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BRIEF REPORT



Assessing delivery of and attitudes toward a randomized intervention to increase mammography uptake among childhood cancer survivors: A report from the Childhood Cancer Survivor Study

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ABSTRACT



Objective: This study characterizes utilization of, and attitudes toward, a two-part intervention of (1) mailed materials, including educational laminated cards for patients and healthcare providers, and (2) telephone counseling, that aimed to increase screening mammography uptake among adult female survivors of childhood cancer compared to attention controls.

Methods: Participants ($n=136$, median age 35 years, range 25–49 years) were diagnosed with cancer between 1976 and 1999 before age 21 years and had been treated with chest radiation. At study end, participants completed a questionnaire asking about their use of and attitudes toward the intervention components. Fisher's exact tests assessed associations.

Results: Among 130 survivors who completed the survey, 45 (35%) received a mammogram. Eighty-five (65%) survivors recalled receiving both intervention components; about half ($n=73$, 56%) found the laminated cards helpful and/or described the telephone counseling as positive or activating ($n=81$, 62%). Of the 96 women who provided responses, approximately two-thirds ($n=64$, 67%) reported little to no fear/anxiety regarding the intervention. Women were more likely to obtain a mammogram if they remembered receiving

KEYWORDS

Survivorship; intervention fidelity; childhood cancer survivors; breast cancer screening; mammography uptake; health behavior intervention

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both intervention components compared to women who reported receiving one or no components (45% vs. 24%, $p=0.050$), reported using the laminated card to discuss screening with a healthcare provider (72% vs. 51%, $p=0.086$), or found the telephone counseling motivational (61% vs. 30%, $p=0.003$).

Conclusions: In summary, the two-part intervention was well-received and elicited minimal fear/anxiety. Receiving intervention messaging in multiple forms and sharing it with a healthcare provider was associated with intervention efficacy.

Background

Adult female survivors of childhood cancer treated with chest radiotherapy have a high risk of breast cancer, with cumulative incidence by age 50 estimated to be near 30%.^{1,2} Despite multiple guidelines³⁻⁵ recommending regular breast cancer screening for this population, previous studies have found that as high as approximately 70% of this population are nonadherent to these recommendations.⁶⁻⁹ Reasons for this nonadherence are multifactorial and include care transition difficulties, limited provider awareness of high-risk screening guidelines, and financial and logistical barriers, all potentially compounded by psychosocial factors such as fear of results or competing health priorities.^{7,8,10-14} The EMPOWER study (ClinicalTrials.gov identifier: NCT01579552) was a randomized clinical trial designed to evaluate an intervention aimed at increasing screening mammography uptake among these high-risk women.¹⁰

Guided by the Health Belief¹⁵⁻¹⁷ and Transtheoretical Models,¹⁸⁻²² the intervention consisted of mailed educational materials followed by a telephone-delivered, brief motivational interview. The intervention significantly increased mammography uptake relative to the attention control arm (33.1% vs. 17.6%). Nevertheless, the proportion of survivors who received the intervention and obtained a mammogram within 12 months, the trial's primary outcome, remained less than 40%.¹⁰ While major barriers identified were imaging costs, lack of physician recommendation, survivors' deferred actions, and symptom absence,¹⁰ the intervention's delivery, utilization, and acceptance have not previously been reported and may help explain this less than ideal rate. Evaluating participants' experiences following a randomized multi-component intervention may help better understand which elements modify participants' behavior and how to translate an evidence-based intervention into clinical practice. This analysis evaluated the 130 of 136 participants in the EMPOWER study's intervention arm who completed a post-intervention survey to characterize utilization of, and attitudes toward, the delivered intervention, and associations with completing a mammogram.

