HHS Public Access

Author manuscript

Ann Surg Oncol. Author manuscript; available in PMC 2016 March 01.

Published in final edited form as:

Ann Surg Oncol. 2016 March ; 23(3): 708–714. doi:10.1245/s10434-015-4904-6.

Oncologists' Perspectives of their Roles and Responsibilities during Multi-disciplinary Breast Cancer Follow-up

Heather B. Neuman, MD, MS[1,2], **Nicole M. Steffens, MPH**[1], **Nora Jacobson, PhD**[3], **Amye Tevaarwerk, MD**[2,4], **Bethany Anderson, MD**[5], **Lee G. Wilke, MD**[1,2], and **Caprice C. Greenberg, MD, MPH**[1,2]

[1]Wisconsin Surgical Outcomes Research Program, Department of Surgery, University of Wisconsin School of Medicine and Public Health

[2]University of Wisconsin Carbone Cancer Center, University of Wisconsin School of Medicine and Public Health

[3]School of Nursing, Institute for Clinical and Translational Research, University of Wisconsin-Madison

[4]Department of Medicine, Division of Hematology and Oncology, University of Wisconsin School of Medicine and Public Health

[5]Department of Human Oncology, University of Wisconsin School of Medicine and Public Health

Abstract

Background—Improving the quality of follow-up provided to the 3 million U.S. breast cancer survivors is a high priority. Current guidelines do not provide guidance regarding who should participate in follow-up or what providers' specific responsibilities should be. Given the multidisciplinary nature of breast cancer care, this results in significant variation and creates the potential for redundancy and/or gaps. Our objective was to provide insight into why different types of oncologists believe their participation in follow-up is necessary.

Methods—A purposeful sample of breast medical, radiation and surgical oncologists was identified (n=35) and in-depth one-on-one interviews conducted. Data were analyzed using content analysis.

Results—Medical oncologists were driven by a sense of *Responsibility for Ongoing Therapy*, perceived *Strong Patient Relationship*, and belief that their systemic approach to follow-up represented a *Specific Skillset* beneficial to patients. In contrast, surgical and radiation oncologists were selective about which patients they followed, participating when they perceived their *Specific Skillset* of enhanced local-regional assessments would be valuable. Additionally, they endorsed participating to *Ensure Follow-up is Received* or not participating to *Minimize Redundancy*. These individual decisions led to either a Complementary Oncologist Team or Primary Oncologist follow-up approach.

Corresponding author: Heather B. Neuman, MD, MS, H4/726 CSC, 600 Highland Ave, Madison, WI 53792-7375, Phone: (608) 265-5852, Fax: (608) 263-7652, Neuman@surgery.wisc.edu.

Disclosures: None

Conclusions—Oncologists' feel responsible for the cancer-related components of follow-up. Differences amongst oncology specialists' perceived responsibilities influenced decisions to provide ongoing follow-up. Based on these individual decisions, a Complementary Oncologist Team or Primary Oncologist model of care evolves organically. Guidelines that explicitly direct patients into a care model have the potential to significantly improve care quality and efficiency.

INTRODUCTION

The cost of follow-up for the greater than 3 million U.S. breast cancer survivors is substantial.[1] Current guidelines recommend frequent follow-up visits to evaluate for new primary cancers, recurrence, and treatment side-effects.[2,3] With a projected shortfall of oncologists, this may translate to fewer visits available for newly diagnosed patients, leading to delays in care.[4] In addition, survivors may incur both financial and emotional costs in association with follow-up due to visit co-pays, time away from work and family, and anxiety. The costs associated with providing follow-up, combined with the large number of breast cancer survivors affected, makes breast cancer surveillance a high-impact area for quality improvement.

Current guidelines are written broadly based on consensus, with limited supporting evidence. This leads to significant variation in visit frequency as well as in *who* is providing the care.[5–10] The lack of guidance regarding *who* should provide follow-up creates the potential for both redundancy (overuse) and gaps (underuse) in care, as each provider makes an individual decision to actively participate in follow-up or defer care to another provider. Little is known about the specific responsibilities different types of oncologists perceive they have in breast cancer follow-up. The prior research that does exist has largely focused on medical oncologists.[11–15] However, we demonstrated that >60% of patients follow with multiple types of oncologists,[10] emphasizing the importance of considering radiation and surgical oncologists' perspectives. This study addresses a gap in our current understanding by providing insight into why different types of oncologists believe their participation in follow-up is necessary, and why they are uncomfortable delegating care. Our objective was to explore what each type of oncologist perceives he contributes to breast cancer patients' follow-up and how decisions about participation in follow-up are made.

