

Oregon's *Familias en Acción* Replicates Benefits for Underserved Cancer Co-Survivors  
through *Un Abrazo Para la Familia*

**Running title:** Meeting Co-Survivor Needs in Cancer Care through *Abrazo*

Catherine A. Marshall, PhD, Associate Professor of Research<sup>1</sup>  
Department of Disability and Psychoeducational Studies  
[marshall@email.arizona.edu](mailto:marshall@email.arizona.edu)

Melissa A. Curran, PhD, Associate Professor<sup>1</sup>  
Department of Family Studies and Human Development

Gail Brownmiller, Executive Director and Ambar Solarte, *Abrazo* Program Coordinator  
*Familias en Acción*, Portland, OR

Julie Armin, PhD, Assistant Professor, Research<sup>1</sup>  
Department of Family & Community Medicine

Heidi A. Hamann, PhD, Associate Professor<sup>1</sup>  
Departments of Psychology and Family & Community Medicine

Janice D. Crist, PhD, RN, FNGNA, FAAN, Associate Professor<sup>1</sup>  
College of Nursing

Mika Niemelä, PhD  
Department of Psychiatry, Oulu University Hospital and  
Center for Life Course Health Research, University of Oulu  
Oulu, Finland

Terry A. Badger, PhD, RN, PMHCNS-BC, FAPOS, FAAN, Professor and Chair<sup>1</sup>  
Community and Systems Health Science Division, College of Nursing and  
Professor, Department of Psychiatry

Karen L. Weihs, MD, Professor<sup>1</sup>  
Department of Psychiatry

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<sup>1</sup>The University of Arizona

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## Abstract

**Objective:** Our goal in this study was to determine if we could replicate initial findings when providing the intervention, *Un Abrazo Para La Familia* (“Abrazo”). Abrazo is a community-focused psychoeducational preventive intervention addressing the cancer information and coping needs of low-income, underserved family members of cancer survivors, developed and first implemented in Tucson, Arizona.

**Methods:** We used a pre-intervention and post-intervention evaluation design to assess the effectiveness of replicating the Abrazo intervention with underserved Hispanic/Latino family members facing cancer as co-survivors. We describe lessons learned in an expansion of Abrazo from one region of the US to another.

**Results:** Portland promotoras demonstrated that when the Abrazo intervention is provided via a culturally congruent, accessible format, the significant gains in cancer knowledge and self-efficacy reported by underserved co-survivors can be replicated. This is important because Oregon represents a US region different from Abrazo’s origins in the Southwest.

**Conclusion:** Our replication study provides a useful roadmap for others focusing on the psychosocial needs of Hispanic/Latino co-surviving family members of cancer. A manualized 12-hour training program based on the initial discovery and efficacy work was developed to train promotoras as a part of this study. The manual provides a clear protocol for others to replicate our intervention and evaluation procedures. Abrazo may be particularly important for family-centered care if the family does not have the cancer knowledge or self-confidence needed to fully participate.

## BACKGROUND

The term “co-survivors” designates family members who are not themselves diagnosed with cancer, but who are significantly affected by it.<sup>1</sup> Cancer co-survivors may or may not identify as caregivers,<sup>2</sup> though they may serve in caregiving roles and provide assistance and health-related support. Co-survivors are emotionally and physically affected by the cancer experience.<sup>2</sup> *Un Abrazo Para La Familia* [Embracing the Family] (“Abrazo”) was developed as a psychoeducational preventive intervention<sup>1,3,4</sup> to address current and future needs of co-survivors. Abrazo was developed for low-income, primarily Spanish-speaking families who reported that they 1) needed more information about cancer, 2) were having trouble communicating with oncologists, and 3) experienced considerable stress related to the cancer diagnosis of a loved one and were positioned for future co-survivor depression and family strain.<sup>5</sup> Here, we synthesize our experience with a dissemination initiative of Abrazo in a community setting.

