



Published in final edited form as:

J Community Support Oncol. 2018 ; 16(2): e66–e71. doi:10.12788/jcso.0392.

Integrating survivorship care planning in radiation oncology workflow

Karol J Huenerberg, MSN, FNP-BC, APNP^a, Bethany M Anderson, MD^a, Amye J Tevaarwerk, MD^b, Heather B Neuman, MD, MS^c, Lee G Wilke, MD^c, Lori A Seaborne, MPAS, PA-C^d, and Mary Sesto, PhD, PT^{b,e}

^aDepartment of Human Oncology, University of Wisconsin School of Medicine and Public Health, Madison, Wisconsin;

^bDivision of Hematology and Oncology, Department of Medicine, University of Wisconsin School of Medicine and Public Health, University of Wisconsin Carbone Cancer Center, Madison, Wisconsin;

^cDivision of General Surgery, Department of Surgery, University of Wisconsin School of Medicine and Public Health, University of Wisconsin Carbone Cancer Center, Madison, Wisconsin;

^dDepartment of Surgery, University of Wisconsin Carbone Cancer Center, Madison, Wisconsin;

^eDepartment of Industrial and Systems Engineering, College of Engineering, University of Wisconsin, Madison, Wisconsin

Abstract

Various groups, including the American College of Surgeons' Commission on Cancer and the National Accreditation Program for Breast Centers, are mandating the provision of a survivorship care plan (SCP) to cancer survivors who have completed curative-intent treatment as a requirement for oncology practice accreditation. This article reviews the development of survivorship care, including survivorship care in radiation oncology. Challenges of developing treatment summaries and SCPs and implementing their delivery are explored. Details of the article include how the University of Wisconsin Health radiation oncology department integrated a survivorship visit into the existing radiation oncology workflow. Oncology practices may benefit from the model described here to meet accreditation requirements for SCP delivery to cancer survivors.

In January 2016 there were an estimated 15.5 million people in the United States who were living with a cancer diagnosis, representing 4.8% of the population. That number is expected to increase to 20.3 million by 2026.¹ The 5-year relative survival rate for all cancers diagnosed during 2005 to 2011 was 69%.² As more individuals with a cancer diagnosis now live longer, cancer survivorship is receiving increased attention. A report from the Institute of Medicine³ identified the essential components of survivorship care, including the provision of a survivorship care plan (SCP) containing specific diagnosis, treatment, and follow-up information (Table 1). To maintain accreditation in their respective organizations,

Correspondence: Karol J Huenerberg, MSN, APNP; huenerberg@humonc.wisc.edu.

Disclosures: The authors report no disclosures or conflicts of interest.

the American College of Surgeons' Commission on Cancer and the National Accreditation Program for Breast Centers (NAPBC) have included standards on providing treatment summaries and SCPs in person to those patients who have completed cancer treatments given with curative intent.^{4,5}

SCPs are personalized documents presented to cancer patients at the end of treatment that summarize key aspects of cancer treatment and recommend appropriate ongoing medical care and self-management. The purpose of the SCP is both to educate cancer survivors and to create a portable document that can be shared with primary care providers to facilitate coordinated care.⁶ There are multiple barriers to SCP implementation, which may include the time required to create an SCP, inadequate reimbursement for the time spent creating and delivering the plan, a lack of risk-stratified guidelines for coordinated care, and the incomplete automation of diagnosis and treatment summarization by the electronic health record (EHR).⁷

Survivorship care in radiation oncology

The American College of Radiology includes the recommendation for regular, ongoing follow-up in the standards for accreditation for radiation oncology practice.⁸ Radiation oncology practices often provide the initial follow-up appointment about a month after the prescribed radiation treatment has been completed. The twofold purpose of this appointment is to assess the response to treatment and to evaluate acute treatment-related effects.⁹ The appointment may include a skin evaluation, assessment for any acute treatment effects, informal counseling on maintaining a healthy lifestyle, and recommendations for posttreatment care and follow-up. The appointment may also be an opportune time for delivering the SCP because radiation therapy is often the final treatment modality in active therapy for breast cancer patients.