Methods

Participants

EMPOWER was nested within the Childhood Cancer Survivor Study (CCSS), a multi-institution retrospective cohort with longitudinal follow-up of five-year survivors of childhood cancer diagnosed before age 21 years between 1970 and 1999 at one of 31 institutions in North America.^{23,24} Female participants in CCSS who were recommended to obtain an annual mammogram and breast magnetic resonance imaging (MRI) per Children's Oncology Group guidelines²⁵ and met the following eligibility criteria were enrolled in EMPOWER from October 2010 through April 2014: (1) treated with chest radiotherapy (20 Gy or greater), (2) at least 8 years from chest radiation, (3) age 25–50 years at enrollment, (4) English-speaking, (5) no history of breast cancer or myocardial infarction, and (6) no mammogram or breast imaging in the previous 24 months.^{4,10} Institutional review board and informed consent were obtained.

Components of intervention

Shown in Figure 1, the intervention had two components.¹⁰ The mailed materials (see Supplement in Oeffinger et al.¹⁰) included two laminated cards highlighting breast cancer screening recommendations (one for the participant; one to share with her healthcare provider). The materials also included a one-page “Potential Benefits and Other Considerations of Breast

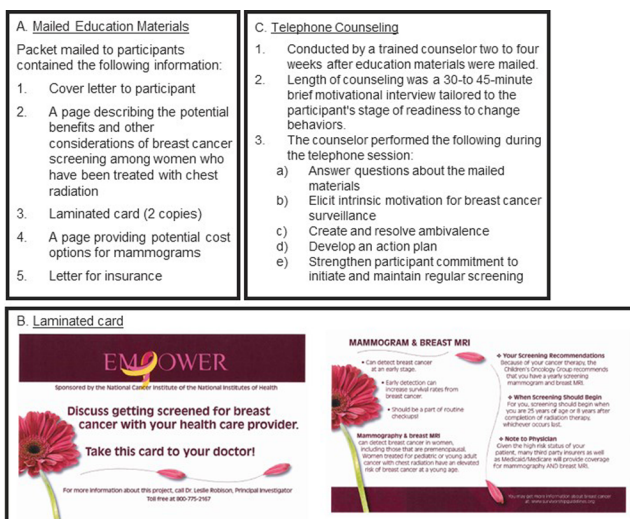


Figure 1. (A) Mailed education materials in packet sent to participants in the intervention arm, (B) picture of laminated card included in mailed packet—one copy for the participant to keep and another copy to be given to their healthcare provider, (C) telephone counseling description and the counselor's discussion points.

Screening,” a templated letter for breast MRI pre-authorization, and sources of low-cost imaging. The telephone motivational interview was based on the Transtheoretical Model.^{19,20}

EMPOWER study outcome and questionnaire

EMPOWER’s primary outcome was self-reported completion of a mammogram by 12 months after randomization. At follow-up, participants were asked to complete a questionnaire that elicited breast cancer screening uptake, descriptive data on physician visits, and receipt of intervention components. Participants could provide open-ended responses and ratings using a five-point Likert scale to questions focused on attitudes toward intervention components.

Analysis

Qualitative analyses used content analysis with an inductive, data-driven approach.^{26,27} Open-ended responses were coded by three research team members (H.V.W., J.S.F., C.S.M.) to establish uniformity in coding.²⁸ The coded data were categorized for summary and an examination of frequency. Associations between questionnaire responses and mammogram completion by 12 months were evaluated using one-sided Fisher’s exact tests with $p \leq 0.05$. All statistical analyses were performed using StataSE 18.0 for Windows (STATA, College Station, TX; Computing Resource Center, Santa Monica, CA).

Results

Among the 130 women who completed the 12-month questionnaire, 15% were a racial/ethnic minority, 71% were diagnosed with a childhood cancer between 10 and 20 years old, and Hodgkin lymphoma (65%) was the most common cancer. At trial enrollment, 75% were between 25 and 39 years old and 25% were between 40 and 50 years old. Most (85%) reported having health insurance or were a Canadian resident. Telephone counseling was successfully delivered to 107 participants. Of the 130 women, 45 (35%) reported obtaining a mammogram (Table 1).

