Original Contribution

Leveraging Electronic Health Record Systems to Create and Provide Electronic Cancer Survivorship Care Plans: A Pilot Study

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Abstract

Purpose: The Institute of Medicine (IOM) recommends cancer survivors receive survivorship care plans after completing active cancer treatment. However, care plan creation requires significant time and effort, contributing to diminished adoption of this recommendation. Electronic health record (EHR) systems have been proposed as a solution. We assessed the feasibility of creating and delivering care plans within an EHR system.

Methods: Thirty-eight breast cancer survivors without existing care plans were recruited during a follow-up visit to their primary oncologist. Using an EHR template, an oncologist created an individualized care plan for each participant. Time spent creating each plan was recorded. Participant use and feedback were collected.

Results: Participants enrolled a median of 19.7 months after diagnosis (range, 4.3 to 57 months). A minority of IOM-recommended plan elements could be automatically imported without any manual entry. The majority of elements required interpretation and manual import by the clinician. However, with an established infrastructure for importing elements, the time needed to create a care plan electronically was short (median, 3 minutes; range 2 to 12 minutes). Most survivors (n = 36; 95%) successfully accessed their care plans online and spent a median of 12 minutes (range, 0.5 to 61.9 minutes) reviewing them. Survivors perceived the plans as useful and did not generally report difficulty in accessing them online or understanding content.

Conclusion: Rapid care plan creation and delivery within an EHR is possible. Plans were available to all (survivors, oncologists, primary care physicians) via the EHR. Further research is required to explore the barriers to automating data importation into plans as well as the impact of EHR-integrated plans.

Introduction

The number of cancer survivors is growing faster than ever as a result of modern tools for early diagnosis, improved therapies, and decreased mortality from competing comorbidities.[1,2] The estimated 13.7 million survivors[3] pose new challenges for the health care system. Chiefly, because of inadequate provider-to-provider and provider-to-patient communication, survivors may not receive necessary routine care.[4] Literature suggests that many survivors are unable to provide important information about their diagnoses and treatments.[5,6]

To address this problem, numerous organizations[7-11] and the Institute of Medicine (IOM) have recommend survivorship care plans as standard of care.[4] The IOM recommends that plans include diagnosis and treatment, tumor characteristics, dates of treatment, types of therapy received, potential late effects, and other challenges, along with recommended ongoing care and resources.[4,9,12] The Journey Forward program[13] and American Society of Clinical Oncology (ASCO)[14] templates have received significant recognition. These templates require manual review and transfer of medical record data into care plans—which may lead to inaccuracy or incompleteness; 47% of plans prepared at comprehensive cancer centers failed to include basic elements.[15] Furthermore, care plans have not been widely adopted.[16] The significant time required to create them has been cited as a major barrier,[17-20] although other issues contribute.[21-26]

An efficient process with adaptable features is needed for preparing care plans. Current processes are inefficient, are potentially error prone because of reliance on manual data transcription, and prohibit easy updating of plans. Care plan autopopulation using an electronic health record (EHR) has been proposed as a solution but is unstudied.[17] The University of Wisconsin (UW) breast oncology group created a breast-specific template within our EHR. This template (UW Cancer Summary and Care Plan [UWCaSP]) can be quickly prepared within the EHR via autopopulation of data and is visible to the entire health care team (oncologists, primary care providers [PCPs], other specialists) as long as members have access to the EHR. Plans can be provided to survivors online through the Web-based patient health portal of the EHR or as printed hard copies.

The objective of this pilot was to examine the feasibility of creating and delivering the UWCaSP, thus providing an opportunity to assess the effectiveness of an EHR in preparing care plans. A secondary objective was to assess survivor use of these electronically prepared and provided care plans. We report here how the IOM-recommend elements were provided, the time required to create plans, and survivor usage and feedback.

Methods

This pilot study was approved by the institutional review board at the UW (OS11101; review board submission identification No. 2011-0695). Written informed consent was obtained from each participant before enrollment.

UWCaSP Template

The UWCaSP template was created within and thus fully integrated with the EHR from conception. The template was created using existing functionality available to clinicians; no additional programming or EHR configuration was required. To create the UWCaSP, two oncologists reviewed ASCO[14] and Journey Forward[13] templates and IOM-recommended elements of a survivorship care plan.[4,9] A list of each desired element for the UWCaSP was created, and the existing technology of the EHR was reviewed to determine how each element could be integrated. The final UWCaSP template consisted of an introduction (statement of purpose, summary of contact numbers), treatment summary, follow-up plan, and glossary of terms (the UWCaSP template is provided in the Data Supplement).