When developing Abrazo, we drew on conceptual frameworks considering culture, social class, and family systems<sup>6-9</sup> understood within an overarching biopsychosocial model.<sup>10-13</sup> Our theoretical approach allows understanding of how the illness of one family member can affect the whole family.<sup>14</sup> Abrazo is delivered using psychoeducational and skill teaching techniques.<sup>3</sup> Skill teaching, or the specific instruction in new behaviors,<sup>15</sup> is associated with best practices for reducing racial and ethnic disparities in accessing health care.<sup>16</sup> Abrazo is a brief (3-hour) intervention presented in the language of choice (Spanish or English) of participants, grounded in culturally-congruent practice<sup>17</sup> and in strength-based approaches to working with families. Abrazo addresses psychosocial domains identified by the Institute of Medicine (IOM)<sup>18</sup> and noted in cancer disparities literature: cancer knowledge, options for cancer treatment, emotional coping, and work and financial impacts. The Abrazo intervention addresses the stress, anxiety, and feelings of helplessness of co-

survivors by working with participants to access cancer information and resources, learn the skills necessary to help their loved one, and negotiate cancer-related systems.<sup>1,3</sup>

The Abrazo curriculum<sup>3</sup> and initial program evaluation research results<sup>1,4</sup> have been reported elsewhere and are summarized here to provide a context for our implementation discussion. Abrazo is provided by *promotoras* [community health workers] trained to deliver the intervention. Participant outcomes include increased cancer knowledge and self-efficacy.<sup>1,3,4</sup> Self-efficacy is defined as confidence in cancer knowledge.<sup>1</sup> Both knowledge of illness and self-efficacy are associated with managing illness-related stress and serve as preventive and protective factors against depression in self-care management and caregiving situations.<sup>19,20</sup>

Of particular concern, and relevant to psychosocial cancer disparities, Hispanics\* are more likely to be diagnosed with late-stage diagnoses than non-Hispanic Whites.<sup>21</sup> Further, cancer is the leading cause of death among Hispanics.<sup>21</sup> Once diagnosed with cancer, Latinos with limited English proficiency may be less likely to understand the disease and treatment options, or share in decision making.<sup>22</sup> Those with lower education levels were more likely to request assistance in understanding their cancer, and those who were uninsured lacked knowledge about tumor stage. Clearly, “patients may benefit from culturally tailored psychoeducational interventions that aim to empower patients to take a more active role and request more information about their disease.” (p. 464) Informing our own previous work, low-income predominately Hispanic co-survivors in one Southwestern city reported that having needed information gave them the power to participate in treatment decision-making.<sup>5</sup>

### **Abrazo Beginnings: Putting the Embrace of Families into Practice**

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\* We use the terms Hispanic and Latino interchangeably unless specified in previous work. We direct the reader to an explanation by the American Cancer Society of these terms “without preference or prejudice.” See American Cancer Society. *Cancer Facts & Figures for Hispanics/Latinos 2015-2017*. American Cancer Society; 2015, p. 1.

Abrazo was developed and tested in partnership with El Rio Community Health Center, a federally qualified health center in Tucson, Arizona; the initial program evaluation was carried out with breast cancer co-survivors. In Year 1, the first author (CM) and one trained promotora were co-facilitators of Abrazo and worked with 60 co-survivors.<sup>1</sup> For Year 2, CM trained two promotoras who then delivered Abrazo. Year 2 served as a pilot test of Abrazo's reproducibility, demonstrating it as an effective program that can be disseminated independent of the developer. In both years, results indicated statistically significant improvements for Abrazo participants in cancer knowledge and self-efficacy.<sup>1,3,4</sup> This successful use of trained promotoras provided the basis for the dissemination initiative in Portland, Oregon.