Interventions received by participants

Of the 130 questionnaire respondents, 101 (78%) reported receiving the mailed education materials, 96 (74%) said they received the telephone counseling, with 85 (65%) receiving both intervention components. Women were more likely to obtain a mammogram if they reported receiving both

Table 1. Demographic characteristics of women in the EMPOWER randomized controlled trial who received the intervention arm and completed the survey.

Age at time of childhood cancer diagnosis	Count ($n = 130$)	
0–9 years old	38	29.2%
10–20 years old	92	70.8%
Age at assessment and intervention		
25–39 years old	97	74.6%
40–50 years old	33	25.4%
Race and Ethnicity		
White, non-Hispanic	111	85.4%
Other	19	14.6%
Black/African American	5	3.8%
Hispanic	11	8.5%
Asian, Pacific Islander, or Native American	3	2.3%
Diagnosis		
Leukemia	4	3.1%
Hodgkin lymphoma	85	65.4%
Non-Hodgkin lymphoma	9	6.9%
Kidney (Wilms)	6	4.6%
Neuroblastoma	11	8.5%
Soft tissue sarcoma	5	3.8%
Bone cancer	10	7.7%
Insurance status		
Have insurance or a Canadian resident	110	84.6%
No insurance	19	14.6%
Unknown	1	0.8%

intervention components compared to women who reported receiving one or no components (45% vs. 24%, $p = 0.050$).

Attitudes to the laminated card component of the intervention

Ninety-five participants (73%) indicated they read the laminated card (Table 2). Sixty-nine women (53%) reported the card made them want to find out more about their risks as long-term survivors. Fifty-seven (44%) reported the information was new. Attitudes were primarily positive; more than half (56%) reported it was “helpful.” Of the 96 women who responded to the question inquiring whether the card caused fear/anxiety, approximately two-thirds endorsed little to no fear/anxiety. However, among those who reported feelings of fear/anxiety, mammogram completion was high (66%). Forty-one women provided written responses of their reactions. Of these, 34 reported an activating response: made me more vigilant (15), felt anxious/fearful (11), and made me more informed (8). Women were more likely to have obtained a mammogram when they indicated the card made them want to find out more information about their health risks compared to women who reported it did not (49% vs. 29%, $p = 0.049$).

Healthcare provider interactions

Twenty-five women reported using the laminated card in discussions with their healthcare provider (Table 2). Among them, the majority (85%) noted

Table 2. Attitudes and responses of women to components of the EMPOWER intervention overall and among survivors who did and did not complete mammography screening.

	Total ^a	Completed mammogram ^b		<i>p</i>
	<i>N</i>	No	Yes	
Number of participants who responded to survey	130	85 (65.4%)	45 (34.6%)	
Interventions received (self-reported)				
Both components	85	47 (55.3%)	38 (44.7%)	0.050
One or none	25	19 (76.0%)	6 (24.0%)	
Laminated card				
Received packet, including laminated card	101	60 (59.4%)	41 (40.6%)	
Read the card				
Yes	95	54 (56.8%)	41 (43.2%)	0.201
No	6	5 (83.3%)	1 (16.7%)	
Reason why card was not read				
I already discussed with my doctor	1	1 (100%)	0 (0.0%)	0.857
I did not receive it/I do not remember	6	5 (83.3%)	1 (16.7%)	
Information on card was new				
Yes, new information to me	57	28 (49.1%)	29 (50.9%)	0.049
No	38	26 (68.4%)	12 (31.6%)	
Feelings toward information on the card				
Helpful	73	37 (50.7%)	36 (49.3%)	0.293
Unhelpful or elicited a negative emotion	9	6 (66.7%)	3 (33.3%)	
Card caused feelings of anxiety and fear				
Yes	32	11 (34.4%)	21 (65.6%)	0.002
No	64	43 (67.2%)	21 (32.8%)	
Response to the card				
Activating response	34	17 (50.0%)	17 (50.0%)	0.222
Feel anxious or fearful	11	6 (54.5%)	5 (45.5%)	
Made me more vigilant	15	6 (40.0%)	9 (60.0%)	
Made me more informed	8	5 (62.5%)	3 (37.5%)	
Non-activating response	5	4 (80.0%)	1 (20.0%)	
Card made you want to find out more information				
Yes	69	35 (50.7%)	34 (49.3%)	0.049
No	28	20 (71.4%)	8 (28.6%)	
Desire to get more information about health risks				
Yes, more information	7	5 (71.4%)	2 (28.6%)	0.462
No	17	14 (82.4%)	3 (17.6%)	
Healthcare provider interactions				
Saw a healthcare provider	81	44 (54.3%)	37 (45.7%)	
Saw a primary care provider/ internist				
Yes	58	32 (55.2%)	26 (44.8%)	0.256
No	44	28 (63.6%)	16 (36.4%)	
Saw an obstetrician/gynecologist				
Yes	35	16 (45.7%)	19 (54.3%)	0.042
No	67	44 (65.7%)	23 (34.3%)	
Saw an oncologist				
Yes	14	7 (50.0%)	7 (50.0%)	0.330
No	88	53 (60.2%)	35 (39.8%)	
Saw a provider in another field (i.e. dermatologist, endocrinologist, etc.)				
Yes	29	13 (44.8%)	16 (55.2%)	0.057
No	73	47 (64.4%)	26 (35.6%)	

