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Improving breast cancer survivors' knowledge using a patient-centered intervention

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Abstract

Background—Low-income, minority women with breast cancer experience a range of barriers to receiving survivorship information. Our objective was to test a novel, patient-centered intervention aimed at improving communication about survivorship care.

Methods—We developed a wallet card to provide oncologic and follow-up care survivorship information to breast cancer patients. We used a prospective, pre–post design to assess the intervention at a safety net hospital. The intervention was given by a patient navigator or community health worker.

Results—Patient knowledge ($n = 130$) of personal cancer history improved from baseline pretest to 1 week after the intervention for stage (66–93%; $P < .05$), treatment (79–92%; $P < .05$), and symptoms of recurrence (48–89%; $P < .05$), which was retained at 3 months. The intervention reduced the number of patients who were unsure when their mammogram was due (15–5% at 1

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SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at <http://dx.doi.org/10.1016/j.surg.2015.03.056>.

week and 6% at 3 months; $P < .05$). Nearly 90% reported they would be likely to share their survivorship card with their providers.

Conclusion—A patient-centered survivorship card improved short-term recall of key survivorship care knowledge and seems to be effective at reducing communication barriers for this population. Further studies are warranted to assess long-term retention and the impact on receipt of appropriate survivorship follow-up care.

There are >3.1 million breast cancer survivors in the United States, with projections of a 30% increase within 10 years.¹ Long-term care spans adherence to adjuvant endocrine therapy, ongoing surveillance, and monitoring for recurrences; all are effective at improving cancer control. Equally important are efforts to manage treatment side effects, such as the physical changes, from surgery or chemotherapy, and emotional challenges, which are very common.^{2–5} Survivorship care encompasses ensuring all of these ongoing needs.⁶

Oncologists, until recently, served as the primary stewards for providing survivorship care. However, the oncology workforce is now unable to meet demands of the growing number of cancer survivors; shortages of 2,500–4,000 providers are estimated by 2020.⁷ Given this gap, more patients will transition survivorship care from specialty clinics to primary care. After completion of acute treatment of the cancer, patients are increasingly left without a clear provider or path for ensuring adequate survivorship care.

Disparities in survivorship care are prominent in underinsured and minority populations, because they are often cared for in overburdened public health care systems with limited resources. Compounding these challenges are a variety of barriers impairing effective communication, such as language, cultural, and socioeconomic impediments.⁸ There is a need to provide better patient-centered knowledge so that patients can play an active role in their care. This information can help to augment or start provider discussions on survivorship health needs. Clear, language-appropriate messages may prove beneficial in these populations. Community health workers, members of a community chosen to provide basic health care or information, and patient navigators may be particularly effective at imparting this type of health knowledge and possibly better than medical providers.⁹ Survivorship treatment summary and care plans provide useful and detailed information for providers, but a patient-directed version is needed.

To improve health communication, we developed a literacy and content-appropriate breast cancer patient survivorship wallet card containing cancer and treatment history along with recommendations for follow-up care. The goals of this study were to evaluate the effectiveness of this alternative strategy at communicating targeted survivorship messages directly to patients. We assessed changes in patient knowledge and short-term retention along with assessing satisfaction with the survivorship wallet card intervention.

METHODS

Patient recruitment

Study participants were consecutive women prospectively recruited from the breast cancer navigation program at a single public safety net hospital (December 2013–October 2014).

Eligibility criteria included (1) English- or Spanish-speaking women, (2) diagnosed with stage 0–III breast cancer, and (3) completed active therapy 2 years earlier. All patients were provided standardized educational information throughout active treatment. Patients with stage IV breast cancer or those speaking languages other than English or Spanish were excluded. Approval was obtained from the hospital's institutional review board.

