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Accuracy and Thoroughness of Treatment Summaries Provided as Part of Survivorship Care Plans Prepared by Two Cancer Centers

Amye J. Tevaarwerk, William G. Hocking, Jamie L. Zeal, Mindy Gribble, Lori Seaborne, Kevin A. Buhr, Kari B. Wisinski, Mark E. Burkard, Douglas A. Wiegmann, and Mary E. Sesto

QUESTION ASKED: The accuracy and thoroughness of diagnosis and treatment information (also known as treatment summaries) being delivered with survivorship care plans are poorly understood. To be useful, treatment summaries must be complete and accurate. What were the accuracy and thoroughness of treatment summaries prepared at two cancer centers?

SUMMARY ANSWER: A significant proportion of cancer treatment summaries prepared for cancer survivors enrolled in a clinical trial contained at least one error (25%) or omission (22%).

WHAT WE DID: Two cancer centers conducted a clinical trial assessing the change in survivor knowledge after receipt of treatment summaries delivered as part of survivorship care plans. The accuracy and thoroughness of the treatment summaries were assessed in a planned exploratory analysis. Diagnosis and treatment data for 121 patients with cancer were abstracted from the medical records. Each survivor's medical record data were cross-checked against the individualized treatment summary. Errors were defined as inaccurate information, while omissions were defined as missing information on the basis of the Institute of Medicine recommended elements for a treatment summary.

WHAT WE FOUND: A significant proportion of summaries contained at least one error or omission, and at least some were potentially significant. Mismatches between the clinical scenario and treatment summary templates contributed to many of the errors and omissions.

BIAS, CONFOUNDING FACTOR(S), AND DRAWBACKS: Many of these treatment summaries were prepared and delivered independent of care planning visits, which might have facilitated identification of omissions and/or errors by patients. Moreover, we did not examine the impact of identified errors and omissions as part of this analysis.

REAL-LIFE IMPLICATIONS: Accuracy and thoroughness are necessary if treatment summaries and survivorship care plans are to fulfill their intended role as tools facilitating communication and coordination. Survivorship programs should consider quality measures to reduce rates of errors and omissions in the data being delivered to cancer survivors. Furthermore, steps should be taken to decrease inadvertent contributions from templates and support use of data audited for other purposes (such as drawing diagnosis or treatment data directly from the electronic health record or from cancer registries). **JOP**

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Abstract

Purpose

Treatment summaries prepared as part of survivorship care planning should correctly and thoroughly report diagnosis and treatment information.

Methods

As part of a clinical trial, summaries were prepared for patients with stage 0 to III breast cancer at two cancer centers. Summaries were prepared per the standard of care at each center via two methods: using the electronic health record (EHR) to create and facilitate autopopulation of content or using manual data entry into an external software program to create the summary. Each participant's clinical data were abstracted and cross-checked against each summary. Errors were defined as inaccurate information, and omissions were defined as missing information on the basis of the Institute of Medicine recommended elements.

Results

One hundred twenty-one summaries were reviewed: 80 EHR based versus 41 software based. Twenty-four EHR-based summaries (30%) versus six software-based summaries (15%) contained one or more omissions. Omissions included failure to provide dates and specify all axillary surgeries for EHR-based summaries and failure to specify receptors for software-based summaries. Eight EHR-based summaries (10%) versus 19 software-based summaries (46%) contained one or more errors. Errors in EHR-based summaries were mostly discrepancies in dates, and errors in software-based summaries included incorrect stage, surgeries, chemotherapy, and receptors.

Conclusion

A significant proportion of summaries contained at least one error or omission; some were potentially clinically significant. Mismatches between the clinical scenario and templates contributed to many of the errors and omissions. In an era of required care plan provision, quality measures should be considered and tracked to reduce rates, decrease inadvertent contributions from templates, and support audited data use.