Our team identified three methods through which information could be integrated into the UWCaSP template based on existing EHR functionality. First, the EHR could automatically import data; for example, if a mammogram was ordered and performed within the UW system, the EHR could import the date (method one, automatic import). Second, the EHR could store details that would be retrieved using a command. Such data required initial manual entry, but they could be imported thereafter by entering the command to retrieve them (method two, one-time manual entry). For example, for TNM staging, a surgeon could enter TNM details into the EHR's extant staging system during a patient's initial clinic visit. Other providers (medical or radiation oncologist) could later import that patient's TNM stage (as determined by surgeon) by entering the relevant command. The UWCaSP included IOM-recommended resource information in the following way: Prespecified language was created by our oncologists and stored as text within the UWCaSP template. Hyperlinks directing participants to Web sites for additional information on lymphedema management, nutrition, and so on were used to avoid creating a lengthy document that would require frequent updating. Sections not relevant were removed (eg, if patient did not receive chemotherapy, chemotherapy future/late adverse effects were removed). Third and finally, information could be manually entered into the UWCaSP, either by typing, selecting from a drop-down menu, or searching clinical notes and using copy/paste to transfer the details into the care plan (method three, repeated manual entry).

The difference between methods one (automatic import) and two (one-time manual entry) may seem trivial. However, information incorporated via method one did not require any human agent for manual entry and was not subject to error based on user entry. The key difference between methods two and three was that information incorporated via method two had already been entered into the EHR as part of standard clinical care. Any information incorporated via method three (repeated manual entry via free text or copy/paste) could not be directly imported from the EHR and was continuously subject to potential error resulting from repeated user entry. Furthermore, for method three, the individual creating the UWCaSP had to already know where to find the data or be able to search and interpret complicated treatment details from clinical notes.

Table 1 lists each element deemed necessary for inclusion and the method by which it could be incorporated in the UWCaSP. Many elements required copy/paste from clinician notes, even when a participant received all care within the UW system (where care would be ordered via EHR, and thus, data were present within EHR.) In cases where a participant received treatment outside the UW, the number of elements available for automatic import was lower.

Study Population

Patients were approached at follow-up by the primary oncology team; during the time that the trial was open to accrual, all eligible survivors seen in clinic were approached. All patients were receiving follow-up cancer care within the UW system, but they could have received some or all of their active treatment (surgery, chemotherapy, or radiation therapy) elsewhere. Eligible patients had stage 0 to III breast cancer, completed active treatment (surgery, chemotherapy, or radiation therapy) within the past 5 years, and agreed to have patient health portal accounts (which required valid e-mail accounts). Patients were excluded because of bilateral primaries or recurrent disease or because they already had care plans.

UWCaSP Preparation

An oncologist prepared each participant's UWCaSP within 2 weeks of the enrollment date (all participants were enrolled at clinic visit). The EHR recorded the time spent creating each UWCaSP (based on time from template being loaded to time UWCaSP was signed, to nearest minute). Independent researchers checked for missing elements or incorrect information. The oncologist was then offered the opportunity to revise each UWCaSP (time spent on revision was not captured).

UWCaSP Delivery

Participants initially had access to their UWCaSPs on a secure Web site via password-protected accounts. This additional step of posting the UWCaSP on a Web site was undertaken to track usage data. The Web site collected data on plan usage (eg, number of logins, frequency and length of use, time spent on individual pages) and hyperlinks accessed. At study completion, accounts were inactivated, and UWCaSPs were sent to the participants and PCPs via the EHR. Participants also received paper copies, as did PCPs without access to the UW EHR.

Participant Feedback

At baseline, participants completed an online multiple-choice questionnaire that rated satisfaction with their knowledge in three areas (diagnosis, treatment and adverse effects,

