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Development and Evaluation of a Survey to Assess Survivor Knowledge Change after Survivorship Care Plans: WiSDOM-B (Wisconsin Survey of cancer DiagnOsis and Management in Breast cancer)

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Abstract

Purpose—The oncology community has increased efforts to inform survivors about long-term risks and planned follow-up after cancer treatment. Survivorship Care Plans (SCPs) have been recommended since 2005, yet the benefits of implementation are only now being assessed. SCPs are hypothesized to enhance patient knowledge. The WiSDOM-B was developed to measure changes in breast cancer survivor knowledge pre and post delivery of an SCP.

Methods—The Wisconsin Survey of DiagnOsis and Management in Breast cancer (WiSDOM-B) was developed with input from oncologists (medical, radiation, and surgical), patient advocates, cancer survivors, and survey design experts. An initial 9 patients evaluated survey content, and modifications were made to enhance clarity. Subsequently, 38 patients were enrolled in a randomized pilot trial assessing SCP impact on knowledge of diagnosis, treatment, late effects and followup (WiSDOM-B) and satisfaction with knowledge (existing survey).

Results—The WiSDOM-B was developed using feedback from multiple stakeholders. Baseline knowledge was poor and remained stable in the control arm. There was a suggestion of increased survivor knowledge following receipt of SCPs in the intervention arm (68.4% vs. 74.4%). Change was not statistically significant compared with the control arm. Despite knowledge deficits, baseline satisfaction with knowledge was high for both groups, with 100% of patients being satisfied/very satisfied with information provided. Satisfaction did not change significantly following SCP receipt.

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Conclusion—The WiSDOM-B assesses survivor knowledge of cancer diagnosis, treatment, follow-up, and side effects. It will be a useful tool for future studies assessing the impact of care plans on survivor knowledge.

Keywords

Breast cancer; Survivor Knowledge; Survivorship care plans; Late effects

INTRODUCTION

The Institute of Medicine (IOM) report “Lost in Transition” acknowledged that many cancer survivors do not receive recommended, routine care following active treatment.[1] Care for cancer survivors remains suboptimal.[2, 3] Providing adequate care will become ever more challenging as the number of survivors continues to increase,[4] and leads to a demand for oncologists expected to exceed the available supply.[5] The IOM recommends providing cancer treatment summaries and survivorship care plans (SCPs) to improve provider-survivor communication and coordination of care.[6] Studies indicate that survivors desire SCPs[7] and experience greater satisfaction when one is provided.[8] However, little research has been conducted to validate SCPs as a tool to improve provider-survivor communication or survivor outcomes. To our knowledge, two randomized trials of SCPs have been performed. Both studies were conducted within the Canadian health system, and neither demonstrated a positive impact.[9, 10] These studies have been criticized because the outcomes assessed (distress, functioning, and well-being) are not directly targeted by SCPs.[11] Despite lacking evidence for efficacy, several national organizations recommend delivery of SCPs to all survivors,[12, 13] and SCP delivery has been set as a quality measure by the Commission on Cancer.[14] Breast cancer represents nearly one-quarter of the cancer survivor population, making it an ideal population for initial evaluation.[13]

A critical element appears to be missing from the SCP debate: *do SCPs impact survivor knowledge?* Survivor knowledge of diagnosis and treatments received is poor. For instance, only 42% of breast cancer survivors receiving doxorubicin could identify that they had received this medication.[9] Findings like this are concerning in light of the growing understanding that cancer treatments may lead to chronic or late side effects.[15, 16] In childhood cancers, patients lack knowledge of individual risk for late complications.[17] Little data exists on breast cancer survivor’s knowledge of risk of late effects. A survivor’s long-term health may depend on understanding not only their diagnosis and treatment, but also potential long-term, adverse effects of treatments received and recommendations for future cancer screening.[1] Nissen et al recently demonstrated that patients who received a SCP improved their knowledge of stage of disease, morphology, ER/PR status, and receipt of either hormone therapy or doxorubicin.[9] Although not randomized, this study supports the hypothesis that SCPs may improve knowledge. However, Nissen et al focused on knowledge of diagnosis and treatment, without evaluating awareness of specific side effects or future screening recommendations. Curcio et al assessed survivorship knowledge, including late effects and follow-up, after SCP receipt. This study assessed if patients recalled hearing about side effects and recommended follow-up, rather than asking them to identify specific effects for which they are at risk.[18] We hypothesize that SCPs will

