel any little bump, I go into panic mode, and it'd obviously be cancer coming back, and you know, I go kinda crazy for a little while."

Although cancer follow-up was perceived to accomplish many things, survivors stated that obtaining reassurance that the cancer had not come back and "providing significant peace of mind" was the most important to them. Additional prioritized reasons for follow-up included assessing side effects of ongoing or completed treatment and renewal of endocrine therapy prescriptions.

Strong preference for oncology-based follow-up

Survivors had a strong preference for oncology-based cancer follow-up as compared to follow-up by their PCP. As one survivor stated, "I think my preference would be staying with the cancer group that got me through the whole situation." Survivors thought that seeing an oncology specialist, whether surgeon, radiation oncologist, medical oncologist, or mid-level provider working within an oncology office, provided more reassurance about their cancer than they would receive from seeing their PCP. Further, they preferred to direct their cancer concerns to their oncologists, because they wanted to "deal with someone who knows that stuff inside and out." Finally, survivors recognized that cancer care is complex and evolving. Oncology-based follow-up was thought to be an important way to keep informed of new advances in cancer care.

"I must say that my primary care, has been doctoring for many, many years, and he has a wealth of knowledge about being a [primary doctor]. But you should go to somebody who specializes."

"I think it's important that I know that someone is doing research behind the scenes to make sure that if something new comes up they know to call me and tell me."

However, survivors thought that continuing to see their PCP while undergoing oncology-based cancer follow-up was important. Although survivors perceived that their PCPs were not directly providing cancer follow-up, survivors thought that they were "involved in caring for me as a person" and were important because they remembered survivors' "bigger story instead of just my cancer story" when providing perspectives.

Perceived roles of different types of oncology providers in follow-up

Survivors conceptualized different roles for their oncology providers during follow-up. In most cases, survivors identified their medical oncologist as their primary follow-up doctor. This stemmed from the perception that medical oncologists took a more global approach to follow-up, something that was perceived to be very valuable.

"I think it's more of an all-over type follow-up, as opposed to just a physical, the side-effects. It's also emotional, mental. I

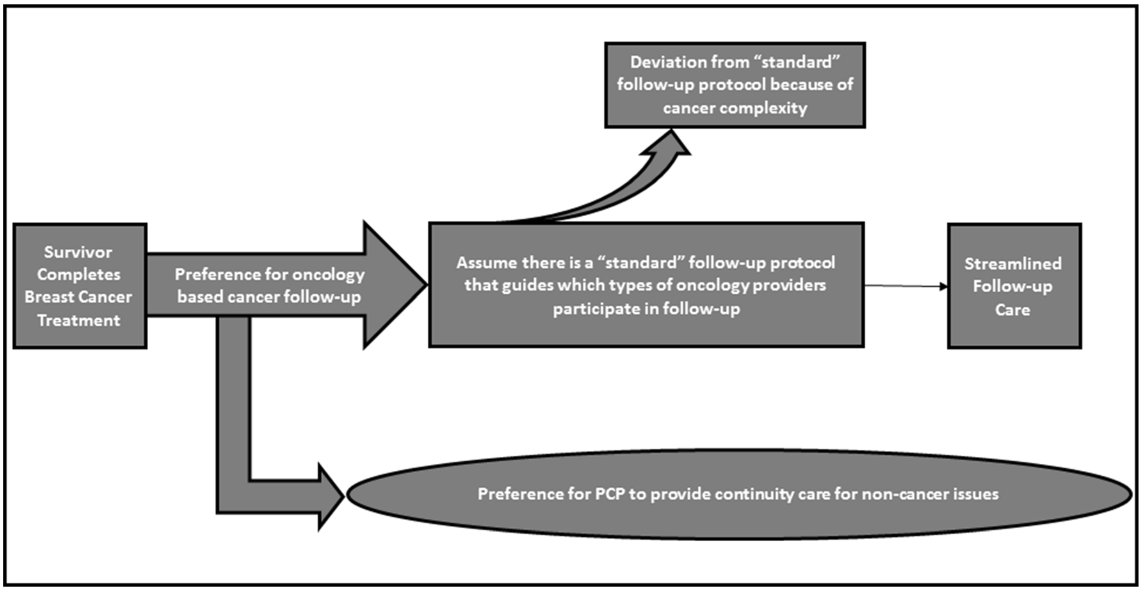

Fig. 1 Survivors who complete breast cancer treatment have a strong preference for oncology-based follow-up, although they think that PCP should play a supporting role. Most survivors thought that recommendations for which oncology providers participated in follow-up were based on a standard protocol that would result in the best cancer outcomes and in streamlining follow-up care. Patients with more complex cancers or challenging treatment course may require more intensive follow-up and deviate from the standard protocol. Survivors recognized potential disadvantages of standard follow-up, including the burden frequent visits pose for time away from work and intensification of anxiety about cancer recurrence around follow-up cisits, but felt that these chalenges were acceptable