METHODS

Recruitment

We conducted one-on-one in-depth interviews with medical, radiation and surgical oncologists across Wisconsin. Purposeful sampling captured participants across the spectrum of practice settings (community-based vs. academic practices, breast-specialized vs. general oncologists). We sent email invitations to potential participants, and identified additional participants through snowball sampling. Each participant was offered a gift card equivalent to $75 for their time. The University of Wisconsin Institutional Review Board approved the study.

Data Collection

The semi-structure interview guide was developed based on a review of the literature. Guide domains included what occurs during usual follow-up visits and factors influencing oncologists' decisions to provide follow-up care for breast cancer patients. Additionally, a common breast cancer scenario was presented to elicit oncologists' descriptions of what follow-up would be provided for that patient in their practice. In-depth, face-to-face or telephone interviews were conducted (median 28 (19–48) minutes) by a trained interviewer (N.S.). Accrual continued until data saturation was achieved (i.e. the point at which no new themes were encountered).

Data Analysis

Interviews were audio recorded and transcribed verbatim. The resulting data were analyzed using an inductive approach to content analysis.[16,17] Open coding was performed independently (N.S. and H.N) on the first ten transcripts to create a preliminary list of codes. The two investigators then reviewed each transcript 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. Qualitative analysis software (NVIVO 10 software, QSR International) was used to organize the data.

RESULTS

Thirty-five interviews were completed (Table 1). Key themes explaining why different types of oncologists choose to participate in their breast cancer patients' follow-up are presented (Table 2).

Responsibility for Ongoing Therapy

For medical oncologists, a sense of responsibility for managing both compliance and toxicity associated with the treatments they prescribe was the primary determinant of follow-up participation. Because treatments provided by medical oncologists are often still ongoing during follow-up (e.g. endocrine therapy), medical oncologists typically described feeling "*a little more burden or responsibility, just because [patients] continue to take a drug that potentially has toxicities and risks*" and were uncomfortable delegating medication management to providers in other specialties. Radiation and surgical oncologists concurred that they preferred the responsibility of managing side-effects of endocrine therapy remain with medical oncologists.

Strong Patient Relationship

Medical oncologists' decision to participate in follow-up was influenced by their perception that patients preferred follow-up with them. This was perceived to be due to a strong doctor-patient relationship established during the course of chemotherapy. Additionally, patients

sometimes used them as substitutes for their primary care providers given their training in internal medicine. Although some radiation and surgical oncologists described the strength of their patient relationships, these relationships less commonly influenced decisions for follow-up.

Specific Skillsets

Providers' perceptions about the value of their specific skillset for a given patient influenced their decisions to participate in follow-up. However, the skillsets described varied by specialty. Both radiation and surgical oncologists believed that they were especially adept at examining the breast to assess for local-regional recurrence. Lack of confidence in the physical examination provided by other providers led some to feel strongly that their specialty should participate in the follow-up of every patient they treat. However, others took a more selective approach if they perceived a competent exam was being performed by others. For example, these radiation oncologists acknowledged that although they may look at late radiation effects a little differently than other oncologists, this was not the most critical element of patients' follow-up as these toxicities are rare. Rather than advocate routine follow-up for all patients, they selected patients that would benefit most from the unique expertise of their specialty.

> *I do feel a little bit uncomfortable delegating complete follow-up in brachytherapy patients. I've seen them go through a lot of stress when a seroma cavity will come out and a medical oncologist unfamiliar with this will say, "You have a recurrence and you need a mammogram STAT." So now I usually follow the brachytherapy patients closely.* Radiation Oncologist

Surgical Oncologists also cited circumstances where they perceived patients would benefit from surgical follow-up.

> *I select those who I think have the highest risk of local regional recurrence or have a post-operative problem that we've already detected. Like a significant post-mastectomy pain syndrome, or major lymphedema of an arm, then those are patients where I think I have something to add to long-term follow up.*
>
> Surgical Oncologist

In contrast, medical oncologists saw their systemic focus as the aspect of follow-up unique to their specialty. Medical oncologists felt that all oncologists share responsibility for monitoring for local-regional recurrence. However, medical oncologists described concern for local-regional events as only "*a small part of what I'm having someone come in for*", explaining that they also focused on side-effects of drug treatment, signs of distant metastatic disease, and issues related to overall well-being. Importantly, some medical oncologists perceived that radiation and surgical oncologists were less comfortable addressing these issues, making it important for medical oncologists to continue to follow.