increase survivor knowledge of features of tumors at diagnosis, treatments, *as well as* late side effects, and recommended follow-up. This increased knowledge would have the potential to translate into improved health outcomes. However, a survey to assess survivor knowledge is needed to evaluate the impact of SCPs on these four components of cancer care for breast cancer survivors.

The aim of this study was development and evaluation of a survey to assess breast cancer survivor knowledge of initial diagnosis, types of treatments received, potential long-term complication, and follow-up recommendations. Here, we report on the design and evaluation of this survey, as well as the use of this survey in a pilot randomized, controlled trial investigating the effect of a SCP on survivor knowledge.

METHODS

Survey Development and Variables

We reviewed the literature and conference proceedings for samples of surveys assessing survivor knowledge of diagnosis and treatment. Existing surveys did not include questions pertaining to long-term complications or follow-up recommendations.[19–22] Using these survey references, NCCN and ASCO guidelines, and review of the literature, two oncologists created questions addressing knowledge of diagnosis, treatments received, late complications, and expected follow-up. Questions were reviewed and revised for content and thoroughness based on input from the following focus groups: physicians (medical, surgical, and radiation oncologists), patient advocates, and the research team. Next, the Research Shared Service (SRSS) reviewed and revised questions. SRSS provides expertise and experience in the design and implementation of cancer-related surveys.[23] As part of their review, SRSS administered the survey to a group of patient advocates and another group of cancer survivors. SRSS evaluated survey understandability, thoroughness, sensitivity of language, time spent on survey completion, and participant impressions of the survey. Based on feedback, the survey was revised and administered to a development cohort of patients. SRSS assessed the ease of administering the survey online, and evaluated content and understandability in the development cohort by verbal feedback from participants. Time spent on survey was captured by the online survey tool. Following assessment in the development cohort, the survey (WiSDOM-B) was finalized for use in a pilot randomized controlled trial of SCP impact on survivor knowledge (test cohort). The Preparing for Life as a New Survivor (PLANS) survey, developed at the University of Michigan, was utilized to evaluate survivor satisfaction with 1) own knowledge of diagnosis, treatment, and side effects, and 2) communication with the cancer team regarding diagnosis, treatment, and side effects.[24] PLANS questions assess the level of agreement with statements regarding satisfaction with a 4-point scale (strongly disagree, somewhat disagree, somewhat agree, strongly agree) for each statement.

This study was approved by the local institutional review board, and conducted in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki. All participants in the test and development cohorts were consented prior to enrollment. Participants received SCPs upon study completion, and participants in the test cohort also received a small monetary compensation.

Patient Population

All breast cancer patients were enrolled at a clinic visit with medical oncology. Patients were eligible if they met the following criteria: diagnosed with Stage 0-III breast cancer, had completed active treatment, and had an email account. Active treatment was defined as surgery, chemotherapy or radiation; patients could still be receiving adjuvant endocrine or HER2-targeted therapy. Patients were excluded for: breast cancer diagnosis > 5 years prior to enrollment, more than one primary breast cancer, local recurrence (due to concern for confusion regarding question content), metastatic breast cancer, or previous receipt of a SCP.

Development Cohort

The purpose of the development cohort was to assess ease of online survey completion, and clarity of questions. Survey 1 (WiSDOM-B + PLANS) was administered online by SRSS in clinic. Following Survey 1 administration, SRSS conducted verbal assessments regarding content and clarity of the surveys. Based on these assessments, minor modifications were made to the WiSDOM-B prior to the second administration. Four weeks later, survivors were invited by e-mail to complete Survey 2 (the revised WiSDOM-B + PLANS). Survey 2 was taken online outside of clinic. Participants were asked to complete the survey without using any references or help from others. The average time to complete each survey was recorded.