Patient survivorship card development

The breast cancer patient survivorship wallet card was developed collaboratively by a patient navigator, a breast surgeon, and medical oncologists. The card included items adapted from the Breast Cancer Adjuvant Treatment Summary Form developed by the American Society of Clinical Oncology (ASCO).¹⁰ The card contains patient's breast cancer tumor stage, nodal status, and treatment received. Follow-up recommendations, based on the ASCO's Breast Cancer Survivorship Care Plan, were included, as was information on recurrence and related symptoms. Recommendations for good health (ie, healthy diet, exercise) were provided. Although not intended to be a comprehensive record, the card included important elements of diagnosis, treatment, and follow-up care in a convenient, easy-to-carry wallet size using a simple format (Fig 1). An English and Spanish version of the patient survivorship card was developed.

Intervention

After completing active breast cancer treatment, patients were identified by the breast navigator program for an exit interview to assist with the transition to primary care. Patients were screened for eligibility for the study. Patients were contacted in person or by phone and asked if they were interested in participating. Patient consenting to participate underwent a pretest baseline interview (discussed elsewhere in this article).

In the intervention, the patient was presented with the survivorship wallet card. The study coordinator completed portions of the card detailing their cancer stage, nodal status, treatment received, and recommendations for follow-up care (5 minutes). The information on the card was reviewed one-on-one with the patient by a navigator ($n = 3$) or community health worker ($n = 2$), which lasted 10–15 minutes. A standardized script was used to guide review of the information.

Questionnaires

Patients completed 3 questionnaires by interview with a trained study staff in the participants' language of preference. First, patients completed a baseline questionnaire at time of recruitment (5–8 minutes). Second, they completed a follow-up questionnaire within 1 week (8–10 minutes). Third, patients completed a questionnaire at 3 months in person or by phone (5 minutes). Study staff that completed the pretest baseline questionnaires with the patients were not responsible for completing the intervention to minimize potential bias with the responses.

At pretest baseline, we collected demographic information on age, country of origin, language of preference, and years in the United States. Patients were asked about cancer stage and nodal status, treatment received, recurrence risk, and treatment recommendations

(timing of mammogram and physical examination). Health literacy was measured using the Single Item Literacy Screener, and participants were asked their highest attained education level.

For the 1 week postintervention follow-up questionnaires, patients were asked about their history of breast cancer, treatment, risk of recurrence, and timing of recommended treatments. Patients were asked if they had a primary care physician. Questions were asked about intent for communication with providers, satisfaction with the card, and ease of understanding the materials. At 3 months, patients were contacted by phone, but had the choice to complete it in person or at an upcoming appointment. Patients were asked the same questions pertaining to survivorship at 1 week. Additionally, they were asked if they remembered receiving the card, knowledge of its location, and whether they shared it with other providers (or planned to).

The intervention was pilot tested before full implementation ($n = 7$). Open-ended questions were used to test the validity of the questionnaires, and minor changes were made in response (data not shown).

Statistical analyses

Concordance between patient reported knowledge and the actual medical record (cancer stage, nodal involvement, treatment received) was performed using the z -test of proportions. Retention of information provided by the intervention was assessed at 1 week and 3 months compared with baseline. Group comparisons between baseline and 1-week postintervention and 3-month follow-up were made using the unpooled z -test of proportions. Subgroup analyses were performed to assess whether there were notable differences in patients lost to follow-up compared with those completing the full study, as well as assessing differences in knowledge based on delivery of the intervention by a patient navigator or community health worker. Continuous variables were compared using Wilcoxon signed ranks test (age and time in United States) and categorical by the pooled z -test of proportions. Three attempts to contact patients for the follow-up questionnaires were made before determining them to be lost to follow-up. All statistical analyses were completed using STATA 13 (StataCorp, College Station, TX).