Ensure Follow-up is Received and Minimize Redundancy

Radiation and surgical oncologists considered the follow-up already being provided by other oncologists when deciding their own role. Most medical oncologists did not consider who else might be participating in follow-up when they made their own decisions, being

influenced instead by the themes discussed previously. In contrast, both radiation and surgical oncologists were very aware of these other follow-up visits and expressed concern about the burden frequent follow-up poses for their patients.

> *But I think an awful lot of oncologists do [visits] every three months and for every patient, that's just overkill. I think we're trying to get those patients to be beyond their cancer and that just keeps them on the loop*. Surgical Oncologist

Minimizing duplication was a priority for radiation and surgical oncologists. As a result, they were willing to defer follow-up if they felt that there wasn't another strong reason (as discussed in *Specific Skillsets*) for their specialty to participate. However, they participated if they had any concern that quality follow-up would not be received.

Proposed models of breast cancer follow-up

Oncologists described two models of breast cancer follow-up: Complementary Oncologist Team and Primary Oncologist models (Table 3). In determining follow-up for a given patient, each provider considered how important their *Specific Skillsets* were. For some patients, the skillsets of medical, radiation, and surgical oncology were all considered to be valuable, leading to a Complementary Oncologist Team approach. However, for others, one skillset was perceived to be most relevant, with care from other oncologists representing overlap; this led to a desire for a Primary Oncologist approach. Having a Primary Oncologist was believed to improve follow-up efficiency and minimize the risk of something being overlooked. Which type of provider should assume the role of primary oncologist varied based on the individual patient's needs.

DISCUSSION

We identified several reasons why oncologists feel it is necessary to participate in follow-up for breast cancer survivors, and demonstrated how these rationales differed by specialty. Medical oncologists' decisions to participate in breast cancer follow-up were driven most strongly by their perceived *Responsibility for Ongoing Therapy* and their belief that their systemic approach to follow-up represented a unique *Specific Skillset*. They also perceived that patients preferred medical oncology-based follow-up. In contrast, whether radiation and surgical oncologists perceived a need for their *Specific Skillset* of local-regional assessment determined their follow-up participation. However, these providers were flexible regarding what patients they followed, changing practice in response to follow-up provided by other oncologists. It is important to note that all oncologists felt most responsible for the cancer-related components of survivorship, i.e. surveying for recurrence and assessing treatment toxicities. Consequently, opportunities to delegate other important aspects of survivorship care, such as screening for other cancers and general preventive health, likely exist.

Understanding which cancer-related components of follow-up each type of oncologist is reluctant to defer is critical to our understanding of current oncologist-based follow-up and identifying opportunities to improve care quality. Currently, significant variation exists in how follow-up care is delivered, both with regards to visit frequency as well as in what oncologists are providing care.[5–10] As who should provide care is not addressed in current practice guidelines, each oncologist makes an individual decision (guided by the reasons

outlined in this study) to actively participate in follow-up or defer care. This creates the potential for both redundancy (overuse) and gaps (underuse) in care. This potential is then further exacerbated by the challenges associated with coordinating care amongst the multi-disciplinary oncology team. Delineating the roles and responsibilities of oncologists and providing guidance regarding who should participate in follow-up is one approach which could lead to not only improved care quality but also efficiency.

The findings of this study suggest two overarching models of oncologist follow-up care congruent with oncologists' priorities that may lead to improved care: Complementary Oncologist Team and Primary Oncologist models. In the Complementary Oncologist Team model, each type of provider contributes *Specific Skillsets*. The assumption is made that the value associated with a team approach (where you do not rely on a single individual's evaluation) will outweigh any potential negatives associated with dispersing care across multiple providers. In a Complementary Oncologist Team, medical oncologists' expertise is systemic, while radiation and surgical oncologists contribute a local-regional focus. Potential overlap between radiation and surgical oncologists exists. However, having both specialties involved does not always represent redundancy given their attention to unique treatment-related toxicities. In current practice, an explicit decision for a Complementary Oncologist Team approach is usually lacking; rather this evolves implicitly as each provider independently weighs the patient's risk in the context of what they believe they contribute to follow-up, and then makes an individual determination of whether to participate. For medical oncologists, this determination occurs when decisions for chemotherapy or endocrine therapy are made. The decision for radiation and surgical oncologists, however, is less immediate, as the factors relevant to decision-making evolve with time (e.g. final cosmesis, lymphedema). This decision would optimally occur at a time removed from the immediate post-operative or post-radiation period (for example at one year).