ASSOCIATED CONTENT



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INTRODUCTION

The number of cancer survivors is increasing rapidly because of improvements

in detection and therapy, with nearly 18 million cancer survivors predicted by 2026.¹ The majority of these survivors will

live \geq 5 years after cancer diagnosis.¹ Inadequate coordination after the completion of active cancer treatment has been shown to result in failures to provide necessary surveillance as well as increased costs due to duplicative care.²⁻⁴ The Institute of Medicine (IOM) recommends that a personalized survivorship care plan summarizing diagnosis, treatment (also known as treatment summary), and recommendations for expected follow-up be prepared at the end of cancer treatment for every survivor and his or her primary care provider. Care plans may increase care coordination, with the end result of improving survivor health outcomes.⁵ Improvements in communication and care coordination may be especially critical, given the forecasted shortage of oncologists⁶ and anticipated increase in survivors transitioning to shared or primary care-directed follow-up.⁷ However, determining the value and impact of survivorship care plans has proven challenging, as have adoption and implementation. Despite these challenges, accreditation guidelines have been issued by the Commission on Cancer (CoC), mandating 75% or more of survivors receive a survivorship care plan by 2019.⁸

Care plans are intended to serve as tools facilitating communication between the oncology team and primary care, primary care and survivors, and the oncology team and survivors. To serve as an effective communication tool, the diagnosis and treatment summary information must be both accurate and complete. For example, if a survivor received anthracycline-based chemotherapy for Hodgkin lymphoma, then this chemotherapy needs to be correctly listed in order that the survivor and primary care team (eg, the end users) are aware of the possible future sequelae (increased risk of congestive heart failure and myelodysplastic syndrome). Efforts have been made to quantify the thoroughness of care plan templates.⁹ A 2012 study of the National Cancer Institute-designated comprehensive cancer centers noted that none delivered a plan containing all the elements recommended by the IOM.¹⁰ However, few published data exist with respect to the accuracy and thoroughness of the treatment summary portion of care plans delivered for real-world use. External accrediting bodies such as the CoC have created an impetus for plan creation and provision. This has led to a rapid increase in the number of treatment summaries being prepared, with potential consequences for quality. Declining accuracy and thoroughness could diminish impact.

As part of a larger randomized trial assessing the impact of care plans on survivor knowledge,¹¹ we conducted a prospective exploratory analysis of the accuracy and thoroughness of

treatment summaries prepared at two cancer centers. We present these results here.

METHODS

The two Midwestern cancer centers conducted a clinical trial to determine whether care plans improved breast cancer survivors' knowledge of cancer diagnosis, treatment, and recommended follow-up.¹¹ Patients with stage 0 to III breast cancer within 2 years of completing active primary treatment and who did not already have a care plan were eligible and were randomly assigned to immediate versus delayed receipt of a care plan. Active treatment was defined as curative-intent surgery, chemotherapy, and/or radiation. Active treatment did not include human epidermal growth factor receptor 2 (HER2) –targeted therapies for HER2-positive cancer or endocrine therapies for estrogen receptor (ER) –positive or progesterone receptor (PR) –positive cancers.

Individual treatment summaries were prepared per the standard of care at each cancer center (the method used to create a summary was not the basis of randomization). Receipt of a care-planning visit was not required by the trial; at the time, no guidelines required a visit (the CoC has since issued guidelines mandating a care-planning visit accompany the care plan document¹²). In creating the treatment summaries for inclusion in the care plan document, the two centers relied on different methods^{13,14} to provide a document containing IOM-recommended and/or CoC-required content (Table 1).¹⁵ The two methods are as described below but are largely distinguished by whether an external software program not integrated with the EHR was used in the creation of the treatment summaries. We focused our analysis on the process used rather than on the institution, as such processes could be adapted or changed by other institutions.

EHR-Based Method

Cancer Center 1 used an EHR-based method, where each care plan was autopopulated using diagnosis and treatment data that had previously been entered into the EHR for clinical use. Diagnosis and treatment data were entered by the treating physicians throughout the course of diagnosis and treatment.¹³ Each document was then created using a template pulling in diagnosis and treatment data along with prepopulated text about follow-up recommendations, future and chronic side effects, and additional resources. The prepopulated text could be further individualized. A document for each survivor was created within the EHR by either a treating oncologist or