(Continued)

Table 2. Continued.

	Total ^a	Completed mammogram ^b				<i>p</i>
	<i>N</i>	No		Yes		
Used card to discuss breast cancer screening						
Yes	25	7	(28.0%)	18	(72.0%)	0.086
No	37	18	(48.6%)	19	(51.4%)	
Response of healthcare provider to card						
Showed interest	23	5	(21.7%)	18	(78.3%)	0.269
No interest	4	2	(50.0%)	2	(50.0%)	
Reasons card was not used to discuss screening						
Information was already discussed	11	4	(36.4%)	7	(63.6%)	0.352
Did not have card	24	12	(50.0%)	12	(50.0%)	
Physician recommended a mammogram						
Yes	42	20	(47.6%)	22	(52.4%)	0.033
No	70	47	(67.1%)	23	(32.9%)	
Telephone counseling session						
Received session	107	65	(60.7%)	42	(39.3%)	
Remembered session						
Yes	96	55	(57.3%)	41	(42.7%)	0.110
No	17	13	(76.5%)	4	(23.5%)	
Feelings toward overall conversation						
Positive	81	45	(55.6%)	36	(44.4%)	0.227
Negative/do not remember	11	8	(72.7%)	3	(27.3%)	
Thoughts about the counselor						
Positive experience	82	45	(54.9%)	37	(45.1%)	0.169
Negative experience/do not remember	9	7	(77.8%)	2	(22.2%)	
Feelings toward discussion content						
Positive or activating feeling	63	33	(52.4%)	30	(47.6%)	0.265
Negative feeling/do not remember	17	11	(64.7%)	6	(35.3%)	
Counselor was knowledgeable about packet*						
Yes	90	51	(56.7%)	39	(43.3%)	0.605
No/not really	3	2	(66.7%)	1	(33.3%)	
Felt comfortable with the counselor*						
Yes	77	44	(57.1%)	33	(42.9%)	0.479
No/not really	17	9	(52.9%)	8	(47.1%)	
Discussion changed thoughts about mammography*						
Changed	62	35	(56.5%)	27	(43.5%)	0.531
No/not really	31	18	(58.1%)	13	(41.9%)	
Discussion motivated me to get a mammogram*						
Yes	41	16	(39.0%)	25	(61.0%)	0.003
No/not really	53	37	(69.8%)	16	(30.2%)	
Discussion made me fearful of getting breast cancer*						
Yes	13	8	(61.5%)	5	(38.5%)	0.463
No/not really	81	45	(55.6%)	36	(44.4%)	
Discussion helped me create plan for screening*						
Yes	31	12	(38.7%)	19	(61.3%)	0.016
No/not really	62	40	(64.5%)	22	(35.5%)	
Counselor was not helpful**						
Helpful	91	50	(54.9%)	41	(45.1%)	0.175
Not helpful	3	3	(100%)	0	(0%)	

(Continued)

Table 2. Continued.