### **Familias en Acción and Un Abrazo Para la Familia in Oregon**

Based on the initial feasibility and efficacy results, we partnered with a social services nonprofit organization in Portland to disseminate Abrazo. Our community partner, *Familias en Acción* [Families in Action] ("Familias") was founded in 1998 and is the only organization providing health promotion to uninsured and low-income Latinos in Oregon. The mission of Familias is to promote holistic family wellbeing for Latinos through community engagement, education, and advocacy for social change. The Latino population in Oregon experiences significant social and economic barriers to health and is primarily concentrated in the Portland metropolitan region, the state's largest city. The poverty rate in Oregon for Hispanics is 21% (all races) compared to 10% for non-Hispanic Whites.<sup>23</sup>

Familias partnered with CM to initiate training of promotoras to implement Abrazo in response to cancer health disparities and the need for Spanish-language cancer information designed for low-literate survivors and co-survivors. Our overarching program goal was to build skills among underserved Hispanics for living with cancer as a chronic disease including understanding cancer, cancer treatment, patient engagement, psychosocial issues

and support for survivors and co-survivors. Our training goal was to build capacity for promotoras to educate families living with cancer. The objective of the Portland replication was to train 20 promotoras to implement Abrazo in their communities with at least 120 Latino cancer survivors and co-survivors. We developed a training manual<sup>†</sup> based on the initial discovery and efficacy work, and a 12-hour training program to train promotoras as Abrazo facilitators.

We pose three questions based on the Familias implementation and evaluation in Portland:

Q1: What is the effectiveness of the Abrazo intervention in increasing cancer knowledge and self-efficacy among co-survivors for the Portland sample?

Q2: How do the patterns found for Q1 in Portland compare to the patterns found for the Tucson sample?

Q3: What are the lessons learned from the Portland site that can inform future intervention studies carried out in service of underserved populations?

## METHODS

This implementation of Abrazo and evaluation of its effectiveness occurred during 2016-17. We used a pre- and post-intervention evaluation design to determine the effectiveness of the intervention. Familias staff collected the evaluation data.

### Procedure

The intervention was purposely flexible and adapted to family circumstances, both in content and in how classes are delivered (e.g., multiple or single families). The lead author, developer of Abrazo, conducted a two-day manualized program training in Portland on how to facilitate the Abrazo intervention. Familias recruited 17 volunteer promotoras affiliated

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<sup>†</sup> Available from the first author.

with a large medical center, which conducted health outreach via local churches, to participate in the Abrazo training. Promotoras were between 30-50 years old, had low literacy, preferred speaking in Spanish, and were immigrants from Mexico. Familias gave the promotoras \$25 in gas cards to attend the training and an additional \$50 for each completed Abrazo class to cover other expenses (e.g., child care).

● Training involved lectures and discussion regarding critical components of facilitating the intervention following a strength-based focus, as well as experiential practice working in dyads to co-teach the curriculum, which includes skill-teaching via role plays.<sup>3</sup> Of those trained, eight promotoras (47%) delivered Abrazo according to a step-by-step manualized protocol to cancer patients and co-survivors in the Oregon cities of Beaverton, Gresham and Portland. Only those trained promotoras who could match their schedules with the availability of the participants provided the intervention.

## **Participants**

The human subjects protection program of the Oregon Health & Science University and the Knight Cancer Institute determined that the program evaluation by Familias was not human subjects research, was exempt from review by the institutional review board (IRB), and did not require further IRB/research ethics committee oversight. Participant demographics are reported in the Results section.

## **Measures**

### ***Cancer Knowledge***

Participants responded to the 12-item Cancer Knowledge Questionnaire, or (CKQ)<sup>1,24</sup>, as part of the pre-post program evaluation. Sample items include: “Alopecia is a word used to describe loss of appetite” [false] and “The words ‘in situ’ mean the cancer found was non-invasive” [true]. Response choices were *True*, *False*, or *Don’t Know*. CKQ items for the Portland sample were the same as previously reported in the Tucson sample<sup>1,4</sup> with the exception of Item #12: “Women with many risk factors are certain to get breast cancer” was

changed to “Early detection of cancer increases the chances of survival” [true]. For the current analyses, for both pre- and post-, responses were recoded as either correct or incorrect.