Table 1. Treatment Summary Domains With Omission and Error Definitions

Domain	Recommended Elements	Content Evaluated as Part of Accuracy Analysis	Omission Defined As	Error Defined As
Diagnosis	Diagnostic tests performed and results; biopsy/tumor site	Biopsy date, screening and diagnostic results	Lack of biopsy information and date (day/month/year)	Dates counted as error if > 2-week discrepancy
Staging and tumor details	Tumor stage, grade; receptor and marker information	Receptors, histology, margins, grade, laterality	Lack of receptor information (if applicable*) Lack of TNM or stage Lack of laterality	Discrepancy compared with pathology report
Surgery details	Type of surgery, date of surgery; results of surgery: histology, tumor size, nodal involvement, margins	Surgeon name, type/date, pathologic findings including TNM stage	Lack of surgery date (month/year) Lack of surgery type/node dissection Lack of surgical findings: size, grade, nodal findings Not counted: margin status	Dates counted as error if > 2-week discrepancy; discrepancy compared with pathology report
Chemotherapy details	Name of regimen, (neo)adjuvant drugs used, total dosage, dates of first and last chemotherapy, complications/toxicities experienced during treatment	Medical oncologist; regimen name, drugs, dates; complications and toxicities experienced	Lack of completion date (month/year) Lack of regimen name or drugs Not counted: use of term neoadjuvant or adjuvant Not counted: total dosage of individual drugs	Dates counted as error if > 2-week discrepancy; discrepancy compared with medical record source documentation
Radiotherapy details	Total dose, dates of first and last radiation	Radiation oncologist, area treated, total dose and type, date treatment completed	Lack of completion date (month/year) Not counted: total dose	Dates counted as error if > 2-week discrepancy; discrepancy compared with radiation summary note
Targeted and hormonal therapy details	Endocrine drugs used, dates of first and last endocrine therapy	Medical oncologist; drugs used and date started; date if discontinued, with reason	Failure to list an endocrine therapy that patient was receiving at the time of care plan creation was counted as an omission.	Dates counted as error if > 2-week discrepancy; discrepancy compared with current or historical medication list

Abbreviations: HER2, human epidermal growth factor receptor 2.

*HER2 was not generally applicable for ductal carcinoma in situ.

advanced practice provider (APP). Care summaries created by an APP were reviewed and approved by the treating physician before being provided. The document was provided to the enrolled survivor either electronically or as a paper copy and maintained within the EHR such that it could be adjusted and regenerated rapidly. When provided by the APP, the care plan document was always provided as part of a separate care-planning visit (either in person or telephone based).

External Software-Based Method

Cancer Center 2 used a software program external to their EHR (eg, no integration or communication between the software and the EHR) developed to support survivorship care planning.

An oncology registered nurse reviewed each survivor's medical records to abstract the necessary diagnosis and treatment data. These data were then manually entered into the software program to create a care plan document. The registered nurse then provided the document, typically as part of a survivorship care-planning visit (either in person or telephone based). The document was provided to the enrolled survivor either electronically or as a paper copy and then uploaded into the EHR of Cancer Center 2. Any changes to the document required generation of a new plan via the external software and then repeated upload into the EHR. If the clinical data were not stored by the software (eg, if a different computer was used), it would also need to be re-entered.

Data Abstraction and Verification

The randomized parent trial's primary end point was change in a survivor's knowledge of diagnosis and treatment after care plan receipt when compared with baseline. Thus, each participant's clinical data were abstracted at enrollment and served as the basis for the planned exploratory accuracy analysis. Data were abstracted from source documentation (eg, receptor status had to be determined based on the original pathology report and could not be drawn solely from a clinic note). A second audit was performed for every chart at the end of the study.

Establishing Accuracy and Completeness

To establish accuracy and thoroughness (Table 1), medical records data were cross-checked against available individualized summaries prepared as part of this study. In the case of discrepancies between the medical record and care plan, clinicians at each location (A.J.T. or M.G./W.G.H.) reviewed the chart. The correct information was then adjudicated among at least two medical oncologists (A.J.T., W.G.H., K.B.W., M.E.B.). The decision to label each discrepancy as an omission or an error was made by two medical oncologists (A.J.T., W.G.H.). These oncologists (A.J.T., W.G.H.) also attempted to determine the reason (if possible within the limits of retrospectively identifying an issue) for the omission or error by review of the medical record and discussion with the entering or preparing providers. The errors and omissions were communicated to treating physicians as identified so that corrected treatment summaries could be issued if deemed appropriate.