In contrast, the Primary Oncologist model designates one oncologist as primarily responsible for follow-up. A primary oncologist represents a simplified care team with one contact for patient's questions and concerns. With one provider follow-up, visits can be scheduled more efficiently, limiting patient time away from work and family and alleviating providers' burden of coordinating multiple visits. Importantly, providers are able to optimally time visits around needed studies (e.g. mammograms, bone density study) making it less likely studies will be missed. Finally, one provider means a consistent exam, allowing the findings seen at one visit to be reassessed at a subsequent visit, potentially resulting in earlier confirmation of abnormalities. In current care, medical oncologists most commonly serve as Primary Oncologist due to their perceived *Responsibility for Ongoing Therapy* for the nearly 2/3rd of patients receiving endocrine therapy.[18] Scenarios exist where other provider types fill the role of Primary Oncologist. However, this tends to occur only after medical oncologists opt out of follow-up (e.g. DCIS patients).

This study represents the perspectives of Wisconsin oncologists and may not be generalizable. However, our findings are consistent with patterns of care identified through population-based studies.[12,13,19] In this study, we did not directly address the role of primary care providers, choosing to instead build off the substantial existing work.[11–14,20,21] Additionally, although some of providers utilized mid-level providers within their clinics as

surrogates in providing follow-up care, we did not include them in the interviews as we perceived the decision-making for follow-up care initiated directly from the oncology provider.

CONCLUSION

In conclusion, we identified specific cancer-related components of survivorship care that oncologists felt most responsible for as well as opportunities to improve the quality and efficiency of care provided by oncologists. As each oncologist makes an individual decision whether or not to participate in follow-up, a Complementary Oncologist Team or Primary Oncologist model of follow-up occurs. In current clinical practice, these models of care evolve without conscious acknowledgement by providers of the overarching pattern of care delivery, resulting in substantial variation and contributing to both under-and over-utilization of follow-up services. Explicitly delineating which providers should participate in follow-up and each provider's specific responsibilities could address some of this variation by directing patients into a care model (Table 4). This would have a positive impact on both care quality and efficiency. Future work will expand upon our findings by incorporating the expectations of patients into our framework, and examine provider and patient satisfaction with such a follow-up approach.

Acknowledgements

This project was funded through the University of Wisconsin Carbone Comprehensive Cancer Center Academic Oncologist Training Program (NIH 5K12CA087718) and the Building Interdisciplinary Research Careers in Women's Health Scholar Program (NIH K12 HD055894). It was also supported by the Clinical and Translational Science Award program, through the NIH National Center for Advancing Translational Sciences (UL1TR000427).

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Table 1

Participant Characteristics

	N (%) or Median (range)
Type of Oncologist	
Medical	12 (34%)
Radiation	11 (31%)
Surgical	12 (34%)
Male	17 (57%)
Community-Based Practice	25 (71%)
Years in Practice	11 (2–48) years
Percent of Practice Comprised of Breast Patients	50% (10–100%)

Table 2

Key themes representing different types of oncologists' reasons for participation in breast cancer follow-up care

Reasons for Follow-up	Oncology Provider Type	Representative Quotes
Responsibility for Ongoing Therapy	Medical Oncology	*If a patient is getting a medication from me, I would definitely follow the patient because I'm responsible for the medication, so if a patient is getting medicine from me, I always, always follow the patient at least once a year.*
		Do I think that a radiation oncologist or a surgical oncologist could manage those meds? Sure. But do I think that currently they have the comfort level or desire to do it? No, I don't think so. Again, I could be wrong, but I would say, the vast majority of times, those questions are deferred to me, and I think probably rightfully so.
Strong Patient Relationship	Medical Oncology	*I think the medical oncologists probably in some cases become the major person managing the long-term follow-up and the reason that occurs is in part because women who receive chemotherapy develop a relationship based on repeated visits over a period of time… So, I think for the women who receive chemotherapy, there's probably a little more of identification of the oncologist as their physician.*
Specific Skillsets	Surgical Oncology	*So, I feel strongly as a surgeon that my job is to perform a good breast examination, even if the patients have mastectomy, or lumpectomy, I think an operated breast needs to be followed for life by a surgeon.*
	Radiation Oncology	*I think the other reason for a radiation oncologist to be involved is because the morbidity associated with radiation therapy in particular is late-term. It may not even become evident for 15 or 20 years. Our feeling is, nobody can recognize that with the astuteness that we can.*
	Medical Oncology	*Taking a global picture- A systemic difference. That's what I think I'm looking at differently. And I'm sure all the other physicians are doing that as well but I guess I'm trying to look at it from a different standpoint. What I'm more worried about is systemic recurrence of the disease. That's I think the biggest risk.*
Ensure Follow-up is Received and Minimize Redundancy	Radiation Oncology	*One of my pet peeves has always been patients having too many doctors in their follow-up care. So, if a patient has a preference to have me participate in their care, then I will certainly do it that way. If they have no other physicians, I will see them. So, otherwise, if there are already medical oncologists and surgical oncologists in this area that I know of, and I know them and I know their quality, then after the acute check of their radiation reactions and they've healed up, I discharge them.*
	Surgical Oncology	*If it is a patient who is, who has a double mastectomy who's not going to have oncologic follow-up, someone with DCIS whose treatment was entirely surgical, then I will typically follow those in the long run.*