	Total ^a	Completed mammogram ^b		<i>p</i>
	<i>N</i>	No	Yes	
Counselor was personable*				
Yes	80	42 (52.5%)	38 (47.5%)	0.061
No/not really	14	11 (78.6%)	3 (21.4%)	
Counselor was easy to talk to*				
Yes	83	46 (55.4%)	37 (44.6%)	0.428
No/not really	11	7 (63.6%)	4 (36.4%)	
Counselor had a positive attitude*				
Yes	88	48 (54.5%)	40 (45.5%)	0.173
No/not really	6	5 (83.3%)	1 (16.7%)	
Counselor was trying to help me*				
Yes	85	46 (54.1%)	39 (45.9%)	0.157
No/not really	9	7 (77.8%)	2 (22.2%)	
Counselor made me upset*				
Yes	3	3 (100%)	0 (0%)	0.175
Not/not really	91	50 (54.9%)	41 (45.1%)	
Understood what counselor was saying*				
Yes	88	49 (55.7%)	39 (44.3%)	0.468
No/not really	6	4 (66.7%)	2 (33.3%)	
Trust the counselor*				
Yes	67	37 (55.2%)	30 (44.8%)	0.451
No/not really	27	16 (59.3%)	11 (40.7%)	

^aNumbers do not sum to total due to missing/unknown responses. ^bPercentages in parentheses represent row percentages. *Attitudes were elicited *via* a Likert scale (1 = Not at all, 2 = A little bit, 3 = Moderately, 4 = Quite a bit, 5 = Extremely). Responses of "1 = Not at all" or "2 = A little bit" were grouped as "No/not really." Responses of "3 = Moderately," "4 = Quite a bit," or "5 = Extremely" were grouped as an agreement response ("Yes" or "Changed"). **This attitude's Likert scale responses were grouped as the following due to being a negatively worded survey item: "Helpful" (1 = Not at all or 2 = A little bit) and "Not helpful" (3 = Moderately, 4 = Quite a bit, or 5 = Extremely).

their provider "showed interest." Thirty-five women explained why they did not use the card with their provider: 24 participants' responses suggested they did not bring it to their appointment, the remainder indicated the information had already been discussed. While not statistically significant, women were more likely to obtain a mammogram if they reported using the card to discuss screening with a provider compared to women who did not (72% vs. 51%, $p=0.086$). The proportions were similar across provider types: among participants who visited a primary care provider, 45% obtained a mammogram, an obstetrician/gynecologist, 54%, and an oncologist, 50%. Notably, only forty-two (32%) women reported that their provider recommended a screening mammography, despite all women being at risk and eligible for mammography based on current guidelines (Table 3). Women were more likely to obtain a mammogram if their provider recommended a screening mammography compared to women whose provider did not (52% vs. 33%, $p=0.033$).

Attitudes toward telephone counseling

Ninety-six (74%) participants reported remembering their telephone counseling session (Table 2). Reactions were primarily favorable: 62% had

positive feelings toward the overall conversation, 63% reported positive counselor experiences, and 48% described discussion content as positive. Most participants described favorable traits for the counselor: knowledgeable (69%), had a positive attitude (68%), and did not make me upset (70%). Of the 94 women who responded to the question about whether counseling made them fearful of getting breast cancer, 62% reported it did not. Women were more likely to obtain a mammogram if they found the counseling motivational compared to women who did not (61% vs. 30%, $p=0.003$), and if it helped them create a screening plan compared to women who reported it did not (61% vs. 36%, $p=0.016$).