RESULTS

There were 145 patients who met the inclusion criteria and completed the baseline questionnaire; 130 underwent the intervention and completed the postintervention questionnaire (1 week) and 102 at 3 months (Fig 2). About one-third of patients were lost to follow-up. Common reasons for patients who failed to complete the intervention or follow-up questionnaires were reported lack of time or no longer wanting to discuss their cancer diagnosis. There were no differences in patient characteristics compared with the responders. Loss to follow-up was defined as 3 unsuccessful attempts to reach participants by phone. We report baseline results for patients who went on to complete the 1-week follow-up ($n = 130$). For this cohort, 82 (63%) had the intervention performed by a patient navigator and 48 (37%) by a community health worker. Patients in this cohort had a mean age of 54.7 ± 9.2 years and one-half (51%) had stage II or III disease (Table I). The majority

of patients (63%) were originally from Mexico or Central America. Almost one-half (46%) had less than a high school level of education. Of those who completed less than a high school education, 29% had completed 6 or fewer years of school. Overall, 45% indicated needing help with reading health related information (Table II).

Knowledge of cancer stage and treatment history

Notably, a significant proportion of our cohort of breast cancer survivors lacked basic knowledge of their cancer history at baseline. More than one-third (34%) did not know their correct cancer stage, 28% did not know if they had nodal involvement, and 21% could not recall the treatment received (Table III). More than one-quarter of patients (28%) did not understand that their cancer could recur and >50% did not recognize typical symptoms of cancer recurrence. Likewise, 16% did not know when their recommended next mammogram should be and 45% did not know when they needed a physical examination for survivorship care.

After this intervention, patient knowledge of their cancer stage improved (66% concordance at baseline compared with 83% at 3 months; $P < .05$). A greater proportion correctly identified the treatment they received (79% at baseline compared with 90% at 3 months; $P < .05$).

Knowledge of risk of recurrence and recommended treatments

Patients improved their knowledge that cancer can recur from 72% at baseline to 90% at 3 months ($P < .05$). They had better knowledge about the type of symptoms associated with recurrences, 48% at baseline to 93% at 3 months ($P < .05$). The intervention reduced the number of patients who were unsure when their mammogram was due (15% at baseline to 6% at 3 months; $P < .05$) and when they needed a physical examination (42% at baseline to 28% at 3 months; $P < .05$).

Subgroup analysis comparing the groups that received information from community health workers versus patient navigators did not show differences in improved survivorship knowledge (data not shown).

Satisfaction with patient survivorship wallet card

Overall, patients gave the survivorship card a favorable rating, with 93% reporting being very much or extremely satisfied with it. Ninety percent found the language and terms used were either easy or very easy to understand. Importantly, 21% reported they would consider sharing it with their oncologist and 15% with their primary care provider. At 3 months, one-quarter of patients had shared the card with a provider other than their primary care provider and about one-half planned to (Table IV).

DISCUSSION

Baseline survivorship knowledge in our cohort of underinsured breast cancer patients was low, despite involvement in a patient navigator program. Our language-appropriate survivorship card delivered by staff who were not formally medically trained seems to be

effective at increasing knowledge of survivorship information. Improvements were seen in knowledge of cancer stage and treatment out to 3 months. Patients retained knowledge about their need for ongoing care, such as timing of mammogram and physical examination. They reported a high satisfaction with the card and felt the language and content were appropriate.

Providing cancer information in a simple, easier to understand manner is a strategy used by navigation programs to help improve patient outcomes. However, further actions are needed to address continuing barriers, specifically those related to language and health literacy, for successful education and communication of health information. These issues are of specific concern in low-income, medically underserved women, which our patient survivorship card aimed to help address.

Unfortunately, many patients lack basic knowledge about their own cancer history and survivorship needs, which our study highlights. A recent study of patients with early stage breast cancer found that one-half did not respond correctly to basic questions that are critical to understanding treatment decision making, such as differences in recurrence rates for lumpectomy versus mastectomy.¹¹ Survey responses of breast cancer patients found that about one-half were uncertain regarding recurrence knowledge.¹² The reasons are multifactorial, including lack of or poor communication by the provider as well as patient-specific factors.

Katz et al¹³ observed that, among patients with breast abnormalities, those reporting barriers to care were more likely to be Hispanic, Spanish speaking, and uninsured. System-level barriers, including lack of understanding of information provided by health care personnel, difficulty understanding written communication, and not sharing a common language, were the second most commonly reported barriers and were shown to impact time to resolution compared with participants without barriers.