### ***Self-Efficacy***

Participants responded to a one-item confidence in cancer knowledge statement from the CKQ:<sup>1,24</sup> “I am confident that my knowledge of cancer and its treatment is enough for me to be able to do what I need to do.” Response is given via a 10-point scale ranging from 1 (*Not true about me*) to 10 (*True about me*).

### **Statistical Analyses**

We used paired sample t-tests to determine if scores improved in the post-test compared to the pre-test. We report sample sizes for each analysis as the sample size varied pre-test to post-test. To test the robustness of results from Q1, we used a series of repeated measures ANOVA tests, first for summed cancer knowledge and next for self-efficacy, each time controlling for one of the demographic variables that may otherwise explain these significant patterns (e.g., insurance, gender, language preference). We used SPSS for all analyses.

## **RESULTS**

### **Participant Demographics**

A total of 126 Latinos participated in the Abrazo intervention in Oregon. A majority [116 (92%)] identified as co-survivors and is the basis for our analyses; see Table 1 for demographic characteristics.

### **Outcomes for Q1, Q2, and Q3**

Regarding Q1, cancer knowledge significantly increased for co-survivors [ $t(115) = 14.19, p < 0.000$ ] from pre-test to post-test, with a pre-test mean of 5.49 (SD= 2.71) versus a post-test mean of 9.22 (SD= 1.31). Self-efficacy, previously defined as confidence in cancer

knowledge,<sup>1</sup> significantly increased for co-survivors [ $t(85) = 10.99, p < 0.000$ ] from pre-test to post-test, with a pre-test mean of 4.78 (SD= 3.05) versus a post-test mean of 8.71 (SD= 1.69). The increase almost twice the score at baseline. We found only one significant interaction of *Gender* and *Cancer Knowledge* ( $F(1,113) = 3.98, p = .048, \eta^2 = .034$  (small to medium effect), with estimated means on the pre-test higher for women (6.04; SE = 0.25) than for men (5.174; SE = .50) with this pattern reversed for the post-test (women = 9.79; SE = .15; men = 10.13; SE = .30).

Regarding Q2, based on the item level analysis of CKQ items, we found that both samples (Arizona<sup>4</sup> and Portland) did not report statistically significant gains from pre- to post on the item about nausea. Second, we did not see pre- to post-gains for the item about early detection; this question was specific to the Portland sample only. (The full table of results from this item analysis is available as part of Supporting Information for this article; see Supplementary Table 1.)

Regarding Q3, the Portland team documented program adaptation and implementation outcomes to include challenges. An Abrazo manual in Spanish was used by promotoras to facilitate the intervention. Adaptation included developing a role play script specific to lung cancer as one way to move beyond a breast cancer focus. In Oregon, most classes were held as two, 1.5 hour meetings. Promotoras encourage participation through the use of interactive materials (e.g. worksheets) and role playing, for example, communicating with an oncologist. Participants reported that the format made them comfortable in expressing their questions and concerns.

Promotoras trained in the Abrazo curriculum provided positive feedback, **e.g.**, that they gained knowledge and appreciated the new information in Spanish about cancer and services. However, coordination with promotoras was challenging due to their schedules and, as church-based volunteers of a large medical center, they were not directly supervised by

Familias. A subset of promotoras who completed the training did not deliver the intervention. Promotoras who planned to hold Abrazo sessions at their churches found scheduling challenges when church activities conflicted. During the winter months, inclement weather forced the cancellation or postponement of some sessions.

## DISCUSSION

Findings from the Oregon replication support Abrazo as a feasible, efficacious, and effective intervention with the potential for local, community-based dissemination. The percentage of questions answered correctly about summed cancer knowledge significantly increased as did ratings of self-efficacy. Further, we found that of the 11 items that were the same in both studies, participants reported significant gains in knowledge on 10 of the items (90%) in both of the samples. These results are important because participating families weigh the balance between burden and benefit in participating in this preventive intervention, the goals of which include demystifying the diagnosis and treatment process in an effort to prevent further family distress and strain.