Discussion

Our study provided insights to childhood cancer survivors' reception of, and attitudes toward, a multi-component intervention designed to increase cancer screening uptake. Women were more likely to obtain a mammogram if they reported receiving both intervention components, indicated materials made them want to find out more information about health risks, found telephone counseling motivational, and/or reported the counseling helped create a screening plan. The intervention did not appear to be associated with increased anxiety/fear among most participants. From participants' perspectives, healthcare provider feedback about the laminated card was positive. Participants' positive experiences combined with lack of worry/fear elicited suggests intervention components motivated participants to pursue recommended screening.

These results align with previous studies²⁹⁻³¹ demonstrating the effectiveness of multi-component/combination interventions in increasing cancer screening, such as Bloom et al.'s RCT²⁹ where an informative letter followed by telephone counseling increased mammography screening in Hodgkin lymphoma survivors who had received chest radiotherapy. Unique to our study is including two identical laminated cards highlighting screening recommendations in the mailed materials; participants were encouraged to bring the additional card to their healthcare provider for discussion. We found that provider-participant interactions due to the laminated card was an important component to promoting health behavior.

Our findings emphasize the critical role of healthcare provider interactions in influencing mammography uptake. Previous studies have shown the positive influence of healthcare provider communication on promoting healthy behavioral changes,^{32,33} such as smoking cessation and endorsing breast cancer screenings.^{7,34,35} Here, women were more likely to obtain a mammogram if they reported using the laminated card to discuss screening with a provider or if their provider recommended a screening mammogram. These findings emphasize the positive priming effect healthcare

Table 3. Attitudes and responses of women to components of the EMPOWER intervention overall among participants for whom a healthcare provider recommended a mammogram and among survivors who did and did not complete mammography screening.

	Total ^c	Completed mammogram ^d		P
		No	Yes	
	42	20 (47.6%)	22 (52.4%)	
Interventions received (self-reported)				
Both components	32	15 (46.9%)	17 (53.1%)	0.466
One or none	9	5 (55.6%)	4 (44.4%)	
Laminated card				
Received packet, including laminated card	37	18 (48.6%)	19 (51.4%)	
Read the card				
Yes	36	16 (44.4%)	20 (55.6%)	0.218
No	2	2 (100%)	0 (0.0%)	
Reason why card was not read				
I already discussed with my doctor	0	0 (0.0%)	0 (0.0%)	–
I did not receive it/I do not remember	2	2 (100%)	0 (0.0%)	
Information on card was new				
Yes, new information to me	23	11 (47.8%)	12 (52.2%)	0.519
No	14	6 (42.9%)	8 (57.1%)	
Feelings toward information on the card				
Helpful	26	10 (38.5%)	16 (61.5%)	0.321
Unhelpful or elicited a negative emotion	7	4 (57.1%)	3 (42.9%)	
Card caused feelings of anxiety and fear				
Yes	17	7 (41.2%)	10 (58.8%)	0.419
No	20	10 (50.0%)	10 (50.0%)	
Response to the card				
Activating response	16	10 (62.5%)	6 (37.5%)	0.548
Feel anxious or fearful	6	4 (66.7%)	2 (33.3%)	
Made me more vigilant	8	4 (50.0%)	4 (50.0%)	
Made me more informed	2	2 (100%)	0 (0.0%)	
Non-activating response	4	3 (75.0%)	1 (25.0%)	
Card made you want to find out more information				
Yes	25	10 (40.0%)	15 (60.0%)	0.243
No	12	7 (58.3%)	5 (41.7%)	
Desire to get more information about health risks				
Yes, more information	6	4 (66.7%)	2 (33.3%)	0.548
No	4	2 (50.0%)	2 (50.0%)	
Healthcare provider interactions				
Saw a healthcare provider	33	15 (45.5%)	18 (54.5%)	
Saw a primary care provider/internist				
Yes	24	12 (50.0%)	12 (50.0%)	0.465
No	14	6 (42.9%)	8 (57.1%)	
Saw an obstetrician/gynecologist				
Yes	12	2 (16.7%)	10 (83.3%)	0.012
No	26	16 (61.5%)	10 (38.5%)	
Saw an oncologist				
Yes	7	2 (28.6%)	5 (71.4%)	0.249
No	31	16 (51.6%)	15 (48.4%)	
Saw a provider in another field (i.e. dermatologist, endocrinologist, etc.)				
Yes	17	6 (35.3%)	11 (64.7%)	0.155
No	21	12 (57.1%)	9 (42.9%)	
Used card to discussing breast cancer screening				
Yes	10	4 (40.0%)	6 (60.0%)	0.597
No	21	9 (42.9%)	12 (57.1%)	
Response of healthcare provider to card				
Showed interest	9	3 (33.3%)	6 (66.7%)	0.745
No interest	3	1 (33.3%)	2 (66.7%)	