Our intervention aimed to improve communication across several survivorship care areas, namely, treatment, recurrence, and need for ongoing surveillance. Current trends toward primary care provider-led survivorship care also call for prompt action in this area. Haq et al¹⁴ noted patients and oncologists suggested using a paper-based passport or booklet before transitioning to survivorship care. Patients further specified that survivorship documents should be “tailored to the individual’s unique context whenever possible,” and responded positively to a survivorship care plan tailored to their needs. Similarly, our intervention utilized an individualized format where the patient’s specific cancer history, including treatment, was provided. Although improvements in short-term knowledge were observed, long-term assessment is needed.

Our study is limited by being a single-institution experience in a public safety net hospital with a predominantly Hispanic population that may not generalize well. We are limited by the lack of a randomized design and other potential confounders could have influenced our results, namely, patient frequency or pattern of reviewing wallet card, or changes in information provided by the oncologists. Another potential limitation is differences in how the information in the intervention was delivered by the community health workers versus patient navigators.

In conclusion, the use of a patient-centered survivorship card improves short-term, patient-specific breast cancer knowledge and survivorship care. Delivery of the information seems successful with use of both patient navigators and community health workers. This approach was effective in ethnic minorities that demonstrate difficulty with provider communication. Future work needs to determine long-term retention of the survivorship information. Sustainability may require interval updates on survivorship cards to reinforce the communication longitudinally. Our results have strong relevance to improving cancer disparities for breast cancer survivors, but may also translate broadly for patient-centered survivorship of other oncologic populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Front cover

TREATMENT SUMMARY		Initials: _____		
Stage: 0	I	II	III	Lymph Nodes: _____
Surgery/Year: _____				
Chemotherapy:		<input type="checkbox"/> None	<input type="checkbox"/> Before Surgery	
			<input type="checkbox"/> After Surgery	
Herceptin: No Yes				
Radiation Therapy: No Yes				
Hormone Therapy: No Yes: _____				
<small>Providers: www.nccn.org for current hormonal therapy guidelines Olive View-UCLA Medical Center AVON Cares for Life </small>				

Inside fold, left side

RECOMMENDATIONS		
<small>(Adapted from American Society of Clinical Oncology)</small>		
Year after Diagnosis	Follow-Up Tests	How often
1, 2, 3	Physical Exam	Every 3 to 6 months
	Mammogram	6 months after end of therapy*; then every year
4 and after	Physical Exam	Every 6 to 12 months
	Mammogram	Every year

* This is for the breast that had cancer

Inside fold, right side

Other recommendations for good health	
Healthy diet	Less fried, less salty, less processed meat 5 or more servings of fruit & vegetables a day
Exercise	At least 30-60 minutes, 5 days a week
Healthy weight	Talk to your doctor about your ideal weight
Healthy Bones	Talk to your doctor about how much vitamin D and Calcium you should take every day

Back cover

Please make sure to visit your doctor as recommended	
The risk of breast cancer continues	
Report these symptoms to your doctor:	
New lumps	Headaches that will not go away
Abdominal Pain	Bone Pain Chest Pain
Breathing problems or shortness of breath	

Fig 1.
Patient survivorship card.