A review of the literature yields scant data on the incorporation of SCPs into a radiation oncology practice. A 2014 survey of members of the American Society of Radiation Oncology¹⁰ for a response percentage of 14.7%. Almost all providers follow their patients after treatment (97% (n = 574 respondents/3987 total membership, 14.4% response rate) showed that although most radiation oncologists provide long-term follow-up care to their patients after treatment completion (97%), fewer than half of those surveyed indicated that they delivered SCPs for curative-intent patients (40%), and even fewer delivered for palliative-intent patients (19%). Standards for the American Society for Radiation Oncology's Accreditation Program for Excellence¹¹ outline content for end-of-treatment documentation. Typically, the documentation includes a detailed treatment summary prepared by the treating radiation oncologist. This treatment summary includes the patient's diagnosis, the area treated, radiation doses received, number of fractions delivered, therapy start date, therapy completion date, and overall tolerance of treatment in a clinical summary. The treatment summary is communicated to other providers involved in the patient's care to promote care coordination, but it is not typically provided to patients.

Development of University of Wisconsin survivorship care planning

As an important component of maintaining NAPBC accreditation, the University of Wisconsin (UW) Health Breast Center began the process of formalizing and optimizing SCPs for breast cancer survivors who are followed at the center. Multidisciplinary input from surgical, medical, and radiation oncology was obtained. Representatives from those disciplines met regularly to reach consensus on the treatment summary and SCP content. The following 3 documents were created for use during a transition visit at the end of treatment: the written individualized SCP to be provided to the survivor and his/her primary care providers, a general survivorship patient education booklet, and a patient questionnaire to identify survivors' concerns and additional resources that may be beneficial.

Treatment summary

Working in collaboration with IT specialists, we enabled out-of-the-box functionality within our EHR. This cancer-specific functionality provides a central and standard location within each survivor's problem list to systematically document information regarding cancer diagnosis, stage, and treatment associated with a specific cancer diagnosis. Each treating provider (surgeon, medical oncologist, radiation oncologist, genetic counselor, etc) is responsible for entering and updating the relevant components within the treatment summary (ie, the surgeon enters and maintains the surgical details, the medical oncologist does likewise for chemotherapy and other medical therapies, etc). Information is updated and current, creating a dynamic documentation of diagnosis and treatment that can be used in clinic notes, patient after-visit summaries, and SCPs.

Survivorship care plan

This same EHR functionality is leveraged to generate, populate, and maintain the individualized SCP for each breast cancer survivor. The Treatment Summary section of the SCP can be quickly prepared within the EHR by autopopulating data previously entered by treating providers. Content and language for SCP templates in breast, colorectal, prostate, and gynecologic cancers are in use at the time of publication. The templates are developed as a collaborative effort between oncology subspecialists, with input from the UW Health survivor and family advocacy councils.

Each template contains a Treatment Summary section and an SCP section. The Treatment Summary section includes survivor general information, diagnosis and treatment information, and the clinical and supportive/survivor care team names and contact information. The SCP section includes follow-up recommendations, signs of recurrence and/or symptoms to report, healthy lifestyle and maintenance, chronic or late effects of specific treatment if applicable (eg, surgery, chemotherapy by drug, radiation therapy, and endocrine therapy), and general resources for common psychosocial concerns (Table 1).^{12,13}

Each SCP is visible to the entire health care team, including other specialists and primary care, as long as they have access to UW Health's EHR.¹⁴ The result is a readily accessible, comprehensive document that is individualized for each survivor, residing in a standard location with standardized format and content to facilitate review and use.¹⁵

General survivorship patient education booklet

Many cancer survivors request additional information about their posttreatment concerns. The “UW Health Facts for You: Cancer Survivorship, Carbone Cancer Center” booklet was developed by a multidisciplinary team including oncologists, advanced practice providers (APPs), navigators, social workers, program leadership, cancer survivors, and caregivers. The guide includes detailed information for the cancer survivor on topics including nutrition, exercise, sleep, tobacco cessation, sexual health, and spirituality. Common concerns and symptom management are addressed as well as a comprehensive list of community resources. The booklet can be found at <http://www.uwhealth.org/healthfacts/cancer/7834>.

Survivorship questionnaire

Breast cancer survivors often have multiple concerns as they transition from active treatment to the survivorship phase of their cancer journey. Specific concerns may vary slightly from one survivor to another. Guided by recommendations for the American Society of Clinical Oncology and the National Comprehensive Cancer Network, we developed a 10-question, 2-page questionnaire to identify those concerns with input from members of the Breast Cancer Steering Committee. Members of the committee include surgical, medical, and radiation oncologists, AAPs, radiologists, pathologists, program leadership, and nurses, along with breast cancer survivors. Elements in the questionnaire include nutrition, activity, mood, sleep, sexual health, employment/insurance, pain/swelling, desires regarding pregnancy or prevention, memory/concentration, smoking, alcohol, genetic testing/counseling, and assistance with establishing care with a primary care provider. By completing the questionnaire, breast cancer survivors identify specific concerns within each category and are able to request additional information about those concerns and/or a referral to appropriate resources. They may also select the *I need nothing further* option if the concern is present but already being addressed.