Errors were defined as data reported that did not match data validated from source documents (eg, right breast cancer reported when imaging and pathology reports stated left). Omissions were defined as IOM-recommended elements missing from the care plan. The thoroughness assessment conducted for this trial focused on diagnosis and treatment details (Table 1). Vast potential differences in the amount of data reported were possible on the basis of the underlying complexity of cancer care. For example, a patient with stage III disease treated with surgery, chemotherapy, radiation, and endocrine therapy would be expected to have far more data for entry into a care plan than a patient with stage 0 disease treated with surgery alone. For this reason, analysis focused on a simple proportion of plans having at least one error and/or omission, rather than calculating an error or omission count or rate per plan.

RESULTS

Participant and Diagnosis/Treatment Characteristics

The two cancer centers enrolled 127 eligible women with breast cancer between November 2013 and December 2014 (85 at Cancer Center 1 and 42 at Cancer Center 2). Median age was 56 years (range, 30 to 80 years); 20 had stage 0 (16%), 57 had stage I (45%), 43 had stage II (34%), and 7 had stage III (6%) breast cancer. In general, patients had received several treatment modalities (51% received chemotherapy, 72% received radiation, and 87% were recommended endocrine therapy). Appendix Table A1 (online only) shows the breakdown for the whole population as well as by care plan method.

Care Plan and Visit Characteristics

Of the 127 participants, six came off study before completing a follow-up knowledge survey, and treatment summaries were either not prepared or not available for audit. Thus, 80 EHR-based and 41 external software-based treatment summaries (n = 121) were audited for this study.

Omissions

Overall, 30 treatment summaries (25%) contained at least one omission. Table 2 lists rates and descriptions of observed omissions. The majority of omissions in EHR-based plans were failures to specifically state information. For example, not specifically reporting "pathologic stage 0" after neoadjuvant chemotherapy was counted as an omission, even though a pathologic complete response at surgery was noted in the treatment summary. Omissions in treatment summaries prepared via external software also occurred because of failure to specifically state information. However, apparent omissions in treatment summaries prepared via external software also resulted from poor match of software options with the clinical scenario. For instance, the software did not have an option to indicate that HER2 status was not assessed (clarifying text was sometimes present in the comments section).

Errors

Overall, 30 treatment summaries (21%) contained at least one error. Table 2 lists rates and descriptions of observed errors. The majority of errors in EHR-based treatment summaries were minor discrepancies in dates. Errors in external software-based plans included chemotherapy regimen, receptors, stage, and types of axillary surgery. External software-based plans were affected by poor fit of the

Table 2. Examples of Observed Omissions and Errors

Method	No.	Example	Identified Reason(s)
Omissions			
EHR based (n = 80)	24 summaries (30%) had at least 1 omission; range, 0-2	Failure to specifically state that both SLND and ALND were performed (only axillary was specified), although the pathology results were reported in SCP as 1/2 sentinel nodes and 1/13 axillary nodes, making it clear that both happened	Information entered by a clinician, who understood from results that SLND was performed in addition to ALND; template was free text for surgery type and results
		Failure to specifically state pathologic stage 0 (ypT0 ypN0), although SCP documented pCR to neoadjuvant chemotherapy	Information prepared by a clinician, who understood that pCR would be pathologic stage 0 (ypT0 ypN0), and the template did not require entry of pathologic stage
External software based (n = 41)	6 summaries (15%) had at least 1 omission; range, 0-1	Failure to note change in endocrine therapy from anastrozole to exemestane	Preparing clinician reported lacking a clear option in template to document such changes
		Nothing reported for HER2 status on invasive cancer	Preparing clinician reported leaving the field blank given lack of a "not assessed" option
		ER, PR, and HER2 not listed for invasive breast cancer	Oversight by entering clinician, software did not require entry of data or flag incomplete data before completing the SCP
Errors			
EHR based (n = 80)	8 summaries (10%) had at least 1 error; range, 0-1	Surgery date listed as September 2014 rather than August 14, 2014	Outside surgery report not available at initial data entry and consult note stated "around Sept 2014"
		Modified radical mastectomy reported rather than mastectomy and sentinel lymph node dissection	Preparing clinician reported initial data entry error; system did not require separate entry of breast and axillary procedures
External software based (n = 41)	19 summaries (46%) had at least 1 error; range, 0-3	Stage 0 (T1N0M0)	Preparing clinician reported wrong stage accidentally selected during SCP creation
		TC chemotherapy listed rather than AC	Preparing clinician reported wrong regimen accidentally selected during SCP creation
		Stage 0 (T2 N1 M0) reported rather than clinical stage II (cT2 cN1) and pathologic stage 0 (ypT0 ypN0)	Preparing clinician reported lack of separate and clearly templated fields for clinical v pathologic stage and clinical v pathologic TNM; use of non-primary source data (incorrect staging in clinic note)