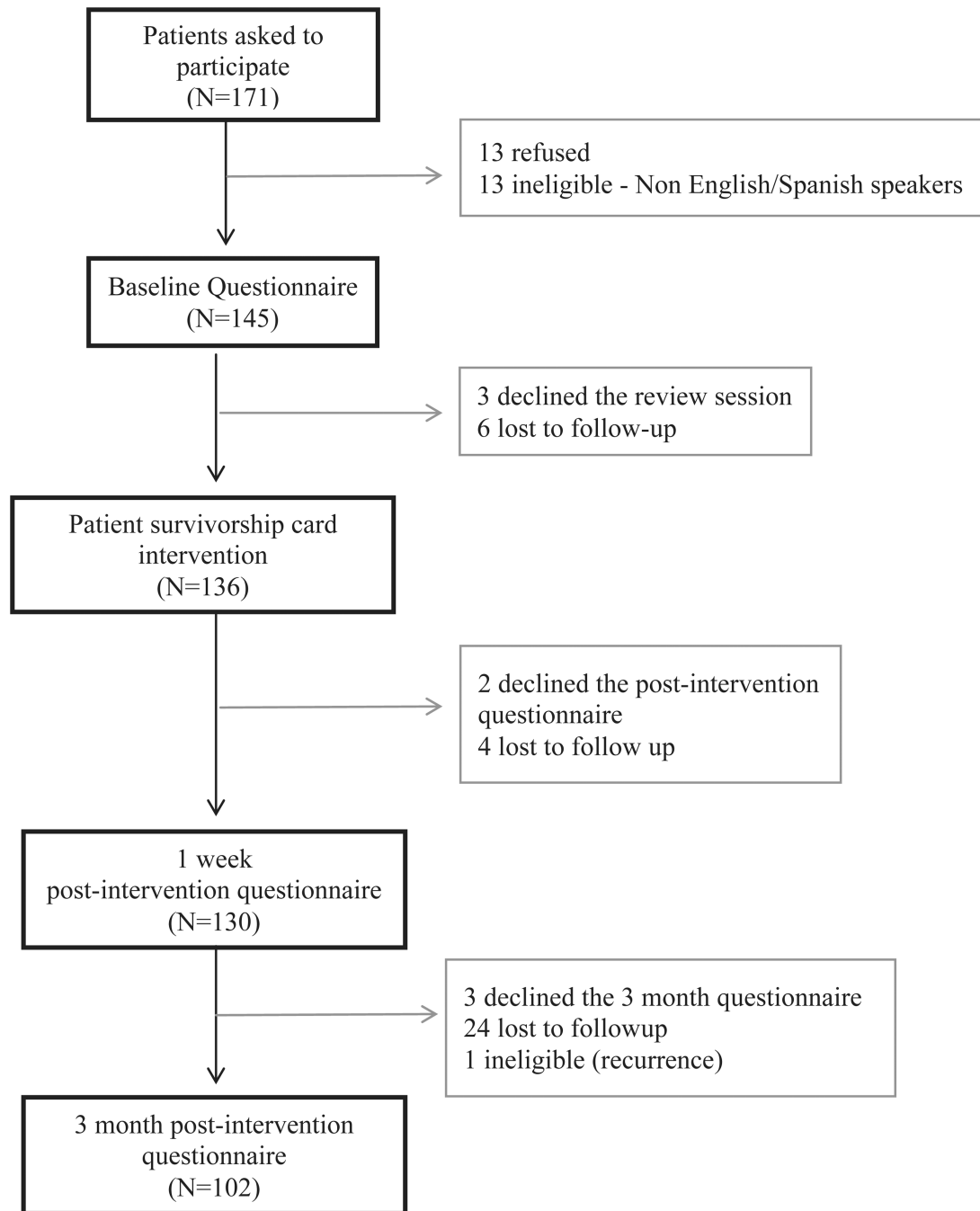


Fig 2.
Participation flow diagram.

Table IPatient characteristics baseline ($n = 130^*$)

Characteristic	Value
Age (y)	
Mean (SD)	54.7 (9.2)
Range	30–87
Stage, n (%)	
0	27 (20.8)
I	36 (27.7)
II	49 (37.7)
III	17 (13.1)
IV	1 (0.8) [†]
Country of origin, n (%)	
United States	20 (15.4)
Philippines	10 (7.7)
Eastern Europe	4 (3.1)
Mexico	40 (30.8)
Central America	42 (32.3)
South America	5 (3.8)
Other	9 (6.9)
Years in the United States (n)	
Mean	23.9
Range	0.6–63
Education	
>High school	70 (53.8)
<High school	60 (46.2)
<6 y	38 (29.2)

* We report data for baseline characteristics only for patients who went on to complete the intervention and the immediate 1 week follow-up.