SCP delivery and the transition visit

The next task in implementation of the care process for survivors encompassed the development of clinical work-flows and processes to provide the document to the breast cancer survivor at the completion of treatment. In a study of breast cancer survivors, it was found that the preferred format for survivorship care planning is generally an in-person consultation at completion of treatment with an oncology professional.¹⁶ The best time for distribution of the written SCP is, however, unclear. Intuitively, it seems optimal to distribute SCPs around the time of completion of active treatment. However, for SCP delivery to be feasible and sustainable, delivery must be integrated into existing clinical care-delivery processes, and content must be streamlined and focused to meet the needs of their intended recipients without becoming overly burdensome to prepare and deliver.¹⁷

Ultimately, and after significant multidisciplinary discussion, it was determined that Stage 0-III breast cancer patients would have a visit focusing on symptoms and transitioning to surveillance follow-up (Transition Visit) as they completed active curative-intent cancer treatment. During this Transition Visit, the SCP document would be provided and reviewed

with survivors. The Transition Visit for breast cancer survivors would be conducted by an APP following the completion of their final stage of active, primary treatment (surgery, chemotherapy, and/or radiation therapy). Additional long-term adjuvant therapy for breast cancer survivors (ie, trastuzumab, endocrine therapy) would continue as indicated during and after delivery of the SCP.

The radiation oncology clinic was chosen as a venue for these Transition Visits for breast cancer survivors whose treatment included radiotherapy. Despite little historical experience with delivery of SCPs in radiation oncology clinics, this was a logical choice given that radio-therapy is usually the final phase of active treatment for these breast cancer survivors, and a follow-up visit about a month after completing radiotherapy is already part of standard practice. Collaborating with the multidisciplinary UW Health Breast Center, we therefore integrated the formal breast survivorship care planning process and provision of the SCP into the current radiation oncology work-flow. About 40% of the roughly 600 breast cancer patients treated by surgical and/or medical oncology at our institution annually also receive radiation therapy at our site. For the remaining 60% of breast cancer survivors who do not receive radiation therapy or who completed radiotherapy at an outside facility, the SCP is provided by an APP within the UW Health Breast Center.

UW radiation oncology survivorship transition visit

The overall workflow of our Transition Visit is depicted in the Figure. Toward the end of the breast cancer survivor's radiation treatments, the radiation oncologist instructs the schedulers to arrange the 1-month, post-radiation Transition Visit with the APP and informs the survivor about the nature of the appointment. The Transition Visit is scheduled as a 60-minute appointment. Before the survivor's arrival, an APP generates the written SCP. The activity includes completing the Treatment Summary, or verifying the accuracy of a prepopulated Treatment Summary, and individualizing the SCP section for the patient based on treatment received and follow-up recommendations using drop-down functionality. As the SCP is printed for review with the survivor, it is simultaneously sent to the survivor's primary care provider. This is accomplished by using EHR functionality to route the document internally to UW primary care providers or automatically faxing the document to external primary care providers. Each SCP is also marked as complete within the EHR for the purposes of documenting compliance with this activity for later data analysis.

On arrival for the appointment, each breast cancer survivor completes the survivorship questionnaire. During the Transition Visit, the questionnaire is reviewed with the survivor and additional information is provided. Referral options are discussed if indicated with desired referrals made by the APP. The survivor is interviewed and examined for any persistent side effects of treatment. Next, the Treatment Summary and SCP are reviewed with the survivor, emphasizing the follow-up plan, signs or symptoms of breast cancer recurrence, and chronic or late treatment-related toxicities. Ample opportunity is provided for the survivor to ask questions and voice concerns.

Follow-up appointments with members of the patient's care team (ie, medical, surgical, or radiation oncology) as well as necessary breast imaging (ie, mammogram, MRI) are

coordinated and scheduled before the survivor leaves the department. A survey of oncologists (medical, surgical, radiation) 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.¹⁸ At our institution, the breast surgical, medical, and radiation oncologists all generally participate in follow-up care through at least 1 year following completion of active, primary treatment.