(Continued)

Table 3. Continued.

	Total ^c	Completed mammogram ^d		P
		No	Yes	
	42	20 (47.6%)	22 (52.4%)	
Reasons card was not used to discuss screening				
Information was already discussed	6	1 (16.7%)	5 (83.3%)	0.148
Did not have card	15	8 (53.3%)	7 (46.7%)	
Telephone counseling session				
Received session	40	20 (50.0%)	20 (50.0%)	
Remembered session				
Yes	35	17 (48.6%)	18 (51.4%)	0.556
No	7	3 (42.9%)	4 (57.1%)	
Feelings toward overall conversation				
Positive	30	14 (55.6%)	16 (44.4%)	0.301
Negative/do not remember	4	3 (75.0%)	1 (25.0%)	
Thoughts about the counselor				
Positive	31	14 (45.2%)	17 (54.8%)	0.114
Negative/do not remember	3	3 (100%)	0 (0.0%)	
Feelings toward discussion content				
Positive or activating feeling	25	10 (40.0%)	15 (60.0%)	0.072
Negative feeling/do not remember	6	5 (83.3%)	1 (16.7%)	
Counselor was knowledgeable about packet*				
Yes	35	17 (48.6%)	18 (51.4%)	--
No/not really	0	0 (0.0%)	0 (0.0%)	
Felt comfortable with the counselor*				
Yes	31	15 (48.4%)	16 (51.6%)	0.677
No/not really	4	2 (50.0%)	2 (50.0%)	
Discussion changed thoughts about mammography*				
Changed	22	11 (50.0%)	11 (50.0%)	0.640
No/not really	12	6 (50.0%)	6 (50.0%)	
Discussion motivated me to get a mammogram*				
Yes	22	9 (40.9%)	13 (59.1%)	0.204
No/not really	13	8 (61.5%)	5 (38.5%)	
Discussion made me fearful of getting breast cancer*				
Yes	6	4 (66.7%)	2 (33.3%)	0.301
No/not really	29	13 (44.8%)	16 (55.2%)	
Discussion helped me create plan for screening*				
Yes	16	6 (37.5%)	10 (62.5%)	0.194
No/not really	19	11 (57.9%)	8 (42.1%)	
Counselor was not helpful**				
Helpful	33	15 (45.5%)	18 (54.5%)	0.229
Not helpful	2	2 (100%)	0 (0%)	
Counselor was personable*				
Yes	32	14 (43.8%)	18 (56.2%)	0.104
No/not really	3	3 (100%)	0 (0%)	
Counselor was easy to talk to*				
Yes	32	15 (46.9%)	17 (53.1%)	0.478
No/not really	3	2 (66.7%)	1 (33.3%)	
Counselor had a positive attitude*				
Yes	33	15 (45.5%)	18 (54.5%)	0.229
No/not really	2	2 (100%)	0 (0%)	
Counselor was trying to help me*				
Yes	33	15 (45.5%)	18 (54.5%)	0.229
No/not really	2	2 (100%)	0 (0%)	
Counselor made me upset*				
Yes	3	3 (100%)	0 (0%)	0.104
No/not really	32	14 (43.8%)	18 (56.2%)	

(Continued)

Table 3. Continued.