Table 1. Incorporation of IOM Elements Into Care Plan Prepared Within EHR

Element Needed for Breast Cancer Treatment Summary and Care Plan[4,9,12]	Method One: Automatic Import	Method Two: One-Time Manual Entry	Method Three: Repeated Manual Entry
Summary			
Tests performed			
Diagnostic or screening mammogram	—	—	X
Ultrasound, MRI	—	—	X
Tumor			
Biopsy, receptors, histology, lymphovascular invasion, margins, grade	—	—	X
Cancer type	X*	—	—
TNM stage	—	X†	—
Surgery			
Types of/dates of complications	—	—	X
Chemotherapy			
Regimen name, drugs, dates of first and last treatments	—	X†	—
Total lifetime dosage	X‡	—	—
Complications/toxicities experienced	—	—	X
Radiation therapy			
Total dose and type, dates of first and last treatments	—	—	X
Endocrine therapy			
Drugs used, dates of first and last treatments	—	—	X
Reconstruction			
Type if applicable and date	—	—	X
Trials			
Clinical trial participation and trial name	—	—	X
Imaging			
Staging studies (CT, PET, bone scan)	—	—	X
Left ventricular ejection fraction	X§	—	—
General information			
Menstrual status, genetic testing	—	—	X
Follow-Up			
Contact information			
Treating institutions and providers	X‖	—	—
Referrals			
Supportive services	—	X	—
Health maintenance			
Recovery from toxicities	—	X	—
Healthy behavior recommendations	—	X¶	—
Last mammogram	X	—	—
Laboratory orders, colonoscopies, Pap, bone densitometry	X	—	—
Screening			
Recommended screening and schedule	—	X¶	—
Late/long-term effects, screening, and symptoms of such	—	X¶	—
Signs of recurrence and second tumors	—	X	—
Resources			
Effects of cancer on marital/partner relationship, sexual functioning, work, and parenting; potential future need for psychosocial support	—	X	—
Insurance, employment, financial concerns	—	X	—
Genetic counseling and testing, chemoprevention	—	X	—
Referrals to specific follow-up care providers, support groups, and PCPs	—	X	—
Cancer-related resources and information	—	X	—

Continued on next page

Table 1. (Continued)

Element Needed for Breast Cancer Treatment Summary and Care Plan[4,9,12]	Method One: Automatic Import	Method Two: One-Time Manual Entry	Method Three: Repeated Manual Entry
Participant seen entirely within UW system	6	14	15
Participant seen entirely outside UW system for surgery, chemotherapy, and/or radiation therapy	2	14	19

Abbreviations: CT, computed tomography; EHR, electronic health record; IOM, Institute of Medicine; MRI, magnetic resonance imaging; PCP, primary care provider; PET, positron emission tomography; UW, University of Wisconsin.

* Available from International Classification of Diseases (ninth revision) code but did not usually specify side and thus not used.

† Although an option, the information had generally not been entered and thus was not available for automatic import, or providers were not satisfied by formatting, clarity, and so on.

‡ Patients seen after 2011 had adequate information to accurately calculate lifetime doses for anthracyclines.

§ Could be automatically imported if echocardiogram.

‖ Only for PCP.

¶ Required editing in order to individualize.

follow-up and plan of care) as well as satisfaction with their communication with the cancer team regarding these same three areas. All ratings were 4-point Likert scales using the "Preparing for Life As a New Survivor" questionnaire.[27] At the end of study (6 to 7 months after enrollment), participants anonymously completed online feedback surveys on plan content, methods of receiving plans, and difficulties accessing the plans electronically. A 10-point Likert scale was used for each question (1, not at all useful; 10, very useful); however, an 11-point scale was used for delivery method (0, not preferred; 10, very much preferred). Open-ended questions were also asked regarding content ("Is there anything that you would like to see added?") and future use ("How do you think you might use your summary in future years?").

Statistical Analysis

For all participants, demographics and baseline diagnostic features were summarized using counts and percentages for categorical data and medians and ranges for continuous data. Oncologists' time spent creating the plans was summarized by median and range, and counts and percentages above selected thresholds were calculated. The number and percentage of participants visiting the Web site were reported, and for those visiting at least once, the per-participant number of visits and total time visiting were summarized using medians and ranges. Total number of visits and total duration visiting external sites were also reported (summed across all participants). Baseline scores of satisfaction with knowledge and communication were averaged across three areas (4-point Likert scores) and summarized using means and standard deviations. For participants completing follow-up surveys, feedback on content, preferred delivery method, and perceived difficulties (10- or 11-point Likert scores) was summarized using means and standard deviations. Tests for differences in assessment of usefulness of content by category and for delivery preference by method were performed using two-factor analyses of variance, with participant and category/method as factors.

Results

Participant Demographics

From July to September 2012, 38 participants were recruited. Participants had a median age of 57.5 years (range, 29 to 77 years) and enrolled a median of 19.7 months after diagnosis (range, 4.3 to 57 months). Most were hormone receptor positive (n = 34; 90%); few were human epidermal growth factor receptor 2 positive (n = 6; 16%). Eight (21%) had ductal carcinoma in situ, and 18 (47%) had stage I, nine (24%) had stage II, and three (8%) had stage III disease. Most had undergone breast conservation (n = 23; 61%) and received chemotherapy (n = 20; 53%) and radiation therapy (n = 28; 74%; Appendix Table A1, online only).