Abbreviations: ALND, axillary lymph node dissection; ER, estrogen receptor; HER2, human epidermal growth factor receptor 2; pCR, pathologic complete response; PR, progesterone receptor; SCP, survivorship care plan; SLND, sentinel lymph node dissection; TC, docetaxel/cyclophosphamide.

templated software fields. For example, the individual preparing plans at Cancer Center 2 reported a lack of clearly templated fields for reporting clinical and pathologic stage and TNM separately. This resulted in confusing situations, where TNM and stage seemed discordant (eg, stage I and

T2N0, because the c designation for clinical and the yp designation for postneoadjuvant were missing). Greater clarity would have been achieved if the software had allowed stage and TNM to be categorized as clinical versus pathologic (eg, clinical stage II [cT2 cN1] and pathologic

stage I [ypT1c ypN0]). Given the lack of accompanying and clarifying c and yp designations, discordant situations were counted as errors (for instance, reporting stage I combined with reporting T2N0).

DISCUSSION

The accuracy and thoroughness of the diagnosis and treatment information (also known as the treatment summaries) being delivered with survivorship care plans are poorly understood. To the best of our knowledge, there is no standard auditing required of care plan documents before cancer survivor receipt. Therefore, as part of a randomized trial assessing care plan impact on survivor knowledge, we conducted a planned exploratory analysis of treatment summary errors and omissions. This analysis demonstrated that nearly one fourth of summaries contained at least one omission and one fifth contained at least one error. Most omissions seemed unlikely to be clinically meaningful; however, some were concerning. Failing to provide any receptors (ER, PR, or HER2) for an invasive breast cancer limits usefulness. Reporting docetaxel-cyclophosphamide rather than doxorubicin-cyclophosphamide as the chemotherapy regimen is also concerning because of the future risks associated with the anthracycline doxorubicin.

Nearly half of plans prepared using external software contained an error. This error rate should not be surprising: manual abstraction of data and re-entry are error prone. Cancer registries relying on manual data collection combined with rigorous audits still have error and incompleteness rates of 4.8% and 3.3%, respectively.¹⁶ Plans prepared by the external software-based method relied on data manually abstracted from the medical record and then manually transferred into an external software program. These data were only used for care plan creation; no systematic audit or quality checks were used. Some errors stemmed from manual abstraction from clinical notes rather than primary source documents (eg, pathology or operative reports). For example, dictated clinic notes were found to contain a staging error that was propagated into a care plan (eg, a 2.0-cm breast cancer was staged as pT2 rather than pT1c, leading to incorrectly reporting stage II rather than stage I). Other errors occurred because the software program's predesignated options did not match clinical situations and did not readily allow free text. This forced the preparer to choose the least incorrect option of omitting data. For instance, the software template did not allow selection of unknown for HER2 status, instead forcing a choice between positive, negative, or entering nothing. The proposed

importation of cancer registry data into external software programs¹⁷ may decrease error rates due to unaudited manual data transfer (note, no registry data were used in the preparation of either center's summaries). Use of cancer registry data does not solve issues related to inappropriate templating options and raises issues regarding use of registry data clinically, with attendant implications for cancer registry data accuracy. Cancer registry data may also not be available until many months after completing treatment, whereas CoC standards require provision within 6 months of completing treatment. Further work is likely needed to ensure that external software templates support information that preparers need to enter and end users require clinically.