	Total ^c	Completed mammogram ^d		P
		No	Yes	
	42	20 (47.6%)	22 (52.4%)	
Understood what the counselor was saying*				
Yes	34	17 (50.0%)	17 (50.0%)	0.514
No/not really	1	0 (0%)	1 (100%)	
Trust the counselor*				
Yes	28	13 (46.4%)	15 (53.6%)	0.466
No/not really	7	4 (57.1%)	3 (42.9%)	

^aNumbers do not sum to total due to missing/unknown responses. ^bPercentages in parentheses represent row percentages. *Attitudes were elicited *via* a Likert scale (1 = Not at all, 2 = A little bit, 3 = Moderately, 4 = Quite a bit, 5 = Extremely). Responses of "1 = Not at all" or "2 = A little bit" were grouped as "No/not really." Responses of "3 = Moderately," "4 = Quite a bit," or "5 = Extremely" were grouped as an agreement response ("Yes" or "Changed"). **This attitude's Likert scale responses were grouped as the following due to being a negatively worded survey item: "Helpful" (1 = Not at all or 2 = A little bit) and "Not helpful" (3 = Moderately, 4 = Quite a bit, or 5 = Extremely).

provider actions can have on patients in behavioral change interventions. Additionally, the findings highlight that putting information in the hands of young adults who survived a childhood cancer does not guarantee they will give this information to their healthcare provider. In this study, the laminated card's impact appeared to be greatest when participants physically brought it to their appointment. Thus, if an intervention promotes participants to bring the received information to their healthcare provider, it could help enhance its intended impact. However, 55% of participants who received both intervention components did not obtain mammograms, reflecting other barriers noted by participants including imaging costs and being too busy, as we previously reported.¹⁰ In addition, it is possible that the laminated cards did not evoke a sense of urgency to get screened as initially intended.

Study limitations include those inherent to survey research: response and recall bias, inability to clarify responses further, and missing data. Although 96% of intervention arm participants returned the questionnaire, some responses were incomplete or missing written responses. Women who did not obtain a mammogram were less likely to provide responses to survey items than study participants who did report obtaining a mammogram, and women who proactively brought the laminated cards to their appointments may already have been more motivated to discuss screenings with their provider, both of which could introduce bias into the results. Further, study participants were from a fairly well-educated, predominately White cohort who receive regular newsletters and tend to have healthcare providers. Additionally, we did not compare outcomes by insurance type (private vs. public). These factors may limit generalizability, underscoring the importance of ensuring future interventions recruit a diverse population.

Conclusion

Receiving multiple forms of messaging and sharing information with healthcare providers is associated with behavior changes in childhood cancer survivors. Interventions aimed at increasing breast cancer screening uptake among high-risk survivors can be implemented with minimal fear/anxiety. Further, engaging and educating healthcare providers is critical to changing patient behavior and improving health outcomes. Future interventions targeting high-risk survivors should strongly consider incorporating multi-component interventions and actively involving healthcare providers. Priority should be given to educating healthcare providers about the serious risk of late effects faced by childhood cancer survivors, including through disseminating guidelines and enabling quick, accurate search engine results.

Disclosure statement

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Data availability statement

The Childhood Cancer Survivor Study is a US National Cancer Institute funded resource (U24 CA55727) to promote and facilitate research among long-term survivors of cancer diagnosed during childhood and adolescence. CCSS data are publicly available on dbGaP at <https://www.ncbi.nlm.nih.gov/gap/> through its accession number phs001327.v2.p1. and on the St Jude Survivorship Portal within the St. Jude Cloud at <https://survivorship.stjude.cloud/>. In addition, utilization of the CCSS data that leverages the expertise of CCSS Statistical and Survivorship research and resources will be considered on a case-by case basis. For this utilization, a research Application Of Intent followed by an Analysis Concept Proposal must be submitted for evaluation by the CCSS Publications Committee. Users interested in utilizing this resource are encouraged to visit <http://ccss.stjude.org>. Full analytical data sets associated with CCSS publications since January of 2023 are also available on the St. Jude Survivorship Portal at <https://viz.stjude.cloud/community/cancer-survivorship-community~4/publications>.

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