Correct responses for diagnosis and treatment were abstracted from the medical chart. A dictionary of potential toxicity was developed by 3 oncologists and reviewed by our Breast Cancer Disease-Oriented Working Group (See Supplementary Material 1). After the development cohort completed Survey 2, the research team reviewed survey questions with high rates of incorrect responses to evaluate for language that could lead to patient errors. Minor modifications to questions were made to enhance clarity and finalize the 22-question WISDOM-B survey for use in the test cohort (See Supplementary Material 2).

Test Cohort

The purpose of the test cohort was to assess for change in knowledge following receipt of an SCP. See Figure 1 for study schema. Participants completed Survey 1 (WiSDOM-B + PLANS) online. Participants were then provided access to a secure website containing links to breast cancer resources. Participants were randomized to immediate access of an SCP (experimental group) or following completion of Survey 2 (control group) via this website. [25] The SCP provided was an online SCP developed at the University of Wisconsin (UW Cancer Summary and care Plan or UWCaSP), which contains all of the recommended IOM elements for SCP.[1, 26] Four weeks after accessing the website, participants were invited by e-mail to complete Survey 2 (WiSDOM-B + PLANS).

Correct responses for the WiSDOM-B questions were identified as previously described for the development cohort. A 32-point system was used for grading. Relatively similar emphasis was placed on diagnosis, treatment, and side-effects with allocation of 8 points, 14 points, and 10 points respectively (Supplementary Material 2). Side-effects questions were worth 3 points, with ½ point subtracted for each incorrect side effect. For example, the

correct list of side effects for a post-menstrual participant receiving chemotherapy with doxorubicin, cyclophosphamide, and paclitaxel was determined to be heart problems, leukemia, and neuropathy; if the patient selected leukemia, neuropathy, and infertility, a full point would be subtracted ($\frac{1}{2}$ point each for including infertility and excluding heart problems) giving a score of $\frac{2}{3}$.

Statistical Analysis

Patient characteristics (age, cancer stage, diagnosis, and treatment received) were summarized for the development cohort and the test cohort (control and intervention groups). Medians and ranges were calculated for continuous variables, and counts and percentages were calculated for categorical variables. For the development cohort, median times to complete the WiSDOM-B and PLANS surveys were calculated. For the test cohort, means and standard deviations of absolute WiSDOM-B scores (out of 32) were calculated and summarized at Survey 1 (baseline) for all participants in aggregate, and by treatment group for Survey 2 for participants completing both surveys. Changes in score from Survey 1 to 2 were calculated for the control and intervention groups; the difference was calculated and tested using an ANCOVA model with baseline score as a covariate. This analysis was powered to detect a 10% difference in survivor knowledge or a difference of 4 points on the 32-point scale. Counts and percentages of correct answers for selected WiSDOM-B questions were also summarized. Mean PLANS scores for satisfaction with own knowledge and with cancer team communication in the areas of diagnosis, treatment, and followup were summarized. Paired Wilcoxon signed rank tests were used to test for changes in satisfaction scores between Survey 1 and 2.

RESULTS

Survey Development Process

To develop WiSDOM-B, questions were modified based on feedback from clinicians, patient advocates, breast cancer survivors, research coordinators, the SRSS, and study participants in the development cohort. See Table 1 for examples of question modifications.

Demographics and Participation

Nine patients in the development cohort and 38 patients in the test cohort were recruited from the UWCCC clinics in February 2012 and June-September 2012, respectively. Patient characteristics are shown in Table 2. For the test cohort, the median age was 57, and the majority of patients received therapies besides surgery, with 53% receiving chemotherapy, 74% radiation, and 84% endocrine therapy. Thirty-five (92%) of the test cohort participants accessed their SCPs. Two patients did not access their SCP online, and one patient who developed intercurrent metastatic disease did not have a SCP posted. Survey 1 was completed by all 38 participants, and survey 2 was completed by 33 (87%) participants.

Time Required for Survey Completion

Testing in the development cohort established that WiSDOM-B could be administered online in a reasonable time frame to assess knowledge. The median time required to complete the WiSDOM-B alone was 12 minutes, and the median time to complete both

WiSDOM-B and PLANS was 19 minutes as assessed via the survey data collection software.

Test Cohort Knowledge and Satisfaction

For the 38 test cohort participants, the mean Survey 1 (baseline) WiSDOM-B score was 21.7 ± 4.6 ($68 \pm 14\%$). Scores ranged from 11.0–29.0 (34–91%) out of a total possible score of 32. For the 33 participants completing both Survey 1 and 2, the mean scores in the intervention group ($n=16$) for Survey 1 and 2 were 21.9 ($SD=3.3$) and 23.8 ($SD=3.8$), respectively, compared to mean scores in the control group ($n=17$) of 22.2 ± 5.4 and 23.0 ± 5.4 . The mean change in the intervention group was $+1.9$ ($SD\ 2.3$) versus $+0.8$ ($SD\ 1.5$) in the control group. This gave a between-group difference of change in score of $+1.1$ in favor of the intervention group, though this difference was not statistically significant ($p=0.10$) (Figure 2). In final analysis, we did not score the question regarding next mammogram as many patients were off by 1 month, which was not felt to be clinically significant. For future use, this question was modified to ask the time frame for the next mammogram (ex. within 1 year). Of the question categories in WiSDOM-B, patients had greater difficulty identifying risks or side effects than characteristics of diagnosis and treatment. For example, participants had difficulty identifying that breast pain, lymphedema, and skin changes were potential side effects of surgery (Table 3).

At baseline, mean scores of satisfaction with own knowledge of diagnosis, treatment, and follow-up were 3.7, 3.6, and 3.6 respectively (1=strongly disagree and 4=strongly agree with the statement “I am satisfied with what I currently know about...”). Mean scores of satisfaction with cancer team’s communication regarding diagnosis, treatment, and follow-up were 3.9, 3.8, and 3.8 respectively. There were no significant differences between these baseline scores and scores on follow-up (all $p > 0.09$).

DISCUSSION

Previous surveys in the survivorship literature have focused on patient knowledge regarding characteristics of diagnosis and cancer treatment. Knowledge of long-term toxicities and follow-up are also needed to evaluate SCP impact.[9, 10] The findings from WiSDOM-B are consistent with the reported literature that survivors have poor baseline knowledge of diagnosis and treatment details.[19] Although Curcio et al previously described that patients could not recall hearing about potential late side effects; our findings clarify this knowledge deficit with evaluation of specific late toxicities. For example, less than half of participants were able to identify low bone density as a long-term side effect of endocrine therapy. In this case, the knowledge deficit may result in patients not receiving bone mineral density evaluation and delayed initiation of bisphosphonate therapy, which could ultimately lead to fractures. Without understanding of chronic or future side effects, patients are at risk for delayed recognition and treatment of side effects from prior therapy, translating into impact on quality of life and potentially mortality.

To our knowledge, the WiSDOM-B is the first survey to include all major components of survivor knowledge: characteristics of cancer at diagnosis, treatments rendered, long-term toxicities and side effects, and follow-up recommendations. Although we did not score the

question regarding next mammography from this evaluation, we will include this important follow-up recommendation on further testing. This survey was developed using the literature and current guidelines, with added multidisciplinary input from physicians, patient advocates, survivors, research personnel, survey development experts, and a development cohort of 9 breast cancer patients. The use of survivor input from the development cohort is a clear strength, as reflected by several specific changes to question language described in Table 1. This comprehensive review, with involvement of multiple stakeholders, not only improves the clarity and content of the evaluation, but also enhances the utility of the survey. For example, our stakeholders identified that stage may change during the time course of cancer diagnosis, particularly for patients receiving neoadjuvant chemotherapy. How should a survivor with a clinical Stage III (cT3 cN2 cM0) and a pathologic Stage 0 (ypT0 ypN0 cM0) breast cancer respond when asked “What is the stage of your cancer?” This is a source of potential confusion on the survey used by Nissen et al. Furthermore, we attempted to limit questions about diagnosis and treatment to those with clinical relevance – in other words, what an oncologist might ask a new patient who arrives without accompanying records. Because our stakeholders noted many survivors know the regimen name (e.g. CMF) but not the drug names (cyclophosphamide, methotrexate and fluoruracil), we incorporated a regimen question. This survey can be administered online, making it accessible, easily retrievable, and decreasing data entry costs for a research study or quality improvement initiative. Online surveys might also be incorporated into electronic medical records to provide support for discussion amongst care providers and patients, both in research and routine clinical practice.

We employed a randomized design, as it allowed us to control for the effect of administering the survey itself, unlike the reported study by Nissen et al. In the control group, several participants demonstrated improvement in knowledge. This may reflect participant access to online breast cancer references via the study website or other knowledge-seeking behavior prompted simply by asking the Survey 1 questions. In the intervention group, there was a suggestion towards greater improvement in survivor knowledge after receipt of the UWCaSP (the study was not powered to detect a difference of less than 10%.) A larger number of patients may be required to detect a smaller but clinically meaningful difference. However, the positive trend from our data supports the conclusion by Nissen et al that SCPs enhance knowledge.[19] Further analysis of a larger randomized sample is required to better characterize whether knowledge (as measured by the WiSDOM-B) changes following SCP receipt. We are currently conducting a multicenter, randomized trial assessing knowledge pre and post-SCP (both the UWCaSP and Journey FORWARD)[27] using WiSDOM-B.

We emphasized personal risk for side-effects over the general survivor population risks. We felt each survivor should have access to *individualized* information, concentrated on her own risk related to her diagnosis and the specific therapies she received, rather than having to remember which out of a long list of potential side effects applied to her particular situation. For example, even though infertility may be a potential effect of chemotherapy, a post-menopausal woman could not experience this side effect and should not be counseled about this risk. By focusing on the potential side effects relevant for a particular patient, we aim to

minimize knowledge burden, the influence of outside sources, and emphasize provider-survivor communication via SCPs.

WiSDOM-B has several limitations. First, we excluded patients with recurrent and bilateral breast cancer. These exclusion criteria were necessary for initial survey development to ensure question clarity. A revised version of WiSDOM-B has been created to allow these survivors to participate in future studies (Supplementary Material 2). Second, our pilot population consisted entirely of English-speaking women. Third, all women had access to e-mail. This may have selected for a better-educated population and online surveys might limit the ability to enroll participants without computer access. Further assessment would be needed to establish use in paper format. Fourth, the optimal time for delivery of an SCP remains unclear and our study included women at very different distances from diagnosis. The median time from diagnosis was 19.7 months. It is possible that the impact might be larger (or smaller) for patients who receive their care plan immediately after completion of therapy. Fifth, SCPs were not verbally reviewed with patients, potentially changing the impact of the SCP intervention. A final limitation is potential controversy regarding attribution of side effects to specific therapies. The correct responses to our survey were based on a side effect catalog developed by our research team. Other providers might identify additional side effects, use different terminology in communication with patients, or disagree with our interpretation. In the setting of SCP evaluation, this limitation may be negligible as the correct answers could be re-set based on information as provided by SCPs.

The PLANS survey demonstrated that most patients were very satisfied with their knowledge level and the information provided by their oncologists. Given the high baseline satisfaction, this endpoint may not improve with SCP receipt. There was a discrepancy between survivor satisfaction with knowledge (97% were satisfied/very satisfied with their own knowledge) and actual ability to correctly identify key elements of diagnosis, treatment and risk (median 67% correct on WiSDOM-B). This data suggests survivors are not aware of knowledge deficits, contributing to failure to seek additional information about their cancer. This knowledge deficit may inhibit the ability to recognize complications of therapy or seek appropriate screening. Education of survivors will be important in maximizing their ability to receive appropriate care after diagnosis.