Cancer burden for low-income Hispanic family members may include factors such as a more severe disease stage of their loved one,<sup>6</sup> as well as subjective burdens of caregiving.<sup>25</sup> We have long understood that “family members may find themselves without adequate access to external social supports, particularly support from health care providers” (p. 179)<sup>26</sup> and may need an intervention specific to their needs. Latino patients being discharged with continued needs may not be evaluated for home health care services if there is a lack of insurance.<sup>27</sup> Latino patients disproportionately report less Medicare and private insurance and are more likely to only have Medicaid or be uninsured than their non-Hispanic White counterparts. For the Portland sample, insurance coverage did not alter the significant findings from the Familias intervention.

We must find ways to measure the benefit of participation against a choice not to participate for various family members. One question: How do we do that for family members who do not yet have a choice or voice in the decision making, such as young children? We have written previously of the need to reach all family members<sup>2</sup> and the impact on children's mental health when their parents have had cancer.<sup>28,29</sup> A challenge noted in Portland was the need to improve the Abrazo intervention to be inclusive regarding the participation of children and adolescents. Others have reported that children are affected by parental cancer,<sup>30</sup> but survive better with better family functioning.<sup>31</sup>

The flexibility of Abrazo allows for implementation in a variety of settings and family interests and needs. Providing the Abrazo intervention in participants' homes is helpful to integrate the family and close friends into the classes, while minimizing scheduling conflicts. Partnering with organizations working with the Latino community ensures participation within a trusted environment. Enabling the promotoras to provide participants with handouts and booklets is essential to the Abrazo curriculum, which requires that materials be read out loud by a family member or the promotora, allowing for varying levels of literacy among participants. Thinking carefully about the structure and purpose of the Abrazo intervention is necessary to proactively address issues related to recruitment, scheduling, and fidelity.

### **Next Steps**

Based on the initial efficacy and pilot implementation of Abrazo in Tucson<sup>1,3,4</sup> and Portland, we have expanded its reach and scope. This opportunity arose in 2017 with a grant from the Merck Foundation as part of a larger effort among University of Arizona Cancer Center (UACC) investigators and community partners to improve patient-centered cancer care for vulnerable and underserved populations in Southern Arizona. The UACC is one of six sites identified as part of The Merck Foundation Alliance to Advance Patient-Centered

Cancer Care, an initiative to increase timely access to high-quality cancer care and reduce disparities for underserved US populations. In addition to an expanded geographical reach, the Southern Arizona Abrazo implementation focuses on training more promotoras and broadening outcome measurement, including an analysis of implementation constructs associated with the RE-AIM framework.<sup>32</sup>

● Earlier efforts<sup>1,3,4</sup> had emphasized the importance of close collaboration with community partners. Our partner for the Southern Arizona expansion is the Arizona Community Health Workers' Association. Our collaboration focuses on promotora training, intervention fidelity, and continuing education. Each of these activities will be evaluated to inform our intervention and help identify “best practice” elements to disseminate.

### **Implications for Future Research**

A full-scale implementation of Abrazo should include children or adolescents who are cancer co-survivors in that they are experiencing parental cancer. Parenthood and parenting are demanding roles when parents have cancer. In particular, fathers experiencing cancer suffer increased levels of anxiety.<sup>33</sup> Parents report struggling with questions like how to be a good parent, how to tell children about their cancer, and how to maintain routines at home at the time of the illness,<sup>34</sup> emphasizing the need to take account of the needs of all members of the family—and importantly children, when treating adult cancer patients in health care.<sup>35</sup> Yet, only 9% of parents reported receiving support in how to cope as parents with children when parental cancer occurs.<sup>33</sup> Latino women with metastatic cancer are often burdened by concerns of their families' grief, in particular, that of their young children who may not be prepared for their mother's death.<sup>36</sup> Indeed, one review of the literature found that among consistent indicators of a child's positive functioning in the context of cancer were parents' psychological well-being and family communication.<sup>37</sup>