UWCaSP Creation

Time spent by each oncologist (n = 3) in creating each UWCaSP ranged from 2 to 12 minutes (median, 3 minutes). Only six plans (16%) equired more than 5 minutes to create, and only one (3%) required more than 10 minutes. Time spent on review by research staff or revision was not captured. A total of 36 UWCaSPs underwent some revision, largely consisting of clinically insignificant edits (eg, date of diagnostic test entered via method three [manual entry] listed as 6/2010 and not including day, number of radiation fractions and end date of radiation reported but not starting date). Edits were largely required for data provided by method three, but occasionally they were required for information recorded by method one (usually when participant had received treatment elsewhere, and auto-imported UW information that was less current).

Participant Usage Data

Thirty-six participants (95%) logged onto the Web site to view their UWCaSPs (Table 2). Of note, accurate visit durations could not be captured unless participants logged out. Despite verbal instructions and automated reminders, participants failed to log out 58 of 106 total visits. This resulted in an inability to accurately calculate the time spent on the last page visited during a session. Thus, times reported may underestimate visit duration, because time spent on the last page visited was eliminated from our calculations for participants who did not log out. Fourteen participants (39%) accessed external sites for additional resources.

Participant Feedback

Thirty-five participants were invited to provide feedback at study end (of original 38, one participant who developed met-

Table 2. UWCaSP Usage (N = 38)

Site Use	No. of Visits	Total Duration (minutes)*
UWCaSP		
No. of visits		
Mean	2.6	
Median	2	
Range	0-6†	
Time spent visiting UWCaSP, minutes‡		
Per-patient total		12.0
Range		0.5-61.9
Hyperlinks§		
Susan G. Komen for the Cure	7	48.9
National Center for Complementary and Alternative Medicine	5	9.7
UW Web-based patient health portal	4	11.3
Journey Forward	4	9.9
LiveSTRONG	3	22.7
National Lymphedema Network	3	3.4
Living Beyond Breast Cancer	3	3.0
ASCO	3	1.1
Cancer and Careers	3	0.4
ASCO guidelines on follow-up care	2	7.8
Plan Beyond Cancer	2	1.1

Abbreviations: ASCO, American Society of Clinical Oncology; UW, University of Wisconsin; UWCaSP, UW Cancer Summary and Care Plan.
* Duration of all visits combined. Regarding hyperlink use, trackable only if participant returned to study Web site after visiting external hyperlink.
† Two participants never logged on.
‡ For those with > one visit.
§ Sites visited by > one participant.

astatic disease during study and two who never accessed their UWCaSPs were excluded). Thirty feedback survey responses (86%) were collected from December 2012 to January 2013; five participants did not complete feedback surveys. Participants rated the overall usefulness of their UWCaSPs as high. Participants felt that the information was adequate, and most did not desire additional elements be included; a few (n = 5; 17%) felt that elements should be removed (Table 3; Appendix Table A2, online only). When asked if the UWCaSPs contained novel information, participants reported familiarity with all elements (Table 3), with no significant differences between elements ($P = .08$). Overall, participants had no significant preference for any method of care plan delivery (e-mail, patient portal, mailed letter, or paper copy after clinic visit [$P = .38$]).

Participants did have some concerns. Some (n = 9) had difficulty accessing their UWCaSPs once they were removed from the Web site and installed in the EHR patient portal. Most of these difficulties (n = 6; 67%) involved forgotten passwords. Additionally, six participants reported some missing information (as result of studies conducted at outside facilities) or out-of-date information (as result of delay between UWCaSP creation and completion of feedback survey).