Table 3

Proposed models of breast cancer follow-up endorsed by different types of oncologists

Follow-up Model	Oncology Provider Type	Representative Quotes
Complementary Team	Surgical Oncology	*I do have the bend that I think that it is nice and actually valuable that a patient gets more than one perspective on their physical exam and on their care. Because I think my perspective is going to be more from a local regional control, and I think a medical oncologist is looking more for systemic control. I think a radiation oncologist is looking for their long-term side-effects. So I think there is some value in getting all three perspectives.*
	Medical Oncology	*Because we are all looking at different aspects, surgeons focus on the surgical aspect and the radiation focus on their aspect and then we focus on the medical treatment aspect, so I don't think anyone is particular should be the dominant one. I think we should work as a team.*
	Radiation Oncology	*Our goal is to have at least two different people, sets of hands examining the patient, because what one person may miss, the other person may notice.*
Primary Oncologist	Surgical Oncology	*Personally I think that once actual treatment is done, one person could probably monitor that and for one particular patient it might be better suited to perhaps be the medical oncologist, radiation or the surgical oncologist, depending on maybe where they feel more comfortable.*
	Radiation Oncology	*I think probably the most efficient way to do it, is to have one provider provide all of the follow-up. Because there's less chance of the patient falling through the cracks, there's less chance of dropped balls…*
	Medical Oncology	*If they go with the alternating approach, yes, we can all provide the care. But my concern is then they go to one person and they say, "You know what, this one spot on my breast has been kind of bothering me." And [that provider] examines it and they maybe send me a note, but then the next time I'm seeing [the patient], well, I didn't examine it three months ago… to me there's something about that continuity of one person being that main person.*

Table 4

Illustrative patient examples of how the Primary Oncologist and Complimentary Team models could be applied

		Patient #1	**Patient #2**	**Patient #3**	**Patient #4**
Model of Follow-up		**Primary Oncologist Surgical Oncology**	**Complimentary Team Medical, Radiation Oncology**	**Primary Oncologist Medical Oncology**	**Complimentary Team Medical, Radiation Surgical Oncology**
Stage		Stage 0	Stage 1	Stage 2	Stage 3
Breast Surgery		Mastectomy	Partial mastectomy	Partial mastectomy	Mastectomy
Axillary surgery		SLN	SLN	SLN	ALND
Radiation		None	Brachytherapy	Whole breast	Chest wall, Level I–III, supraclavicular nodes
Endocrine therapy		None	Yes	Yes	Yes
Chemotherapy		None	No	No	Yes
Provider Type		Surgical Oncology	Medical Oncology, Radiation Oncology	Medical Oncology	Medical Oncology, Radiation Oncology, Surgical Oncology
Rationale by Specialty	Medical Oncology	No *Ongoing Therapy*	*Ongoing Therapy* necessitates follow-up	*Ongoing Therapy* necessitates follow-up	*Ongoing Therapy*, prior chemotherapy, and increased risk of systemic recurrence (*Specific Skillset*) necessitates follow-up
	Radiation Oncology	Did not treat	Need for *Specific Skillset* given receipt of brachytherapy and challenging physical exam	No need for *Specific Skillset*	Need for *Specific Skillset* given risk of local recurrence and risk of lymphedema
	Surgical Oncology	Need for *Specific Skillset* given that local recurrence is primary reason for follow-up	No need for *Specific Skillset*	No need for *Specific Skillset*	Need for *Specific Skillset* given risk of local recurrence and risk of lymphedema

SLN, sentinel lymph node; ALND, axillary lymph node dissection