Outcomes, quality improvement opportunities, and continued challenges with the process

There is presently a lack of long-term outcome data about the impact of SCPs. As mandates for the provision of SCPs are made, research focusing on whether SCPs result in improved health behaviors and outcomes, reduced burden in care transitions from the oncology setting, and increased cost-effectiveness will be needed.¹⁹ The long-term effects of SCPs on psychological, oncologic, and resource outcomes should be evaluated,²⁰ as well as the impact on health behaviors, such as smoking cessation or participation in rehabilitation programs.²¹

Following the implementation of our Transition Visits in 2015, we conducted a quality improvement review. This review included summation of 69 recent breast cancer questionnaires from Transition Visits with our APPs (Table 2 and Table 3). The most common concerns raised by our breast cancer survivors include desire for weight loss, improving diet, and increasing physical activity. Of note, concerns did not often translate into a desire for more information or referrals.²² Survivors were generally satisfied with the timing of the Transition Visits and generally indicated that the visits were helpful, with self-reported improvements in their understanding of planned follow-up. A Canadian group evaluating breast and head and neck cancer survivors has suggested that SCPs could produce long-term improvements in healthy lifestyle behaviors; however, further research is needed to determine the extent to which SCPs might improve follow-up care over the long term.²³

Finally, although efforts to date have been focused on the breast cancer survivor at the completion of treatment, long-term survivors may also benefit from receiving the SCP. A study by the American Cancer Society found that long-term cancer survivors had unmet informational needs, particularly with regard to screening, long-term cancer and treatment effects, and healthy lifestyle behaviors.²⁴ Identifying and subsequently delivering an SCP to eligible long-term survivors is a challenging prospect, which depends on further refinement of EHR-based tracking of the date of diagnosis, cancer stage, and end-of-treatment date.

Summary and recommendations

Survivorship care has been efficiently integrated into our 1-month post-radiation follow-up appointment for breast cancer survivors. By using current resources in the radiation oncology department, the process has provided an effective way to deliver the SCP to breast cancer survivors. Future plans include implementing the process for all patients receiving curative-intent radiation for additional solid tumor survivors. Quality improvement projects will be developed to assess survivor satisfaction and the impact on health behaviors.

Acknowledgments

The authors thank Amy Heath, MS, RTT, for editorial and manuscript preparation assistance.

References

1. Statistics. National Cancer Institute, Division of Cancer Control & Population Sciences website. <http://cancercontrol.cancer.gov/ocs/statistics/statistics.html>. Updated October 17, 2016. Accessed March 6, 2018.
2. Cancer facts & figures 2016 American Cancer Society website. <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2016.html>. Published 2016. Accessed February 27, 2018.
3. Hewitt M, Greenfield S, Stovall E, eds. From cancer patient to cancer survivor: lost in transition. Washington, DC: National Academies Press; 2006.
4. Knutson A, McNamara E. Cancer program standards: ensuring patient-centered care. American College of Surgeons web-site. <https://www.facs.org/quality-programs/cancer/coc/standards>. Published August 2016. Accessed March 6, 2018.
5. National Accreditation Program for Breast Centers. NAPBC standards manual. American College of Surgeons website. <https://www.facs.org/~media/files/quality%20programs/napbc/2014%20napbc%20standards%20manual.ashx>. Published 2014. Accessed March 6, 2018.
6. Salz T, McCabe MS, Onstad EE, et al. Survivorship care plans: is there buy-in from community oncology providers? *Cancer*. 2014;120(5):722–730. [PubMed: 24327371]
7. Mayer DK, Nekhlyudov L, Snyder CF, Merrill JK, Wollins DS, Shulman LN. American Society of Clinical Oncology clinical expert statement on cancer survivorship care planning. *J Oncol Pract*. 2014;10(6):345–351. [PubMed: 25316025]
8. Dobelbower RR, Cotter G, Schilling PJ, Parsai EI, Carroll JM. Radiation oncology practice accreditation. *Rays*. 2001;26(3):191–198. [PubMed: 11925792]
9. Hartford AC, Conway PD, Desai NB, et al. ACR-ASTRO practice parameter for communication: radiation oncology. The American College of Radiology website. <http://www.acr.org/~media/ACR/Files/Practice-Parameters/RadOnc.pdf>. Updated 2014. Accessed March 6, 2018.
10. Koontz BF, Benda R, De Los Santos J, et al. US radiation oncology practice patterns for posttreatment survivor care. *Pract Radiat Oncol*. 2016;6(1):50–56. [PubMed: 26603597]
11. American Society of Therapeutic Radiation Oncologists. APEX program standards. ASTRO website. http://www.astro.org/uploaded-Files/_MAIN_SITE/Daily_Practice/Accreditation/Content_Pieces/ProgramStandards.pdf. Published February 1, 2016. Accessed March 6, 2018.
12. Clinical practice survivorship guidelines and adaptations. American Society of Clinical Oncology website. <http://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship>. Published 2013. Accessed March 6, 2018.
13. National Comprehensive Cancer Network. Supportive care guidelines. NCCN website. http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#supportive. Updated February 16, 2018. Accessed March 6, 2018.
14. Donohue S, Sesto ME, Hahn DL, et al. Evaluating primary care providers' views on survivorship care plans generated by an electronic health record system. *J Oncol Pract*. 2015;11(3):e329–e335. [PubMed: 25804989]
15. Tevaarwerk AJ, Wisinski KB, Buhr KA, et al. Leveraging electronic health record systems to create and provide electronic cancer survivorship care plans: a pilot study. *J Oncol Pract*. 2014;10(3):e150–e159. [PubMed: 24520142]
16. Smith SL, Singh-Carlson S, Downie L, Payeur N, Wai ES. Survivors of breast cancer: patient perspectives on survivorship care planning. *J Cancer Surviv*. 2011;5(4):337–344. [PubMed: 21643836]
17. Stricker CT, O'Brien M. Implementing the commission on cancer standards for survivorship care plans. *Clin J Oncol Nurs*. 2014;18(suppl 1):15–22.