Discussion

Survivorship care plans may improve care coordination among oncologists, survivors, and PCPs. A recent ASCO statement notes that use is low overall and cites as a cause the significant time and resources required to create care plans.[17] To overcome this barrier, better use of EHRs is suggested: "Development of an automated, programmable application to expedite . . . the process of care plan summaries is an important goal."[17(p4)]

We assessed whether we could create care plans entirely within an EHR and specifically identified care plan elements that could be automatically incorporated. Our pilot demonstrates that existing technology allow the creation of care plans entirely within an EHR. Such care plans leverage the EHR to automatically import some of the elements recommended by the IOM. Our plans required relatively little time to create and were rated as useful by survivors. The average time spent preparing each UWCaSP was shorter than the estimated 15 to 60 minutes required for a Journey Forward care plan.[28] However, our time did not include that spent on reviewing completeness or making revisions (changes were generally minor). Additionally, our study did not capture time spent on maintaining accurate and ongoing treatment summaries within clinician notes (our group does this habitually to enhance coordination among surgery and medical and radiation oncology departments). Importantly, UWCaSPs could be sent to survivors via the associated EHR patient portal or automatically generated letters. An unexplored advantage was that PCPs with EHR access could view the UWCaSPs as part of the regular medical records.

Barriers to creating care plans within an EHR were encountered. Although some of the IOM-recommended elements could be automatically imported, most still required copy/paste from clinician notes. This copy/paste method is likely faster than manually re-entering such information into a separate document, as shown by the minimal time required to create each UWCaSP. The copy/paste method raises concerns about promulgation of medical record errors[29]; further study would demonstrate if this results in more or different errors than manually re-entering information into a separate document, as currently required by other templates. Many of the elements requiring the copy/paste method could be made amenable to automatic importation with additional programming. A more problematic barrier is the incorporation of outside or older records. The EHR cannot directly import information from other facilities or data from before its implementation. This poses a serious problem in creating fully automated care plans, because patients may receive care from multiple facilities. Current state or health care organization policies as well as the variety of EHR systems may hinder automatic importation of data between health care systems.

Other unique findings from this pilot include data on survivor care plan use. The median time spent reviewing a plan was 12 minutes, and the median number of visits to the care plan Web site was two. These results were somewhat confounded by improper logouts leading to possible underestimation of total time spent (possibility of overestimation also exists, because participants may have been engaged in other activities while visiting Web site). Our

Table 3. Participant Feedback Survey Taken After UWCaSP Provision (n = 30)

Factor	Perceived Usefulness		Information Rated As Familiar		Information Should Be Removed	
	Mean	SD	Mean	SD	No.	%
Summary overall	8.7	1.6	NA	NA	NA	NA
Information regarding future and chronic adverse effects	9.1	1.2	7.7	2.5	0	0.0
Information regarding recommended cancer and primary care follow-up	8.8	1.7	8.1	2.6	0	0.0
Contact information	7.8	2.1	8.9	1.8	0	0.0
Details about						
Diagnosis	9.2	1.2	8.4	1.7	0	0.0
Surgery	8.8	2.1	8.6	1.7	0	0.0
Chemotherapy	7.0	3.8	7.9	2.9	1	3.3
Radiation therapy	7.6	3.3	8.0	2.8	1	3.3
Endocrine therapy	8.1	3.0	8.1	2.6	2	6.7
Introduction explaining purpose of summary and care plan	6.6	2.3	9.1	2.0	2	6.7

Abbreviations: NA, not applicable; SD, standard deviation; UWCaSP, University of Wisconsin Cancer Summary and Care Plan.

participants were relatively distant from diagnosis. This may have affected the duration and frequency of visits to the care plan Web site. We also captured change in survivor knowledge before and after the UWCaSP; this analysis will shed additional light on the impact of electronic care plans. Finally, some survivors requested that the care plans be updated and provided routinely. Thus, static care plans generated at a single point in time (eg, immediately after active treatment is completed) may not be as valuable to survivors.

In conclusion, survivorship care plans can be rapidly created and delivered entirely within an EHR. However, most data still require a human user for interpretation and importation. Survivors reported finding such plans useful and reported little difficulty accessing them in electronic format. Further research and effort are required to explore the barriers to automating care plan creation.

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Appendix

Table A1. Participant Demographic and Clinical Characteristics (N = 38)

Characteristic	No.	%
Age, years		
Median		57.5
Range		29-77
Disease stage		
DCIS	8	21
I	18	47
II	9	24
III	3	8
Time since diagnosis, months		
Median		19.7
Range		4.3-57
Treatment received		
Surgery	38	100
Chemotherapy	20	53
Radiation therapy	28	74

Abbreviation: DCIS, ductal carcinoma in situ.