mean they have a nurse that will help with any problems you might be having emotionally, or anything like that. It's just more of an all over thing than just how you're doing after your surgery."

Another contributing factor was the very strong relationship many survivors developed with their medical oncologist over the course of chemotherapy.

"For me, chemo was truly the more difficult part of my treatment. The lumpectomy, the recovering from that was fine. [The surgeon] did a fantastic job. Chemo was fine as well but that was the tougher part for me, emotionally, physically… so I think there was that better connection with my [medical oncologist]."

Finally, because many survivors receive ongoing treatment prescribed by medical oncology (endocrine therapy), it "makes sense that [medical oncologist] would be the one to see me."

In contrast, survivors viewed radiation oncologists and surgeons as having more focused and limited roles in follow-up. One survivor described that her interactions with her radiation oncologist and surgeon felt "more like a treatment," whereas she associated her medical oncologist more with the "illness that goes along with it." Many other survivors echoed this idea that their radiation oncologist and surgeon had "done their part" during treatment, and were therefore less critical during follow-up.

"I think my relationship with my surgeon and rad onc, they're just pointed. My surgeon had a thing to do and he did his thing. And he did it well. I liked him. I think the same about my radiation oncologist, he had a job to do and he had a certain amount of time to do it, and he did it well. And he was very good and, conscientious, and detailed. But I think my med oncologist is more of a relationship."

Although most survivors were comfortable deferring routine follow-up to their medical oncologist, they emphasized the importance of having their radiation oncologist and surgeon available to them if needed. Survivors described specific circumstances, such as a new breast lump, where they would preferentially direct their concerns to their surgeon or radiation oncologist.

Survivors perceive that a standard follow-up regimen exists that guides follow-up

The vast majority of survivors assumed that decisions regarding which oncology providers participated in follow-up were guided by a standard follow-up protocol (Table 2). This assumption contributed to survivors' belief that their input in the follow-up plan was not needed, as it was "a natural progression." Few survivors recalled ever having a conversation regarding ongoing participation in follow-up. However, most survivors were comfortable deferring these decisions to their oncologists: "they are the professionals, and I felt that they needed to make that call."

Survivors were cognizant of limitations in the oncology workforce. Given the number of patients diagnosed with breast cancer, survivors recognized that their oncology providers "cannot keep seeing everybody" during follow-up, as

Table 2 Patient perceptions that a standard protocol drives follow-up recommendations

Patient number	Representative quote
1	I just always assumed it was just part of the follow-up, that for a certain period of time, you just go back in and you see the two of them to make sure that everything has healed and everything's okay. You know, could I have maybe canceled that last appointment because there was really nothing there, everything was okay? Probably. But again, I think you just go through, you know your schedule, you go through it
2	Because… that's the way, that's the procedure of it. Where I did not know because I have never been through this before.
4	No, I think they know more than I do. What I need. They are the professionals, and I felt that they needed to make that call.
6	I think it's, it's a standard procedure. I, I, I feel they know what they are doing, and I cannot say my opinion would amount to anything.
10	I think it was almost like a natural progression that I ended up with her, and that's who I assumed was gonna do it from here on out.
12	It just kind of checking something off a list, basically.
13	You know I think it's just the routine. I think it's just the way things are that they see you.

they were already "busier than busy" with full clinic schedules. Because of these workforce limitations, survivors thought that oncologists needed to prioritize whom to focus on. Survivors thought that this prioritization should be driven by the complexity of each individual's cancer experience. For example, survivors who perceived that their cancer experience was "simple" thought that oncologists "should be spending their time with people that need them more than I need them." Streamlining care in this way was also thought to directly benefit the survivor, as streamlined care presents a single point person for patient contact. In contrast, survivors who perceived their cancer to be more complex thought they needed more interactions with their oncology providers than may be standard. This concept of the simple versus complex cancer encompassed perceived cancer prognosis, personality of the patient, and complexity of treatment (Table 3). Survivors perceived that weighing of the complexity of each survivor's breast cancer experience was the primary determinant of whether patients received a standard, streamlined follow-up versus a more intensive follow-up with participation from multiple providers.