For EHR-based treatment summaries, the diagnosis and treatment data were used routinely in clinical notes before being used to autopopulate treatment summaries. It may be that such use results in an ongoing audit and correction of errors, but we currently have no means to assess this. Omissions were more common with EHR-based plans than plans prepared via external software: data for EHR-based plans were largely entered as free text rather than into templated fields, as the treating oncologist deemed clinically relevant. Adapting EHR data entry to include standardized templates or other prompts for required elements will likely reduce omissions (such templating is being implemented). However, we also noted in the external software-based plans that difficulties arose when the options could not adequately address unusual clinical scenarios. This suggests a free-text option needs to remain. For many apparent omissions, the information was present in the results or comments section of the care plan, although it was not always readily apparent or accessible to nononcologists. For instance, a pathologic complete response to neoadjuvant chemotherapy might not be understood to correspond to pathologic stage 0 (ypT0 ypN0). Additional work to automatically reformat information as appropriate for the intended end user (clinician v survivor) might also serve to reduce apparent omissions. Both methods (EHR, external software) would benefit from prompting on entry of discrepant data (eg, entry of stage I and T2N0) or emphasizing review of critical data.

Care-planning visits were not required for delivery of the care plan document. Visits may facilitate review for omissions and errors by patients. Our staff do anecdotally report that visits result in the identification of some errors and/or omissions within treatment summaries. The degree to which this occurred

was not captured for this analysis. Furthermore, correcting errors in real time may be cumbersome and time consuming. We note that EHR-based summaries delivered as part of a survivorship care plan at a planning visit had no errors and only one omission (out of 21 summaries). However, these summaries underwent extensive review: treating physicians entered the data, and summaries were prepared and reviewed by the APP and treating physicians before delivery as well as being reviewed with a patient. Patients often cannot correctly identify chemotherapy drugs received, stage, or receptors status^{11,18} and may not be well-positioned to serve in this capacity. We would hesitate to rely on review by patients at care-planning visits as the sole means of correcting errors or omissions.

This analysis did not examine the impact of identified errors and omissions. Some omissions are misleading; for instance, failing to enter anything under chemotherapy could lead to the belief that chemotherapy was not administered, rather than a failure to enter data. This informed the rationale behind the 2014 ASCO guidelines¹⁶ stating that surgery, chemotherapy, and radiation should be explicitly reported as done or not done. Some plans may contain disclaimers about relying on the information provided. However, it seems unrealistic to expect nononcology users to independently verify data, especially when source documents may be difficult to find (eg, treatment occurred multiple years prior) or require specialized knowledge to interpret. Such disclaimers also beg the question: if we cannot rely on the data, what is the value of providing them?

The health care system struggles with error on a daily basis, and it should not be surprising that treatment summaries are also affected. In an era of required care plan provision, some thought should be given to maximizing quality. Defining the truly critical elements of treatment summaries¹⁶ combined with ongoing efforts to refine creation and preparation to minimize the source of errors and omissions are likely to be helpful. Whether EHR based or external software program based, templates could flag critical elements as requiring double-checks. Care plan autopopulation with real-time data abstracted from high-quality cancer registries would likely address some of the concerns raised by our analysis. We believe that continued efforts to increase the autopopulation of treatment summary fields are warranted. Finally, individuals preparing plans should be trained to interpret and extract the data. Accuracy and thoroughness are necessary if survivorship care plans are to fulfill their intended role as tools facilitating communication and coordination. **JOP**

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**Accuracy and Thoroughness of Treatment Summaries Provided as Part of Survivorship Care Plans Prepared by Two Cancer Centers**

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Appendix

Table A1. Demographics and Tumor Characteristics of Participants

Treatment and Tumor Characteristic	All (N = 127)	EHR (n = 80)*	External Software Based (n = 41)*
Median age (range), years	56 (30-80)	54 (30-78)	60 (34-80)
Stage			
0	20 (16)	9 (11)	10 (24)
I	57 (45)	32 (40)	21 (51)
II	43 (34)	32 (40)	10 (24)
III	7 (6)	7 (9)	0 (0)
Chemotherapy			
None	62 (49)	27 (34)	30 (73)
Received	65 (51)	53 (66)	11 (27)
Radiation			
None	35 (28)	20 (25)	15 (37)
Received	92 (72)	60 (75)	26 (63)
Endocrine therapy			
None	17 (13)	10 (12)	7 (17)
Received	110 (87)	70 (88)	34 (83)

NOTE. Data presented as No. (%) unless otherwise noted.

Abbreviation: EHR, electronic health record.

*Audited survivorship care plans only.