18. Neuman HB, Steffens NM, Jacobson N, et al. Oncologists' perspectives of their roles and responsibilities during multi-disciplinary breast cancer follow-up. *Ann Surg Oncol*. 2016;23(3): 708–714.
19. Palmer SC, Stricker CT, Panzer SL, et al. Outcomes and satisfaction after delivery of a breast cancer survivorship care plan: Results of a multicenter trial. *J Oncol Pract*. 2015;11(2):e222–e229. [PubMed: 25784579]
20. Brennan ME, Gormally JF, Butow P, Boyle FM, Spillane AJ. Survivorship care plans in cancer: a systematic review of care plan outcomes. *Br J Cancer*. 2014;111(10):1899–1908. [PubMed: 25314068]
21. Chen RC, Hoffman KE, Sher DJ, et al. Development of a standard survivorship care plan template for radiation oncologists. *Pract Radiat Oncol*. 2016;6(1):57–65. [PubMed: 26778795]
22. Seaborne LA, Huenerberg KJ, Bohler A, et al. Developing electronic health record based program to deliver survivorship care plans and visits at the UW breast center. Poster presented at American Society of Clinical Oncology Survivorship Symposium; January 15–16, 2016; San Francisco CA.
23. Collie K, McCormick J, Waller A, et al. Qualitative evaluation of care plans for Canadian breast and head-and-neck cancer survivors. *Curr Oncol*. 2014;21(1):18–28.
24. Playdon M, Ferrucci LM, McCorkle R, et al. Health information needs and preferences in relation to survivorship care plans of long-term cancer survivors in the American Cancer Society's study of cancer survivors-I. *J Cancer Surviv*. 2016;10(4):674–685. [PubMed: 26744339]