CONCLUSIONS

The WiSDOM-B survey is a tool for assessing breast cancer survivor knowledge of characteristics of cancer diagnosis, treatments rendered, potential side effects and long-term toxicities, and follow-up recommendations. This tool can be used in evaluation of interventions aimed at improving care for survivors, including both research and quality improvement initiatives. The implementation of SCPs is associated with a suggestion of enhanced survivor knowledge using WiSDOM-B.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Fig. 1.
Study Schema

Fig2.

Dotplot of changes in score from Survey 1 to 2 in the control and intervention groups.

Table 1

Examples of Modifications to Survey Questions

Examples of Question Modifications		
Type of Problem	Specific Problem	Modification
Understandability	Unfamiliar with terms "endocrine therapy" or "hormone therapy"	Allow patients to identify specific drugs (i.e. tamoxifen, anastrozole) as well as asking about endocrine therapy
Content	Stage and lymph node assessment for patients receiving neoadjuvant chemotherapy	Addition of question about timing of Stage and lymph node evaluation with respect to timing of chemotherapy
Thoroughness	Scarring could be considered a skin change	"skin changes" included as correct answer for surgery or radiation
Clinical significance	Patients off by 1 month on timing of next mammogram which while technically incorrect was felt to be clinical insignificant	Change question to need for mammography within the next year
Grading	Evidence in development cohort that participants guessing when they did not know correct answer	addition of "I don't know" as a potential response
Sensitivity	Survivors did not like the term "your cancer"	Questions were changed to "the cancer"

Table 2

Patient Demographics

	Development Cohort	Test Cohort Control Group	Test Cohort Intervention Group
Number of Patients	9	19	19
Age: Median (range)	59 (31–68)	57 (36–77)	58 (29–73)
Stage (% of patients)			
0	0 (0%)	5 (26%)*	5 (26%)
I	4 (44%)	9 (47%)	9 (47%)
II	2 (22%)	4 (21%)	4 (21%)
III	3 (33%)	1 (5%)	1 (5%)
Months since Diagnosis			
Median (range)	Not available	21 (4–57)	19 (8–45)
Treatment received			
Surgery	9 (100%)	19 (100%)	19 (100%)
Chemotherapy	5 (56%)	11 (58%)	9 (47%)
Radiation	7 (78%)	13 (68%)	15 (79%)
Endocrine therapy	7 (78%)	16 (84%)	16 (84%)

* includes 2 patients with Stage 0 disease after neoadjuvant chemotherapy

Table 3

Baseline numbers and percentages of correct responses regarding diagnosis, treatment, and specific side effects.

Question	Survey 1 (Baseline)
Tumor Characteristics	
Able to correctly identify stage	24 (63%)
Number of Positive Lymph Nodes	29 (76%)
ER+	33 (87%)
PR+	12 (32%)
HER2+	25 (66%)
Treatments Received	
Chemotherapy	38 (100%)
Chemotherapy regimen correctly identified	23 (61%)
Chemotherapy drugs correctly identified	24 (63%)
Endocrine therapy	27 (71%)
Radiation	38 (100%)
Side Effects (risk for in future)	
Blood clots	28 (74%)
Breast pain	1 (3%)
Fragile ribs	13 (34%)
Heart problems	19 (50%)
Hot flashes	19 (50%)
Infertility	27 (71%)
Low bone density	15 (39%)
Lung damage	20 (53%)
Lymphedema	3 (8%)
Angiosarcoma	10 (26%)
Leukemia	23 (61%)
Uterine cancer	29 (76%)
Skin changes	2 (5%)
Numbness/tingling	20 (53%)
Vaginal dryness	17 (45%)

** For side effects, the number of participants giving correct answers for *all* questions related to that side effect are provided (e.g., side effect of surgery, side effect of chemotherapy, etc.).