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BRIEF REPORT



Culturally-tailored survivorship care planning for rural Latina breast cancer patients: a pilot study

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ABSTRACT

Objective: To explore the feasibility and acceptability of *Proyecto Mariposa*, a culturally-tailored survivorship care program for rural Latina breast cancer patients.

Design: Single group mixed-method approach.

Methods: Feasibility of recruitment, intervention and evaluation, and perceptions about the intervention were assessed with 18 rural Latina breast cancer patients from the US/Mexico border region. Pre-post assessments evaluated change in patients' knowledge and concerns about survivorship care, and their self-efficacy about patient-physician interaction and managing chronic disease.

Findings: Feasibility was generally promising but affected by the COVID-19 outbreak. Participants found the intervention to be acceptable and useful, particularly with regard to information provision and encouraging proactive behavior. There was modest pre-post improvement on self-efficacy for managing disease.

Conclusions: This pilot study suggested feasibility and acceptability of *Proyecto Mariposa* for rural Latina breast cancer patients. Change in outcomes was small indicating the need for research with a larger sample to establish reliable findings.

KEYWORDS

acceptability; breast cancer survivorship care plan; feasibility; Latinas; rural

Introduction

Latina breast cancer (BC) patients may encounter challenges impacting their survivorship care including psychological distress (e.g., depression), lack of understanding of the disease and treatment, lack of access to language concordant services, and unmet symptom management.¹⁻³ Survivorship care is even more challenging for rural Latinx cancer patients living in

the US/Mexico border region in that they frequently travel to neighboring cities or out of the country to seek specialty and follow-up care, complicating care coordination.⁴

To facilitate optimal survivorship care, the Institute of Medicine recommends that all cancer patients receive a survivorship care plan (SCP), a written treatment summary and follow-up care plan when they transition to primary care.⁵ However, implementation of SCP is limited,^{6,7} with only 20% of oncologists reporting providing an SCP, and 13% of primary care physicians reporting receiving an SCP.⁷ Despite concerns about unequal cancer survivorship issues and unmet needs of Latina BC patients,³ little is known about the feasibility and acceptability of implementing a culturally-tailored SCP for rural Latina BC patients. The primary aim of this pilot study was to examine the feasibility and acceptability of *Proyecto Mariposa*, a culturally-tailored SCP intervention for rural Latina BC patients. We also explored the preliminary outcomes of *Proyecto Mariposa* as a secondary aim.

Methods

Study design

This mixed-methods study used a one group pre-post test design to assess the feasibility, acceptability, and preliminary outcomes of the *Proyecto Mariposa* SCP intervention, a one session program followed by a booster telephone call. We assessed a number of implementation factors (e.g., recruitment, retention) for feasibility. Post-intervention assessments included a semi-structured qualitative interview to assess participants' perceived acceptability and usefulness of the SCP intervention. Patients completed quantitative surveys at baseline and at two months post-intervention to assess preliminary outcomes. Data were collected from November, 2019 to May, 2020 in person at a private office at a partnering local nonprofit community-based cancer organization or the participant's home (Pre-COVID), or by telephone (post-COVID). Study procedures were approved by the San Diego State University Institutional Review Board (#HS-2019-0158).

Participants

Participants were recruited from a regional oncology clinic and the community cancer organization located in a rural US/Mexico agricultural border area with high poverty and unemployment.⁸ Inclusion criteria were being Latina, English or Spanish speaking, age 21 or older, having been diagnosed with BC stages 0 to III (verified by medical records), and having completed their recommended course of treatment (e.g., surgery, chemotherapy, radiation therapy) in the past 12 months.

Proyecto Mariposa SCP intervention

Proyecto Mariposa used a joint team intervention approach consisting of culturally and linguistically-matched Latinx oncology clinic nurses and social work patient navigators from the local nonprofit cancer organization. The intervention's cultural adaptation has been described elsewhere.⁹ Upon completing a baseline survey, a research assistant scheduled a clinic intervention visit for the participant for 2–3 weeks later. The content of the intervention focused on, (a) education about the purpose and benefits of an SCP, (b) review of a personalized SCP document based on the patient's medical information and treatment plan, (c) coaching and modeling of proactive behaviors with the help of an animated video, and (d) counseling on psychosocial needs (see Table 1). The 6-minute animated video focused on SCP education and activation of proactive behavior (e.g., sharing SCP with family) within a cultural and situational context (e.g., content reflecting patients' binational lives and health care utilization in both US and Mexico). Details on the theory-driven process and content development considering cultural and linguistic context are described elsewhere.⁹ A booster telephone call was conducted about one month after the SCP intervention session. Methods to insure fidelity of intervention delivery by the joint team included, (a) standardized training and evaluation using a structured training manual, (b) monitoring the intervention delivery by reviewing the joint team's field notes, and (c) documenting the length, activities, and issues that arose during the delivery of intervention.

Measures and data collection

To assess the feasibility of the intervention and approach, participant recruitment, completion of baseline and post-intervention assessments, and

Table 1. *Proyecto Mariposa* intervention content and procedures.

Session	Time	Activities/topic
<i>Proyecto Mariposa</i> session	25–30 minutes	A nurse reviewed the personalized <i>Proyecto Mariposa</i> SCP document, focusing on reviewing the treatment summary, late and long-term effects of treatment, and a follow-up care plan.
	30–45 minutes	A social work patient navigator continued the session supplementing it with individually-tailored information/counseling to further discuss the patient's physical and psychosocial needs, resource referrals, challenges, and lifestyle/behavioral change (e.g., nutrition, physical activity). The social work patient navigator showed a 6-minute animated video aid developed by the research project to provide SCP education, while modeling proactive behaviors.
Single Booster phone call (one month post intervention visit)	15–30 minutes	A social work patient navigator made a follow-up 'booster' phone call (approximately 15–30 minutes) to address patients' psychosocial concerns and questions, and reinforce core SCP components (e.g., encouraged communication with family and primary care physician).

Table 2. Outcome measures for pre-post change.

Measures	Scale	Description
Knowledge of Survivorship Issues	Modified version of the Preparing for Life as a New Survivor scale. ¹⁰	Consists of 11 items with 4-point Likert-type response categories (1 = strongly disagree to 4 = strongly agree). Total score ranges from 11 to 44, with higher scores indicating greater knowledge. Cronbach's alpha reliability coefficient was .77.
Survivor Concerns	Survivor concern scale. ²⁰	Consists of five items with 4-point Likert-type response categories (1 = not at all to 4 = very much) assessing participants' worry about future diagnostic tests, being diagnosed with another type of cancer, cancer recurrence, dying, and their general health. Total score ranges from 5 to 20, with higher scores indicating greater concern. Cronbach's alpha reliability coefficient was .89.
Self-efficacy in patient-physician interaction	Perceived Efficacy in Patient-Physician Interaction (PEPPI) instrument. ^{10,21}	Consists of 10 items with 5-point Likert-type response categories (1 = not at all confident to 5 = very confident). Total score ranges from 11 to 50 with higher scores indicating greater self-efficacy. Cronbach's alpha reliability coefficient was .82.
Self-efficacy to Manage Chronic Disease	Adapted version of the Cancer Survivorship Efficacy Scale. ²²	Consists of 6 items with 10 -point Likert-type response categories (1 = not at all confident to 10 = totally confident). Total score ranges from 6 to 60, with higher scores indicating greater self-efficacy to manage problems. Cronbach's alpha reliability coefficient was .82.

participation in intervention were tracked by the research assistant and social work patient navigators. At the post-intervention assessment, participants reported use of the SCP with health care professionals (HCPs) and sharing with family/friends via the quantitative survey. We also obtained evaluative feedback from the two joint teams of nurses and social work patient navigators who provided the SCP intervention.⁹

For acceptability, participants were interviewed two months post intervention by a research assistant about their perceptions of the usefulness of *Proyecto Mariposa*, focusing on the SCP document, the joint team approach, and the animated video. Qualitative interviews were audio-taped, transcribed, and translated from Spanish to English for data analysis. In addition, we evaluated the quantitative outcomes targeted by the intervention (Table 2). These scales have been tested with Hispanic populations including underserved Latina cancer patients.^{10,11}

Data analysis

Qualitative data were analyzed using thematic analysis,¹² whereby the researchers (EK, MZ, and VC) independently reviewed the transcripts and developed a set of themes and codes. Discrepancies in text coding among researchers were resolved by discussion, reaching consensus, and revising the code. To enhance the rigor of our qualitative analysis, we examined

our roles and values as researchers in health care, and how our values might influence the research process and interpretation of data (i.e., reflexivity). In research group meetings, we routinely discussed our own perspectives and potential biases to guard against misinterpretation of participant narratives.

For quantitative pre/post data, paired samples t-tests and nonparametric Wilcoxon matched pairs tests were conducted to assess change in the outcome measures for those participants who provided both assessments (n = 18). Due to this being a pilot study with a small sample size, alpha was set at .10. Because we had *a priori* hypotheses regarding the direction of change in the four outcomes, one-tailed tests were conducted.

Results

Feasibility of implementation, intervention, and assessment

Table 3 reports feasibility results of the *Proyecto Mariposa* SCP intervention and approach. The original targeted sample size for the study was 35 based on an *a priori* power calculation; however, research activities were halted in mid-March of 2020 due to COVID-19, curtailing referral. Out of 30 referred eligible participants, 27 (90%) were successfully recruited/enrolled into the study. Of the 27 who completed the baseline, six could not be scheduled for the SCP intervention because of the COVID-19 pandemic shutdown, two became ineligible due to the diagnosis of recurrent cancer, and one dropped out because of discomfort with the assessment, for a 67% intervention completion rate (n = 18). The same 18 who completed the intervention complied with the post-intervention assessment. Out of 17 participants who had a clinic visit with an HCP, 47% reported using their SCP for the clinic visit in some way (e.g., preparing questions, sharing it with their physician). Further analysis showed no difference in socio-demographic and cancer-related information between those who used SCP and who did not during their clinic visits. All 18 participants reported having already shared the SCP with family or friends. In addition, the intervention teams reported that

Table 3. Feasibility measures of *Proyecto Mariposa* SCP intervention and approach.

Measure	Actual/targeted	% Success
Participants referred by oncology clinic/community agency	30/35	86
Participants recruited/enrolled	27/30	90
Participants completing baseline assessment	27/27	100
Participants completing intervention	18/27	67
Participants completing post-intervention assessment	18/18	100
Participants self-reported use of SCP with health care provider	8/17	47
Participants self-reported sharing of SCP with family or friends	18/18	100

Table 4. Characteristics and cancer-related variables (n=18).

Variables	Mean (SD) or N (%)
Age (mean years)	55.9 (10.1)
Marital Status	
Married/Living together	10 (55.6%)
Divorced	4 (22.2%)
Never married	2 (11.1%)
Separated	1 (5.6%)
Widowed	1 (5.6%)
Education	
Less than high school	10 (55.6 %)
High school graduate	4 (22.2%)
Some college	4 (22.2%)
Yearly Income	
Less than \$20,000	10 (55.6%)
\$20,000–\$39,000	8 (44.4%)
Time since Diagnosis	
Between 7 month to less than a year	3 (16.7%)
Between 1–2 years	11 (61.1%)
More than 2 years	4 (22.2%)
Breast Cancer Stage	
0	1 (5.6%)
1	5 (27.8%)
2	5 (27.8%)
3	5 (27.8%)
Don't know	2 (11.1%)
Place of diagnosis	
USA	12 (66.7%)
Mexico	6 (33.3%)
Language Generally Used	
Only Spanish	12 (66.7%)
Spanish better than English	5 (27.8%)
English better than Spanish	1 (5.6%)
Language Spoken at Home	
Only Spanish	16 (88.9%)
Spanish better than English	1 (5.6%)
English better than Spanish	1 (5.6%)
Language Used for Thinking	
Only Spanish	16 (88.9%)
Spanish better than English	1 (5.6%)
English better than Spanish	1 (5.6%)
Language Spoken with Friends/Family	
Only Spanish	16 (88.9%)
Spanish better than English	1 (5.6%)
English better than Spanish	1 (5.6%)

delivering the SCP intervention was feasible and beneficial, but that scheduling the SCP session was challenging due to other time commitments of both patients and intervention teams.

Participant characteristics

Table 4 presents the characteristics and cancer-related information of the 18 who completed intervention and both assessments. The participants' mean age was 55.9 years. Over 77% had been diagnosed with BC for 2 years or less, and one-third were diagnosed in Mexico.

Acceptability of the intervention

Major themes identified from the qualitative interviews are as follows:

Information Provision: Participants reported that *Proyecto Mariposa* enhanced their knowledge about cancer and survivorship care. One participant appreciated that the SCP provided the accurate name of her diagnosis. “Well, my family or friends, like say, “What did you have surgery on?” Now I can say “from an invasive ductal carcinoma” (laughs)... before I couldn’t [give an answer], I would just say, “no, well from my chest” (55 year old (YO)).

Participants recognized that the in-person session with the joint teams facilitated better understanding of their cancer care. “The SCP document alone will not be the same as the session by the nurse and social worker because they were explaining [it] to me step by step and number by number...” (54 YO). Another added, “Well, they talked about the whole thing...they asked me a lot of questions and went over my whole history...” (44 YO). The video was seen as helpful for providing a visual presentation of the information. A participant stated, “It was useful because it’s new information. It’s information that the doctors don’t always give you” (55 YO).

Patient Proactiveness: Participants recognized the importance of applying what they learned from *Proyecto Mariposa*. Almost all participants thought the SCP document empowered them to be proactive. One shared, “I could read it (SCP) calmly and ask myself a few questions to ask the doctor on my next appointment” (57 YO). The SCP was also deemed useful for increasing the family’s understanding about the participant’s symptoms, and for involving their family in their care. “I showed it (SCP) to him (husband); (it) also taught him so he understands a little better [about] my symptoms that I sometimes feel, so that he can ask the doctor freely” (58 YO).

Participants valued the joint team’s coaching for proactive behaviors. “[The navigator said] to be sure of what you are going to ask and not be left with doubts.... That’s what I liked a lot” (57 YO). Another participant shared, “[The nurse] also [encouraged] me put down what I need [to ask]” (55 YO). Participants appreciated the video demonstrating the characters’ proactive behaviors. “They are explaining how someone should talk to their doctor” (58 YO). Participants also found that the video messages and scenes reflected their own experiences, motivating them to follow the characters’ proactive behaviors (e.g., preparing questions and asking them). “There’s things you see and say, “Oh, look, I’m going to be like that, and I can do the same thing as her (animated character)” (68 YO).

Table 5. Change in baseline and post-intervention measures for 18 participants.

Measure	Mean (SD) or median		t or		Cohen's <i>d</i> Effect Size
	Baseline	Post	z	Sig.	
Knowledge of Survivorship Issues					
Parametric analysis (means)	39.83 (3.76)	40.72 (3.68)	−1.054	.15	.25
Wilcoxon test (medians)	41.0	42.0	−1.135	.14	.27
Survivor Concerns					
Parametric analysis (means)	14.55 (5.27)	14.00 (4.44)	.826	.21	.20
Wilcoxon test (medians)	17.0	15.0	−.716	.24	.17
Perceived Efficacy in Patient- Physician Interaction					
Parametric analysis (means)	46.83 (4.13)	46.94 (4.56)	−.166	.44	.04
Wilcoxon test (medians)	48.5	49.5	−.141	.48	.03
Self-efficacy to Manage Chronic Disease					
Parametric analysis (means)	7.94 (2.19)	8.41 (1.94)	−1.461	.08	.35
Wilcoxon test (medians)	8.75	9.17	−1.305	.10	.31

Changes in targeted outcomes

Tests of changes in means and medians for the four outcomes are shown in Table 5. Only Self-efficacy to Manage Chronic Disease reached statistical significance at the .10 level. The scores on other measures increased slightly from pre to post, whereas Survivor Concerns decreased, all as expected. Cohen's *d* effect sizes ranged from negligible (.04–.03 for Perceived Efficacy in Patient-Physician Interaction) to small-to-moderate (.35–.31 for Self-efficacy to Manage Chronic Disease).

Discussion

With regard to the feasibility of *Proyecto Mariposa*, results were generally favorable, although the COVID-19 pandemic had an impact on referrals and particularly on completion of interventions (we estimate that two-thirds of intervention non-completion was related to the necessity of discontinuing face-to-face activities due to COVID-19). Others might plan and test strategies to deploy in the case where person-to-person research activities are not possible. There is increasing recognition of the benefits for telehealth in rural regions.¹³ However, we were unable to quickly pivot to a virtual version of *Proyecto Mariposa* due to patients' limited access to digital devices and high-speed internet, as well as the culturally-preferred face-to-face nature of the study activities.⁹

In terms of acceptability, participants' perceptions of the usefulness of the SCP document were positive. However, only 47% of those who had post-intervention clinic visits used the SCP with their HCPs. Further analysis revealed that rushed, relatively short clinic visits for other medical issues (e.g., colds) was mentioned as the reason for not using the SCP with HCPs ($n=5$). This is a challenge in rural clinics that have a large

workflow with limited providers. Adding the SCP document to electronic health records or faxing it in advance of office visits may encourage HCPs to review SCPs, and initiate conversations regarding the SCP with patients in future visits.

Our qualitative findings suggest *Proyecto Mariposa* provided relevant information and patient proactivity. Similar to the findings from previous studies with non-Latinas,^{14–16} the joint team's individually-tailored session appeared particularly helpful for patients' comprehension of the SCP document and interest in active preparation for their interactions with physicians. The non-physician staff (i.e., nurses and social workers) implementing a language-concordant and individually-tailored SCP session can perhaps effectively respond to the needs and challenges of this underserved population and bridge the gap in a resource-scarce rural region. Similar to other studies,^{17,18} the video was perceived as a useful tool to increase participants' interest, comprehension, and attention to messages. Animated characters and videos may reflect participants and their situations and help them better relate to messages.^{17–19}

This study showed a modest positive change on patients' self-efficacy in managing chronic disease, with a small-to-medium effect size of .35. Change in Knowledge, Survivor Concerns, and Efficacy in Patient-Physician Interaction were not statistically significant, with effect sizes ranging from small to negligible. Due to this being a preliminary study with a small sample size, alpha was set at .10. Taken together, the practical significance of the results should be interpreted with caution, and future work should include a larger sample size that provides greater statistical power. Ceiling effects on quantitative measures due to social desirability bias may have been in play. The lack of a control group and a longer follow-up period weakens causal inference.

Conclusion

This small mixed-methods study suggests that a culturally-tailored SCP intervention for rural Latina BC patients was feasible in terms of recruitment and participation in activities, although COVID-19 halted face-to-face activities prematurely. The intervention was well-received and perceived to be useful, although there was limited evidence of meaningful change in outcomes. Larger, more rigorous studies need to establish effectiveness and causal inference.

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Availability of data and material

The data used to report the findings of this study are available upon request. The data are not publicly available.

Code availability

Custom code for qualitative data analysis.

Consent for publication

Patients signed informed consent regarding publishing their data.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Ethics approval

All research procedures in this study involving human participants were in accordance with the ethical standards of the San Diego State University Institutional Review Board and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This study was approved by the San Diego State University Institutional Review Board (Number: HS-2019-0158).

Disclosure statement

The authors have no relevant financial or non-financial interests to disclose.

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