Perceived disadvantages of the "standard" follow-up protocol

Survivors recognized potential disadvantages of the follow-up they received, including difficulty getting time away from work, out of pocket costs of copays, and the long distances survivors sometimes traveled to see oncology providers. However, when discussing these factors, survivors were quick to state that these were theoretical concerns, and that, "for me it wasn't, nothing's been an issue" or that the challenges were an acceptable and "unavoidable problem." Overall, survivors did not think that providers should consider the potential disadvantages of frequent follow-up when making follow-up recommendations.

Table 3 Patient perceptions of complexity of cancer experience and follow-up

Good prognosis of cancer

Because I'd think I'd be one of those because I had stage 1, I am doing very well. So if she [my medical oncologist] ever would have to pass someone, I'd probably be one to be passed.

Patient personality

I did not have chemo, I did not have radiation, I am really fine, and part of it is because I am a nurse practitioner myself, so I am not a very needy patient.

Quite honestly, my level of anxiety was so high that I wanted to see somebody every three months!

Complexity of treatment and side effects

And the outcome was good, I am happy with the way my breast looks after surgery, so, I think that was a very good outcome. It was all pretty straightforward.

Because truly once I got through the radiation, everything was okay. Now if, maybe if I was a patient that had complications or open wounds and scarring and things like that or something did not heal, it might have been totally different. But I did not have any of that, and my skin healed very, very, well. So again, follow-up was very simple for me.

Yeah, and I have been, I have been dealing with some abnormal issues, um, that I think require me to engage my surgeon maybe more than most. My tumor was against my chest wall, and so for clear margins they had to take off part of my pec muscle, and the radiation went deeper as a result of that.
So I do not know that somebody was out having had part of their peck removed, or just the sports injuries history that I have would ever be dealing with the situation I am dealing with, um, which, has been a challenge for my oncologists.

"I'm able to take off work if I need to so it's not a big deal for me for work. And it doesn't really impact my family, we drive up, we're about an hour and a half away, so the drive up there is not that bad."

"Well, I usually have to take the whole day off of work. Because we can't just take a few hours where I work, so I have to take the whole day off, or leave early and make up time. So that's never… pleasant. But once every three months I can handle."

An additional consequence of cancer follow-up was an intensification of anxiety about cancer recurrence prior to the visit: "the week before the appointment, that's all you think about." However, most survivors felt that the reassurance experienced after seeing their oncology provider was much more powerful.

"Everybody is waiting for that six-month check. And you're nervous as hell! It's no different than when you got your initial biopsy and you're waiting for the results. You're nervous as hell, but once you have it, and especially if you get a clean bill of health, I don't think there's anything that could be more freeing and reassuring than that."

Finally, many survivors described very strong relationships with oncology providers that they did not continue to see during follow-up. Although survivors recognized streamlining care made sense, it was also challenging, as "I have to let go of something that was a life-line."

Discussion

In this study examining breast cancer survivors' perspectives on follow-up, the strongest theme was survivors' preferences for oncology-based cancer follow-up in the initial years after their diagnosis. This finding is consistent with other studies conducted within the USA [6, 27–29, 34, 35]. Survivors' primary goal of follow-up was to receive reassurance that their cancer had not recurred, and it is understandable that survivors perceive seeing a member of their oncology team as the best way to achieve this [6]. Survivors also value oncologists' expertise [28]. Survivors recognized that oncology-based follow-up may be an important method to ensure that they hear about any relevant advances in cancer care, such as changes in duration of endocrine treatment or eligibility for expanded panel genetic testing [6]. Further, survivors feel a strong connection with their oncology team [6, 29] and express reluctance to give up this source of support.

Although survivors wanted their oncologist to be responsible for the breast cancer-specific aspects of follow-up, they almost unanimously felt that their PCP needed to be involved as well [28, 29, 34, 36, 37]. Survivors valued having a provider involved in their care who thought of them as a whole person, not just a breast cancer survivor. In this role, survivors thought their PCP's broad base of knowledge and experience was an important complement to the focused expertise of their oncology team.