## CONCLUSIONS

Our collective experiences in Tucson and Portland will enable others to build on our successes and meet challenges of implementations in different contexts. Abrazo delivery relies upon the adaptiveness of skilled promotoras. The Abrazo training for facilitators further develops the skills of promotoras in responding to families' cancer-related needs and interests. Portland promotoras encouraged family engagement as we did initially in Tucson: conducting the intervention in-home with extended family and friends, providing educational materials for all participants, and partnering with trusted community members in Abrazo delivery. It remains to be seen if such family engagement strategies can be implemented on a larger scale in Southern Arizona—a sizeable region of five counties with considerable rural distances to travel to reach individual homes. Nonetheless, we are encouraged that by providing Abrazo in a region of the US different from its origins in the Southwest, the Portland promotoras demonstrated that underserved co-survivors also find significant gains in cancer knowledge and self-efficacy through the intervention. Alternative delivery methods such as a web-based format could be developed to decrease scheduling barriers, but again taking into account literacy levels of the participants. Successful telephone delivery of cancer-related interventions have been documented<sup>38</sup> and could serve as a model for Abrazo when the logistics of face-to-face delivery pose a problem.

### **Study Limitations**

We used a pre- post-intervention evaluation design to determine the effectiveness of the intervention, both in Tucson and in Portland. With both studies, we attempted to balance measurement and intervention fidelity with the real-world issues of working with low-income, Spanish-speaking populations; however, a randomized control study is needed. Also, data were not collected regarding refusal rates, that is, we do not know how many families were approached to participate but did not. We do know that promotoras in Portland

encountered families who desired the participation of children and adolescents because they were directly affected by the cancer diagnosis of their parent or family member. However, to date, only adults have been invited to participate in Abrazo sessions.

### **Clinical Implications**

Abrazo was designed to reduce the stress of families facing cancer who were already burdened by low-income status by taking the (3-hour) intervention to co-survivors in their homes or other local community settings. Abrazo is delivered by promotoras in the participants' language of choice and is designed to be culturally congruent. This cultural congruence is important given that Latinas may struggle to navigate the healthcare system and deal with language barriers during health care interactions, and that their cancer experience is often shaped by cultural values such as familism,<sup>30</sup> relating to strong identification with one's nuclear and extended family. In the cancer care setting, constructs such as familism are the norm to put the survivors' comfort and needs above the needs of the co-surviving other family members and make treatment decisions at the family rather than individual level.<sup>39,40</sup> While a focus on survivors' comfort is justified, Abrazo focuses on the family supporting the survivor. In a clinical setting, this support may be particularly important for family-centered care if the family does not have the cancer knowledge or self-confidence to fully participate in treatment decision making.<sup>22</sup>

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#### **Conflict of Interest**

The authors declare no conflicts of interest associated with this manuscript.

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Table 1

Co-survivor demographic information ( $N = 116$ )

	N	%
<i>Gender</i>		
Female	92	79.3
Male	23	19.8
Unknown	1	0.9
<i>Age range</i>		
18 to 29	20	17.2
30 to 49	52	44.8
50 to 64	28	24.1
65 or older	15	12.9
Unknown	1	0.9
<i>Health insurance</i>		
Yes	66	56.9
No	50	43.1
<i>Spoken language preference</i>		
English	12	10.3
Spanish	104	89.7
<i>Written language preference</i>		
English	13	11.2
Spanish	103	88.5
<i>Cancer diagnosis, loved one</i>		
Breast	39	33.6
Cervical	7	6.0
Colon	5	4.3
Lung	4	3.4
Other	31	26.7
Unknown	30	25.9