[†] One patient was enrolled who had disease progression to metastatic disease during the study period.

Table IIHealth literacy screening, Single Item Literacy Screener ($n = 130^*$)

Response options	<i>n</i> (%)	Responses of sometimes or greater than sometimes
Patients were asked: How often do you need to have someone help you when you read instructions, pamphlets, or other written material from the doctor?		
Always	14 (10.8)	Yes 58 (44.6)
Often	10 (7.7)	
Sometimes	34 (26.1)	
Occasionally	24 (18.5)	No 72 (55.4)
Never	48 (36.9)	

* We report data for the health literacy screening only for patients who went on to complete the intervention and the immediate 1-week follow-up.

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Table III

Patient knowledge of breast cancer history, recurrence risk, and treatment and subsequent recall following the survivorship card intervention

Characteristic	Baseline (<i>n</i> = 130)	1 wk after the intervention (<i>n</i> = 130)	3 mo after the intervention (<i>n</i> = 102)
Concordance with cancer diagnosis and treatment, <i>n</i> (%)			
Stage	86 (66.2)	121 (93.1) [†]	85 (83.3) [‡]
Cancer in nodes	94 (72.3)	112 (86.2) [†]	80 (78.4)
Treatment	103 (79.2)	119 (91.5) [†]	92 (90.2) [‡]
Risk for cancer recurrence	94 (72.3)	114 (87.7) [†]	92 (90.2) [‡]
Symptoms of recurrence	62 (47.7)	115 (88.5) [†]	95 (93.1) [‡]
Recommended next mammogram, <i>n</i> (%)			
N/A	13 (10.0)	14 (10.8)	16 (15.7)
Every 3–6 mo	71 (54.6)	77 (59.2)	52 (51.0)
At least once a y	25 (19.2)	33 (25.4)	28 (27.5)
I don't know	20 (15.4)	6 (4.6) [†]	6 (5.9) [‡]
Missing	1 (0.8)	0	0
Recommended next physical examination, <i>n</i> (%)			
Every 3–6 mo	30 (23.1)	46 (35.4) [†]	40 (39.2) [‡]
At least once a y	42 (32.3)	63 (48.5) [†]	34 (33.3)
I don't know	55 (42.3)	20 (15.4) [†]	28 (27.5) [‡]
Other	2 (1.5)	1 (0.8)	0
Missing	1 (0.8)	0	0

[†]*P* < .05, baseline versus 1 week after the intervention.

[‡]*P* < .05, baseline versus 3 months after the intervention.

Table IVPatient satisfaction with survivorship card ($n = 130$)

Question	<i>n</i> (%)
Overall, how much did you like the survivorship card?	
Extremely	55 (42.3)
Very much	66 (50.8)
Some	4 (3.1)
A little	2 (1.5)
Not at all	1 (0.8)
Refused/unable to choose from options	2 (1.5)
What do you think about the language/terms used in the survivorship card?	
Very difficult to understand	0
Difficult to understand	2 (1.5)
Neither difficult nor easy to understand	9 (6.9)
Easy to understand	72 (55.4)
Very easy to understand	46 (35.4)
Refused/unable to choose from options	1 (0.8)
Do you think you will share the survivorship card with other providers?	
Very unlikely	5 (3.8)
Somewhat unlikely	8 (6.2)
Neither unlikely nor likely	3 (2.3)
Somewhat likely	58 (44.6)
Very likely	55 (42.3)
Refused/unable to choose from options	1 (0.8)
Who would you prefer would share this information with you? (not mutually exclusive)	
My oncologist	27 (20.8)
My primary care provider	20 (15.4)
My care coordinator	71 (54.6)
My breast surgeon	0
Any of the above	24 (18.5)
Other (family)	6 (4.6)