For patients in our study, the ideal model of survivorship care within the first 5 years of diagnosis most closely resembles the shared-care model described by Oeffinger et al. [38, 39]. In this type of model, oncologists retain responsibility for the cancer-specific components of care while maintaining open communication with the PCP, who oversees the non-cancer-related aspects of survivorship. Survivors transition to the PCP as primary provider when the risks related to their cancer or cancer treatment decrease; this timing can be tailored for each survivor [38, 39]. This model meets the needs expressed by the survivors in our study by ensuring active involvement during follow-up by both their oncologists and PCP. However, one limitation of this model of survivorship care is that it does not provide any guidance around which types of oncology providers should fill the role of "oncologist" in the model.

The other significant finding from this study is that most survivors assumed that the decision for which of their oncology providers would participate in cancer follow-up was directed by a standard protocol. Although survivors prefer their oncologists to provide the cancer follow-up [6, 27, 28, 34, 35], most did not have a strong preference for *which* of their oncologists participated. These factors have not previously been reported in the literature, but have the potential to greatly influence how follow-up care is delivered.

In current clinical practice, there is significant variation in both follow-up visit frequency and in which oncology providers are providing the care [12–14, 16, 18, 19, 40]. Some of this variation likely reflects redundancy in clinical care. This redundancy may contribute to the projected shortfall of oncologists and lead to delays in care initiation for patients newly diagnosed with cancer [41]. Further, unnecessary follow-up may lead to financial and emotional costs for the survivors themselves due to visit co-pays, time away from work and family, and anxiety. In our prior work, we examined oncologists' perceptions around breast cancer follow-up, focusing specifically on the factors that influence whether or not an oncologist provides follow-up for a given patient [19]. In this study, oncologists cited patient preference as an important reason for their ongoing participation in follow-up [19]. This belief conflicts directly with the results of this study of breast cancer survivors.

Survivors' comfort deferring decisions regarding which oncologists participate in follow-up represents a significant opportunity to streamline follow-up. Survivors perceived that all members of their oncology team were equally capable of finding a recurrence and seeing any member of their oncology team provided similar levels of reassurance. Our data suggests that many survivors are comfortable having one oncology provider (most commonly their medical oncologist) take the primary role in cancer follow-up. This was especially true if survivors perceived their breast cancer to have been simple, i.e., early stage. For the vast majority of breast cancer survivors with early stage cancer, having their follow-up provided by a single oncology provider would not only decrease the burden of follow-up but also provide patients with a single point person for all cancer-related communications. It is essential that survivors' expectations around streamlined follow-up be set early. Further, survivors prefer that other members of their oncology team still be accessible to answer questions specific to their expertise.

Although this type of streamlined approach works well for many survivors, others—patients who had a more complex cancer or challenging treatment course—would best be followed by a broader oncology team. Additionally, some survivors develop an unusually strong relationship with a specific oncology provider; these patients may have a strong preference for that provider to participate in ongoing follow-up. Considering a streamlined model of follow-up as the standard for most patients, while allowing flexibility to personalize follow-up to account for clinical complexity as well as patient preference, is likely to be the most successful approach.

There are some limitations to our study. We used a snowball sampling approach by asking oncologists involved in our prior study to identify patients with a "perspective that would be important for us to hear." This may have introduced selection bias into the sample, as these patients may not be representative of the broader population. However, it is likely that each oncologist interpreted this broad guidance differently, and it is therefore unlikely that our sampling strategy led to a systematic bias in any one direction. Further, our goal of this sampling method was to obtain a sample with diverse perspectives rather than a sample representative of the broader population. We relied on patient self-report for demographics, treatment characteristics, and providers participating in follow-up. To limit the survey burden and avoid sensitive topics, we did not collect data on education, income, or race, all of which may be relevant to patients' perspectives on follow-up. We also did not collect data on cancer stage of initial follow-up team composition, as we were concerned this data would be reported accurately.

Conclusion

The lack of clear guidance about who should participate in breast cancer follow-up represents a significant gap in current follow-up recommendations [2, 3] and has led to significant variation in the number and types of oncologists that participate in breast cancer follow-up. The findings of this study reveal a significant opportunity to improve guidance and thus decrease variation in follow-up. Importantly, our data demonstrate that not only are patients open to considering this type of streamlined follow-up approach, they think it is already happening. Streamlining follow-up represents a significant opportunity to address oncology workforce shortages, especially critical given patients' strong preferences for oncology-based follow-up.

Compliance with ethical standards

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

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