Table A2. Participant Feedback

Participant Comments*
In response to "How do you think you might use your cancer summary in future years?" or "Do you have any additional comments on the usefulness of your summary?"
Use as reference document/use in comanagement of health
"I now have one document to review whenever I have questions or need to find contact information."
"It's a nice way to remember everything about my diagnosis and treatment plans."
"Refresh my memory of pertinent information. I have used it to double check mg of my calcium and vitamin D to make sure I am on target for the right dosage."
"I'll keep it as part of my medical history and use it as a reference if I need to review it."
"I now have one document to review whenever I have questions or need to find contact information."
"I will access the paper and [patient portal] summaries when I have questions."
"To refresh my memory and as a record of my treatment. I hope it will be updated at least once a year. Thanks."
"Review/refresh what has been done, suggested . . . therapy, periodic doctor visits and reasons for follow-up. Hopefully will not need for future treatment regimens."
"Occasional referral to refresh my memory about details of what I need to know; answer questions related to possible future health concerns."
"To be aware of this summary will help me take better care of myself."
"I felt the &lquote;Understanding Your Disease' part of my patient guidebook was more helpful than the summary, but it is helpful to have a version for my own medical file."
"I had heard much or the information. This brought it together and made things clearer."
"I found the report details very helpful because it is hard to remember everything as you are going through treatment. Now I have a document to refer to when I have questions. I think the report is a great idea for patients. I'm glad I participated in the study."
"It's very nice to have a reference in writing. I was surprised that I forgot some facts about my treatment."
Resource for use with family
"To keep my daughter and grandchildren informed about breast cancer and treatments available, so they will not fear cancer but fight it."
"I am sure I will read over the report yearly and also when any family members have questions."
"To sum up things for others."
Resource to share with other health providers
"It is now part of my medical history to be shared with any doctor I may see."
"I will also let my doctors know of this summary and always discuss it with them for my well-being."
"In case I would be seen by a doctor not with the UW system. I think it would be very useful for them."
"Unsure at this time but as a guide if a change in physicians."
No intended current use
"Hope I don't have to use it."
"I hope I never have to use it much. But if I have to, all my info is right there. It's nice."
"I will file it away for future reference."
"I will file this copy of the summary and this way I will always have the information in case we ever move."
"Summary contained all information which I have received at appointments."
In response to "Is there anything you would like to see added?" or with regard to missing/out-of-date information or additional data
Out of date or missing information
"I know UW Health has received my bone density results (I received a phone call when Dr X received the results), but the [care plan] hasn't been updated since they said they would try to obtain the results from my doctors at [another facility]."
"Will the summary continue to be updated (eg, dates of most recent mammo and bone density [I've had a BMD done in Nov 2012 that is not included]). Also a most recent Vit D level 2012 is not included."†
"The surgery summary was incomplete—there was a second surgery to repair a large hematoma from … the first surgery."‡
"Summary was not accurate—I discontinued letrozole therapy completely."§
Concern or confusion as a result of summary
"I do not recall receiving a summary with a cover letter. What I remember doing is using e-mailed links to review my chart at UW. I was disturbed to see my lymph nodes were positive with negative margins. Last week I saw my surgeon and had my annual mammogram and questioned her about it. She showed me her records stating my lymph nodes were in fact negative, which I had always understood. So, of what benefit is my chart through UW to me if it contains contradictory information? Today, I am simply confused. I can't access it anymore. The link you e-mailed me asks me to contact the administrator, which I have done. How can I revisit this summary? It had incorrect information I would like to see resolved."‖
"Trying to forget the whole experience and leave it behind me—I am sorry that I had radiation therapy and am reading about side effects of having the radiation for the future—it is a regret but it is done so I cannot reverse and pray for the best life possible."

Continued on next page

Table A2. (Continued)

Additional information to add to summary
"I would like more of the *BRCA* genetic test results to be visible. Any pictures of the DNA."
"Yes—I would like the information on the second surgery included."¶
"I would like even more detail on the diagnosis, what we know about prognosis."

Abbreviations: BMD, bone mineral density; UW, University of Wisconsin; UWCaSP, UW Cancer Summary and Care Plan.
* Comments edited for grammar, clarity and content. The feedback survey was anonymous, so unless the participant contacted the study coordinator we could not always verify to what extent complaints about accuracy or missing information were valid. Notes in brackets indicate what we were able to discern.
† Note care plans created from June to September 2012.
‡ Note only primary reconstructive procedures are routinely reported in UWCaSP. Also, timing of hematoma surgery with respect to summary creation was not available.
§ Note we were not able to verify when participant stopped drug with respect to summary creation.
‖ Note that summary was reviewed after participant contacted administrator. UWCaSP stated: "0/7 nodes positive for cancer." Issue clarified to participant's satisfaction.
¶ Note that this is same patient who referenced hematoma after reconstruction.