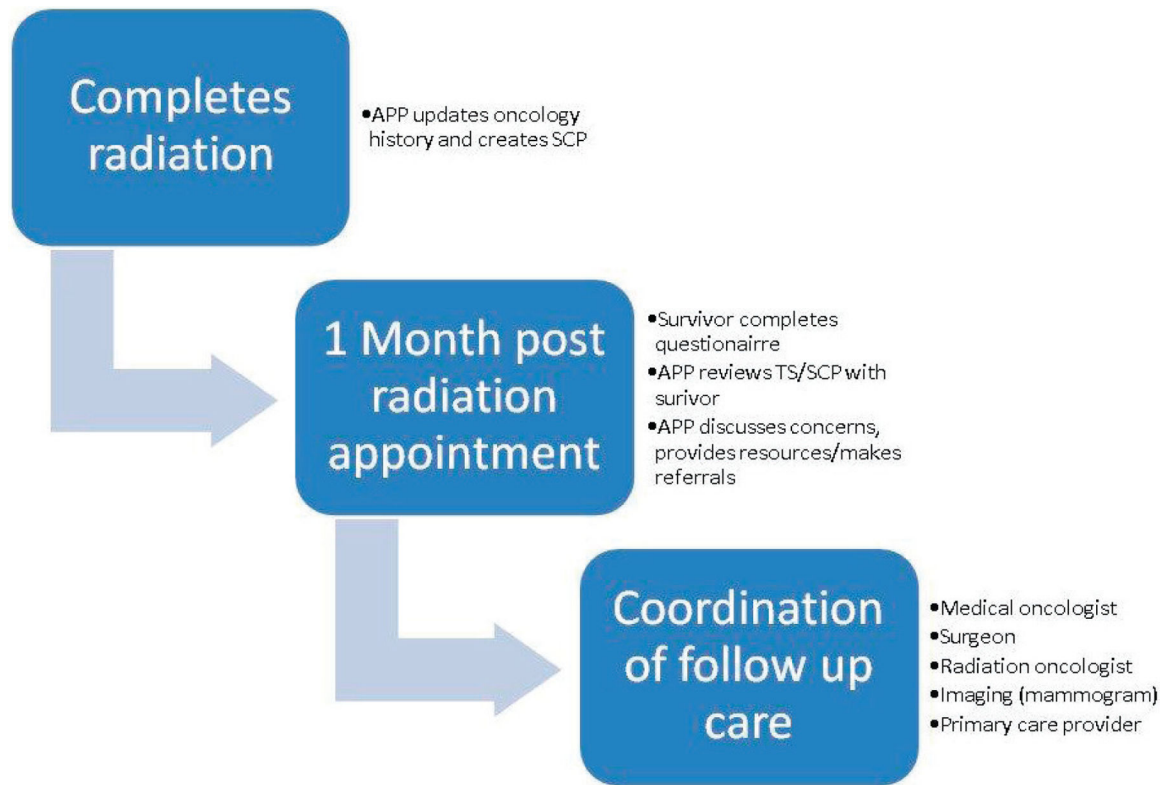


FIGURE. Transition visit workflow.
APP, advanced practice provider; SCP, survivorship care plan; TS, treatment summary

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

TABLE 1Elements of the treatment summary and survivorship care plan^a

Treatment summary**Survivor general information****Clinical care team/supportive/survivor care team and contact information**Diagnostic tests performed & results
(including genetic testing)

Cancer stage

Treatment details
(surgery, chemotherapy, radiation, endocrine therapy)**Survivorship care plan**

Follow-up plan/schedule

Late/long-term effects of treatment

Psychosocial effects of cancer & treatment

Possible signs of recurrence & second cancers

Ongoing health maintenance

Recommended cancer screening

Referrals

Cancer-related resources

^aBased on recommendations from the American Society of Clinical Oncology¹² and the National Comprehensive Cancer Network.¹³

TABLE 2

Findings from questionnaires completed on arrival for Transition Visits (N = 69)

Symptom	At least 1 concern selected by a survivor, n (%) ^a	Information requested	Referral requested
Nutrition	51 (74)	8 ^b	11 ^b
Activity	41 (59)	3	3
Sleep or fatigue	37 (54)	4	0
Sexuality	36 (52)	7	1
Pain	23 (33)	1	0
Mood	17 (25)	2	1

^aSurvey questions allowed patients to select more than 1 concern (eg, for nutrition, could select *I want to lose weight* and *I want to improve my diet*). These numbers were calculated based on the number of patients who selected the *No concerns* option or left all options blank.

^bSome patients requested both information and referral, others may have selected only 1 option.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

TABLE 3

Survivor satisfaction with utility and timing of Transition Visit (N = 69)

Question topic	No. of patients responding, n (%)
Understanding of diagnosis/treatment after TV ^a	
Changed a lot	20 (29)
Changed a little	20 (29)
No change	3 (1.4)
Understanding of follow-up after TV ^b	
Changed a lot	35 (51)
Changed a little	20 (29)
No change	3 (1.4)
Timing of TV ^c	
Keep as is (4–6 wk after end of active treatment)	51 (73)
Earlier	5 (7)
Later	2 (3)
Reporting TV as helpful ^d	56 (81)

^a26,^b11, and^c11 missing responses.^dThree response options: Helpful, Unsure if helpful, Unaddressed concerns (13 missing responses).

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript