



Improvement in quality of life and psychological well-being associated with a culturally based psychosocial intervention for Chinese American breast cancer survivors

Qian Lu¹ · Lingjun Chen¹ · Lilian J. Shin¹ · Carol Wang^{1,2} · Lenna Dawkins-Moultin¹ · Qiao Chu³ · Alice Loh⁴ · Lucy Young⁴ · Carol Wang⁴

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Abstract

Purpose The purpose of this study was to investigate improvements in quality of life and psychological well-being among Chinese American breast cancer survivors who participated in a pilot community education and peer-mentor support program.

Methods One hundred and twenty-nine Chinese American breast cancer survivors who recently completed treatment participated in eight cohorts of the program, Joy Luck Academy, which included weekly education and peer-mentor support sessions. The education sessions covered topics designed to help participants adjust to new life after breast cancer treatment. The peer-mentor support component was designed to provide social support. Quality of life and psychological well-being (e.g., depressive symptoms, anxiety, and low- and high-arousal positive and negative affect) were assessed at baseline and immediately after the intervention.

Results Paired samples *t* tests indicated improvements in quality of life, low- and high-arousal positive affect, and reductions in depressive symptoms, anxiety, and low-arousal negative affect.

Conclusion Our findings suggest that a psychosocial group intervention may improve quality of life and psychological well-being among Chinese American breast cancer survivors. Our intervention has the potential to be applied to other ethnic-minority cancer survivors. Future randomized controlled trials are warranted.

Keywords Breast cancer · Chinese American · Psychosocial intervention · Quality of life · Psychological well-being

Background

Breast cancer incidence has increased as much as 4% yearly among Asian Americans over the past 20 years [1], and Asian

American women born outside the USA consistently have more advanced breast cancer at diagnosis and lower survival rates than do their counterparts born in the USA [2]. Although the Asian American population is the fastest-growing minority group in the USA [3], very little attention has been given to the psychosocial and informational needs of Asian American breast cancer survivors (BCS). Reviews and meta-analyses of the literature have demonstrated that psychosocial interventions, such as facilitator-led peer discussions, groups offering both education and discussion, and cognitive-behavioral therapies, have been effective in enhancing quality of life (QOL), improving emotional adjustment, and alleviating disease-related symptoms in cancer survivors, most of whom were non-Hispanic whites [4, 5]. However, very few studies have tested the effectiveness of social support and psychoeducation in Asian Americans.

✉ Qian Lu
qlu@mdanderson.org

¹ Department of Health Disparities Research, Unit 1440, The University of Texas MD Anderson Cancer Center, 1400 Pressler St., Houston, TX 77030, USA

² Department of Psychology, University of Houston, Houston, TX, USA

³ School of Public Health, Shanghai Jiao Tong University School of Medicine, Shanghai, China

⁴ Herald Cancer Association, San Gabriel, CA, USA

The unique needs of Asian American breast cancer survivors

Although low QOL, depression, and anxiety are commonly reported for Asian American BCS in the USA, these women rarely seek help [6]. Asian American BCS have smaller social networks, lack information about cancer treatment and survivorship management due to low English proficiency, and are reluctant to explicitly ask for social support due to relationship concerns [7]. These cultural and linguistic barriers underscore the need for culturally appropriate interventions that are delivered in participants' native languages, address the social support needs of immigrant Asian American BCS, and provide Asian American BCS the knowledge and skills to cope with cancer-related challenges.

The association between social support and QOL, depressive symptoms, anxiety, and affect

A growing body of evidence indicates a positive correlation between social support and QOL among Chinese and Chinese immigrant BCS. In several studies, a high level of social support predicted increased QOL [8, 9] and explained the observed association between SES (e.g., income and education) and increased QOL [10]. Some evidence indicates that better social support is also associated with decreases in depressive and anxiety symptoms and improvements in affect. Prior studies have shown that greater social support is associated with fewer depressive symptoms in mostly non-Hispanic white women with breast cancer [11, 12]. This pattern has also been found in Asian Americans. A perceived lack of social support was found to explain the association between social constraints and depressive symptoms among Chinese American breast cancer survivors (CABCS) [13]. Family support decreased the risk of developing both major depressive disorder and generalized anxiety disorder in a sample of Asian Americans [14]. Moreover, social support partially attenuated the effects of stress on positive mood among patients with advanced prostate cancer [15], and a reduction in satisfaction with social support was associated with increased negative affect among BCS [12].

The benefits of psychoeducation

Psychoeducation, the provision of information regarding patients' illness and treatment, has been shown to increase well-being in cancer patients. A psychoeducational program focused on preventing and managing the side effects of cancer was found to be associated with reductions in depressive symptoms and emotional distress in a cohort of mostly white women in the USA [16]. A telephonically-delivered psychoeducational intervention improved overall health-related QOL and physical and emotional well-being in a group

of African American breast cancer survivors [17]. Likewise, Korean BCS participating in a psychoeducation program consisting of individual face-to-face education, telephone-delivered health-coaching sessions, and small-group meetings were found to report higher overall QOL compared to those in the control group [18].

Although there appears to be a clear association between having greater social support and participating in psychoeducation and high QOL and psychological well-being, how an intervention combining social support and psychoeducation may impact QOL and psychological well-being has not been tested in CABCS. A study is needed to address these questions.

The purpose and hypotheses of the present study

The present study sought to document and investigate a community-based psychoeducation program, Joy Luck Academy (JLA), and its associated improvements in QOL and psychological well-being among CABCS. Consistent with findings on Asian Americans, CABCS face many cultural and linguistic barriers, such as being unfamiliar with the US health care system, having difficulties expressing their emotions for fear of damaging relationship harmony, receiving insufficient support due to being in a foreign country, and feeling inadequate because they are unable to fulfill their roles as nurturers and caregivers in the family [19]. Psychoeducation and peer mentoring, the two components of JLA, were carefully designed to overcome these barriers. Psychoeducation provided information about various important breast cancer-related topics in participants' native language. Peer mentoring enabled participants to share experiences and receive guidance within a reciprocal and supportive relationship [20].

We hypothesized that the JLA intervention would be associated with improved QOL (Hypothesis 1) and psychological health (e.g., a decrease in depressive symptoms, anxiety, and negative affect and an increase in positive affect; Hypothesis 2).

Methods

Community-based participatory research (CBPR) approach

We have used a CBPR approach [21] in every step of the study, including intervention design, development, recruiting participants, implementation, evaluation, interpreting findings, and dissemination of findings. Herald Cancer Association (HCA), a nonprofit organization serving Chinese immigrants, provides services such as cancer prevention education, cancer screening, and support groups and

workshops to general public and cancer survivors in Chinese American communities. HCA staff, who had developed an accurate understanding of the needs of CABCS collaborated with the investigators to co-design and implement the intervention and study [22]. Specifically, HCA staff designed the JLA program, and the investigator (first author) provided critical feedback and helped to refine the intervention. The investigator developed the program evaluation materials and revised the materials based on HCA's feedback. Two HCA staff, who are CABCS, reviewed all of the evaluation materials. During the implementation stage, HCA recruited participants, implemented the intervention, and collected data. The investigating team conducted data analyses. Throughout all of the stages of study design and implementation, both parties communicated frequently to ensure the successful implementation of the study. The active involvement and equal partnership of the community partners and investigators in all aspects of the study facilitated the incorporation of Chinese cultural values, beliefs, and traditions [23], ensuring the program was culturally sensitive.

Participants

The study was advertised in Southern California local communities and potential participants were contacted by the HCA. CABCS who were interested in the intervention were screened for eligibility. Eligibility criteria consisted of having a breast cancer diagnosis, having completed primary breast cancer treatment (mastectomy, chemotherapy, radiotherapy, or targeted therapy) within the last 12 months, and being comfortable writing and speaking Chinese. One hundred and twenty-nine CABCS participated in eight cohorts of the intervention program.

Procedure

This study received relevant institutional review board approval. Before the intervention, participants completed a baseline questionnaire, which included questions about participants' demographics and medical histories and health outcomes. Immediately after the intervention, participants completed a follow-up questionnaire. All questionnaires were administered in Chinese.

Development and implementation of the intervention

The JLA programs were offered once or twice per year, resulting in a total of eight JLA cohorts (JLA 1–8). The cohort sizes ranged from 14 to 20 participants, with the average of 16. We limited the number of participants in each cohort to ensure that participants would have a better opportunity to know each other. The first JLA program was offered on weekdays, with

10 weekly sessions [24]. Based on participants' feedback of preferring weekend sessions with a smaller number of sessions, the second to eighth JLA programs were offered on weekends, with 6 weekly sessions for JLA cohort 2 and eight weekly 4-h sessions for JLA cohorts 3–8.

In each weekly session, participants started with sharing a healthy meal with their mentors, attended psychoeducational sessions, took exercise break, and then joined group activities led by program facilitators. They shared experiences with others in discussion sessions led by mentors in small groups or led by program facilitator in large groups. Table 1 shows the JLA program curriculum for cohorts 3–8.

The JLA program had two major components: psychoeducation and peer mentoring. The psychoeducation component, which followed a lecture and question-and-answer format, covered various breast cancer-related topics identified by HCA as most important and relevant to CABCS, such as post-treatment issues, self-care and massage in traditional Chinese medicine, diet, emotional management, and communication with family and friends. All presentations were conducted in Chinese by qualified professionals. For the mentoring component, participants were matched with well-adjusted CABCS who had completed treatments. Mentors provide support and advice to mentees during small group discussions. Between weekly sessions, mentors called mentees at least once a week to remind them to attend the next session and to discuss any concerns they may have.

The following procedures were implemented to ensure the success of the mentoring component of the study. HCA staff carefully selected qualified mentors. The key selection criteria were (1) emotional stability, (2) positive outlook and attitude; and (3) willingness to commit and learn. The staff identified potential mentors based on first-hand in-person interactions. Those potential mentors mostly had graduated from the prior cohorts of the pilot JLA program or other similar educational programs, in which HCA staff had the opportunity to closely observe their personalities and adjustment to life after cancer. The final list of mentors was decided by a HCA committee after thorough discussions of each candidate's adjustment and readiness for a mentorship role. Selected mentors were invited to join training sessions that focus on communication and providing emotional support before acting as mentors for the JLA program. The training was provided by experienced HCA staff who were BCS. After each session, mentors had a debriefing session led by the program staff to discuss success and lessons learned to improve the mentorship component.

Furthermore, at the beginning of the program, each mentor and mentee dyad mutually decided on the best mode (e.g., phone calls, WeChat, text) and time to contact the mentee during the week. JLA program staff asked mentees to tell their mentors whether or not they would be attending the upcoming session. During the JLA program, mentors provided this attendance information to HCA in advance on a weekly basis.

Table 1 Pilot JLA course content overview

Weekly theme	Week 1 Introduction	Week 2 Post-treatment	Week 3 Self-care	Week 4 Emotion management	Week 5 Healthy lifestyle	Week 6 Communication	Week 7 Beautiful me	Week 8 Graduation
Opening	Healthy breakfast (30 min)	Healthy breakfast(30 min)	Healthy breakfast (30 min)	Healthy breakfast (30 min)	Healthy breakfast (30 min)	Healthy breakfast (30 min)	Healthy breakfast (30 min)	Welcome and group photos (30 min)
Lecture 1/speech 1	Mentors share breast cancer experiences (60 min)	Understanding pathology report (20 min)	Traditional Chinese medicine as a supplement to cancer treatment (75 min)	Rebuild a new me [developing positive perspectives about cancer and building self-value] (60 min)	Nutrition and healthy eating for breast cancer survivors (75 min)	Art of communication [communication strategies with families and healthcare professionals] (90 min)	Beauty and personal care [personal care and dressing tips after treatment] (60 min)	Slideshow of program activities, address from JLA staff (20 min)
Exercise/break	Each week, the JLA participants did one of the following exercises or had a break during this session: (1) Exercise to relax spine (15 min); (2) Tai Chi (20 min); (3) praise dance (20 min); (4) stretching exercise with elastic bands (30 min)							
Lecture 2/speech 2	N/A	Be a wise survivor [risk factors; follow-up visits; managing post-treatment side effects] (25 min)	N/A	Emotion management [emotion regulation and stress coping strategies] (60 min)	Lymphedema and exercise (60 min)	N/A	Prosthesis and fashion (60 min)	Mentee and mentor sharing (20 min)
Discussion and activities	Small group get acquainted and group photo (60 min), mind game (5 min)	Breast cancer video, get to know each other (large group 45 min)	Small group sharing (60 min)	Large group sharing (25 min)	Slideshow of famous breast cancer survivors (large group 15 min)	Small group sharing (45 min)	Large group sharing (30 min)	Small group sharing (45 min), presentation of certificates (10 min), lunch (10 min), lunch

Mentors were also asked to reach mentees once a week and report to HCA all failed attempts to contact their assigned mentees. Based on mentors' report back to HCA, cases of failed contact were rare. The contact success rate was estimated by HCA staff who implemented the pilot JLA study to be over 95%, suggesting little variation in mentors' success reaching mentees. The high success rate can be attributed to the mentors' high commitment, the close and positive relationship established between HCA and mentors, and the trust the program participants had in HCA.

Measures

At baseline and immediately after completion of the JLA intervention, participants' QOL, depressive symptoms, anxiety, and positive and negative affect were assessed.

QOL

Participants' QOL, including their physical, social, emotional, and functional well-being in the week prior to assessment, was assessed using the 27-item Functional Assessment of Cancer Therapy-General scale (FACT-G) [25]. The scale has been validated among Chinese-speaking BCS [26]. An example item is "I have a lack of energy." The items were rated on a 5-point scale from 0 (not at all) to 4 (very much). Total scores were computed by adding the scores for each of the items. Participants with higher scores had higher levels of well-being than did those with lower scores. Cronbach's alphas of the scale at baseline and follow-up were .82 and .80, respectively.

Depressive symptoms

Participants' depressive symptoms were assessed using the Chinese version of the 10-item short form of the Center for Epidemiologic Studies Depression Scale (CES-D) [27, 28], which has been validated using Chinese-speaking participants [28]. Participants rated the frequency at which each symptom or mood occurred during the week prior to assessment on a 4-point scale, ranging from 0 (less than 1 day) to 3 (5–7 days). An example item is "I felt depressed." Participants with higher scores had more days affected by depressive symptoms than did those with lower scores. Cronbach's alphas of this measure at baseline and follow-up were .93 and .93, respectively.

Anxiety

Participants' anxiety was assessed using the six-item anxiety subscale from the Brief Symptom Inventory (BSI) [29]. Participants were asked to indicate the intensity of their symptoms on a 5-point Likert-type scale ranging from 0 (not at all) to 4 (extremely severe). An example item is "Feeling tense or

keyed up." Participants with higher scores experienced a greater number of symptoms than did those with lower scores. The reliability and construct validity of the Chinese version of the inventory have been established [30]. Cronbach's alphas of this subscale at baseline and follow-up were .96 and .95, respectively.

Positive and negative affect

Participants' affect was assessed using 20 items in the Positive and Negative Affect Schedule (PANAS) [31] and six items from the Revised Positive and Negative Affect Schedule [32]. The two 10-item subscales in the PANAS [31] contain words that describe high-arousal positive and negative emotions and feelings (e.g., "interested," "alert," "afraid," "hostile"). Because low-arousal affect is considered more typical or ideal than high-arousal affect in Asian cultures [33, 34], we added six items from the Revised Positive and Negative Affect Schedule [32]—"calm," "relaxed," and "at ease" versus "bored," "tired," and "sluggish"—to assess low-arousal positive and negative affect. These 26 items form four subscales—positive/low-arousal, positive/high-arousal, negative/low-arousal, and negative/high-arousal. Participants indicated the extent to which they had experienced each listed affect in the week before the assessment using a 5-point Likert scale ranging from 1 (not at all or very slightly) to 5 (extremely). Higher scores indicate greater affect. The Chinese version of the PANAS is reliable and has been validated [35], and the four subscales were also reliable; Cronbach's alphas ranged from .87 to .95 at baseline and .83 to .95 at follow-up.

Data analysis

A series of repeated *t* tests (also known as paired samples *t* tests) were conducted to test the hypotheses that the JLA intervention would be associated with positive changes in participants' QOL (Hypothesis 1) and psychological well-being (Hypothesis 2). Specifically, the mean scores of the outcome variables before and after the intervention were compared. As this was a pilot intervention, the effect sizes (Cohen's *d*) for the differences between baseline and follow-up were also calculated to evaluate the impact of the JLA program.

Results

Of the 129 participants in the JLA program, 124 completed the baseline questionnaire. Of these 124 participants, 106 completed the follow-up questionnaire. The multivariate analysis of variance showed no differences in any of the main variables between participants who completed the follow-up questionnaire and those who did not (Wilks' $\Lambda = .92$, $F(8, 88) = .92$, $p = .51$, $\eta^2 = .08$). This paper focused on the 106

Table 2 Participant characteristics ($N = 106$)

Characteristic	<i>N</i>	Percentage
Marital status		
Single	16	15.1
Divorced	12	11.3
Widowed	5	4.7
Separated	2	1.9
Married	58	54.7
Unknown	13	12.3
Breast cancer stage		
Stage 0	4	3.8
Stage I	31	29.2
Stage II	34	32.1
Stage III	23	21.7
Stage IV	1	0.9
Unknown	13	12.3
Treatment		
Surgery		
Yes	84	79.2
No	10	9.4
Unknown	12	11.3
Chemotherapy		
Yes	62	58.5
No	32	30.2
Unknown	12	11.3
Radiotherapy		
Yes	46	43.4
No	48	45.3
Unknown	12	11.3
Targeted therapy		
Yes	5	4.7
No	89	84.0
Unknown	12	11.3

participants (average age, 55.42 years) who completed both the baseline and follow-up assessments. The characteristics of the 106 participants are shown in Table 2.

For the main analysis, we examined changes in QOL and psychological well-being using a series of repeated-measure *t* tests. Significant differences were found between the baseline and follow-up assessments for all of the outcome variables except for high-arousal negative affect (see Table 3). The effect sizes of the intervention were also calculated, and their absolute values ranged from .19 to .42. These results indicated that the JLA intervention was associated with improvements in QOL, positive affect, and reductions in low-arousal negative affect, anxiety, and depressive symptoms. Additionally, we examined whether there was a decrease from baseline to follow-up in the number of participants who reported being clinically depressed (score ≥ 13 on the CES-D Scale). The proportion of clinically depressed participants dropped from 29.0% at baseline to 23.6% at follow-up.

Given that the length of the program varied between cohort 1, 2, and later cohorts, we compared group differences. We did not find differences in improvement scores among cohort 1, cohort 2, and later cohorts, using a regression analysis with the 7 improvement scores (QoL, high- and low-arousal positive and negative affect, depressive symptoms, and anxiety) as the outcomes.

Discussion

CABCS often face difficulties in understanding cancer treatments, experience cancer-related stigma, and tend to be reluctant to seek explicit social support due to concerns about disrupting group harmony [19]. To alleviate these difficulties, the JLA program was developed using the CBPR approach. Participation in the program was associated with improved QOL and positive affect, and reduced negative affect and depressive and anxiety symptoms.

Our analyses indicated that the JLA intervention was associated with improved overall QOL. This finding is consistent with those of previous studies that found greater social support is linked to higher QOL among Chinese BCS [8] and explains

Table 3 Change in outcomes from baseline to follow-up

	Baseline mean (SD)		Post-intervention mean (SD)		Change scores mean (SD)		<i>t</i> value	Cohen's <i>d</i>
QOL	72.30	(21.19)	78.04	(16.00)	5.74	(15.76)	3.73***	.36
Depressive symptoms	10.13	(7.43)	8.59	(6.79)	-1.54	(4.37)	-3.52***	-.35
Anxiety	.88	(1.01)	.73	(.84)	-.15	(.62)	-2.47*	-.25
PA (high-arousal)	26.56	(7.58)	29.65	(8.18)	3.09	(7.36)	4.13***	.42
NA (high-arousal)	18.14	(8.05)	17.02	(6.95)	-1.11	(5.72)	-1.92	-.19
PA (low-arousal)	9.10	(3.14)	9.81	(2.89)	.72	(3.14)	2.08*	.23
NA (low-arousal)	6.70	(2.74)	6.08	(2.37)	-.62	(2.35)	-2.37*	-.26

* $p < .05$, ** $p < .01$, *** $p < .001$

QOL, quality of life; SD, standard deviation; PA, positive affect; NA, negative affect

the relationship between acculturation and QOL among Korean immigrant cancer survivors [36]. Further work is needed to determine how the specific components of our intervention addressed different aspects of overall QOL.

Depressive and anxiety symptoms were reduced among the JLA program participants from baseline to post-intervention follow-up. This finding is consistent with those from prior studies of CABCS, which found that perceived levels of social support explained the relationship between social constraints (i.e., stigma associated with cancer) and depressive symptoms and that good social support may reduce the impact of cultural-social constraints and depressive symptoms [10, 13, 24]. Additionally, prior studies have shown that social support interventions incorporating informational and emotional support for BCS improve well-being by, for example, reducing depressive symptoms and improving patients' adjustment to cancer [37, 38]. The effectiveness of this type of intervention was replicated in our study as well.

Notably, the JLA intervention was associated with an increase in positive affect (including both high- and low-arousal), and a reduction in low-arousal negative affect but not high-arousal negative affect. Compared to Western cultures, East Asians prefer a dialectical emotional style featuring low-arousal negative and positive affect to emotional extremes [39, 40]. It is possible that, due to emotional suppression to fit cultural norms [41], CABCS' negative emotions and moods may be less reflected in high-arousal affect and more in low-arousal affect. The decreased dullness, sluggishness, and sleepiness participants reported after the JLA intervention may indicate typical improvements in low-arousal negative affect among CABCS.

Finally, the CABCS in our sample are also immigrant minority cancer survivors. This population have particular challenges in their post-treatment adjustment due to the cultural and linguistic barriers they face, which may further exacerbate cancer symptoms and contribute to poor psychological well-being [15]. The JLA, designed to overcome those barriers using the CBPR, demonstrates efficacy for this immigrant population. This intervention and the process of developing the intervention could be a model adapted for other immigrant groups that also experience cultural and linguistic barriers.

Clinical implications

These findings reiterate the urgent need for greater psychosocial interventions targeted at improving QOL and psychological well-being in CABCS. The current study has shown that integrating education, social support (peer mentoring), and culture may be an effective intervention strategy that could potentially be adapted for cancer survivors of other ethnic and cultural groups.

Limitations and future directions

Our study was limited by having only two time points and no control group. Therefore, we cannot draw conclusions regarding any causal or long-term effects of the JLA on participants' health. Future research should include multiple time points to assess participants' QOL and psychological well-being over an extended time and should include a control group. Second, we did not examine the specific underlying mechanisms of the JLA intervention. Future work should examine the intervention components (e.g., education and peer mentoring) to better understand how they improve BCS' well-being. Third, further work is needed to probe for important variables such as acculturation or social support that may potentially affect participant outcomes. Fourth, our sample was largely composed of participants with stage I–III breast cancer and thus, it was unclear whether the results were applicable to metastatic cancer patients. The JLA program was created to help women adjust during the transition from completing treatment to life after treatment. Because stage IV BCS have different needs compared with survivors in the earlier stages, and the interaction among peers may differ between those with early stage and later stage cancer diagnosis, future studies should be conducted to pilot test interventions that are specifically designed for stage IV BCS. Finally, the JLA intervention was designed to address the psychosocial needs of CABCS. Future studies should assess whether the components of the intervention are beneficial for cancer survivors from other cultural and ethnic backgrounds.

Despite these limitations, this intervention was associated with improvement in QOL and psychological well-being in the largely underserved and understudied group of immigrant CABCS, whose prognoses are usually worse than those of their US-born counterparts. Our study suggests that a culturally tailored social support program may be especially beneficial for cancer survivors, especially those from vulnerable groups, such as CABCS, who may face multiple barriers in receiving support.

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Authors' contributions Qian Lu, Alice Loh, Lucy Young, and Carol Wang⁴ contributed to the study conception and design. Data collection was performed by Alice Loh, Lucy Young, and Carol Wang⁴. Data analyses were performed by Lingjun Chen. The manuscript was written by Qian Lu, Lingjun Chen, Lilian J. Shin, Carol Wang^{1,2}, Lenna Dawkins-Moultin, and Qiao Chu. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards (University of Houston IRB protocol number: 10330-EX; The University of Texas MD Anderson Cancer Center IRB protocol number: PA19-0038).

Consent to participate Participants consented to joining the program and completing questionnaires.

Consent for publication The academic investigators did not possess any identifying information about participants. Informed consent for secondary analysis of de-identified data and publication was waived and approved by institution IRB.

Code availability The codes to perform statistical analysis for the current study are available from the corresponding author on reasonable request.

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