

Co-designing the Family Wellbeing Program to address mental health disparities in a Latino community: Lessons learned

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ABSTRACT

Background: Latino caregivers caring for children under 5 years old who are under resourced, and underserved may be most vulnerable for experiencing mental health problems. Furthermore, Latino families with young children – during the Covid-19 pandemic – were at particular risk for multiple and concurrent stressors and acute adversities.

Objectives: The Family Wellbeing Program (FWP) was designed to strengthen Latino caregivers' mental health and mental wellbeing, and facilitate their access to mental health supports and service providers.

Methods: Using the principles of community-based participatory research, a university research team and staff from a federally qualified health care center co-developed and implemented the FWP. Pre- and post-implementation focus groups with six staff were conducted and data analysis was guided by the RE-AIM framework.

Results: Staff identified implementation challenges related to the pandemic and socioenvironmental factors affecting the reach and participation of Latino families. Staff perceived the program improved caregivers' help-seeking behaviors, yet suggestions for improving the FWP for Latino caregivers were noted. Staff also discussed implementation strategies to sustain future programming.

Conclusions: Implementation strategies along the RE-AIM dimensions were identified to improve the participation of Latino caregivers in future adaptations of the FWP. The implications of this work could show promise for sustaining programs designed to address disparities in mental health among Latino caregivers.

KEYWORDS: Mental Health, Health disparities, Implementation Science, Latino, Community-Based Participatory Research, COVID-19 pandemic, Caregivers

Introduction

One in 20 Latino adults receive services from a mental health provider, compared to 1 in 4 White adults.^{1,2} Disparities in mental health services often exist because Latinos may lack awareness about mental health problems, and/or may feel embarrassed or ashamed (e.g., cultural stigma) to talk about a mental health problem with family, friends, or a medical provider.³⁻⁵ Structural barriers, such as limited English proficiency and limited access to culturally competent care, also contribute to these disparities.² Latinos are also susceptible to significant economic and social challenges that may affect their mental wellbeing.^{6,7} These include structural causes of poverty like low educational attainment, unemployment, and low salaries; systemic issues (i.e., discrimination, immigration); and at the same time Latinos can be prone to unexpected lifestyle adjustments (e.g., food insecurity).^{6,8} Latinos who are under resourced and underserved are most vulnerable for experiencing mental health problems.^{2,6,9} Additionally, the Covid-19 pandemic disproportionately impacted communities of color, with long-term psychological consequences.¹⁰⁻¹² The necessity for persons to quarantine has led to feelings of isolation, depression, and anxiety, and has many grieving the loss of family members and friends.¹³⁻¹⁵ Among Latino caregivers caring for children, school closures and closed childcare centers has resulted in caregivers' attempting to balance financial obligations and full-time childcare.^{16,17} In the midst of the Covid-19 pandemic, the Family Wellbeing Program (FWP) was designed in partnership with community members to strengthen Latino caregivers' mental health and mental wellbeing, and facilitate their access to mental health supports and service providers.

Community Context

Maryvale is the most populous of Phoenix's urban villages making up 5% of the state's population. At the time of this study, this community was home to 230,000 residents who are predominantly Latino (76%) making it a minority-majority community.¹⁸ About 33% of the residents are under 18 years old, and most residents (65%) have less than a high school diploma. Over half of the residents have incomes below \$50,000 placing Maryvale as the 2nd highest ranked community with residents living below the

poverty line in Phoenix.¹⁸ Given the socioeconomic characteristics of the community, and disproportionate effect of the Covid-19 pandemic on communities of color, this community was considered at risk of dealing with undetected and untreated mental health issues.

University-Community Partnership

A partnership between a university (School of Social Work at Arizona State University) and a federally qualified health care center (FQHC; Valleywise Health) was newly established for the purposes of co-developing the FWP. Embedded within the FQHC, which provides comprehensive family care, specialty care and emergency care services to the Maryvale community and surrounding area, is the Family Resource Center (FRC) in which staff provide health information, community referrals, parenting classes, and literacy activities to families. The project team from the university included three academic researchers, two graduate students, and two high school students.

Principles of community-based participatory research (CBPR) guided the study's collaborative framework. CBPR involves researchers and community members working together to address health conditions that disproportionately affect underserved populations for the purpose of reducing health disparities.^{19,20} Following CBPR principles, decision-making is collaborative and inclusive involving active participation of key stakeholders (e.g., caregivers, FRC staff) during program development and implementation. This also ensures that the researchers and the community integrate cultural relevance to the design of an intervention and that the implementation of a program is accessible to the population its designed to reach.²¹ For this project, CBPR was an appropriate method for 1) using community-level data (e.g., US Census data) to identify a health disparity that affected the Maryvale community, 2) systematically engaging key stakeholders to co-learn and co-design an intervention, 3) piloting the intervention with families, and 4) evaluating the intervention with input from the FRC staff.

The project team carried out collaborative activities leveraging the strengths of the partnership including the staff and the Parent Advisory Group (PAG). The PAG was an established entity that informed the FRC activities including this project. Using data from 370 family intakes that were collected

at the FRC between July 2019 and June 2020, the staff identified mental health and mental wellbeing as significant needs in the community. Input from the staff and the PAG informed the design of the FWP. In addition, the FRC program director and the project team co-led the design of the implementation and evaluation of the program, which was informed by the RE-AIM framework.²² RE-AIM is an implementation science framework used to assess the applicability (e.g., relevance, generalizability) of five dimensions (i.e., reach, effectiveness, adoption, implementation, and maintenance) of an intervention. Moreover, the partnership aimed to develop a sustainable solution for improving caregivers' perceptions, specifically caregivers caring for children under 5 years old, about mental wellbeing and increase their access to mental health resources and services, particularly during the Covid-19 pandemic.

Methods

Co-designing the Family Wellbeing Program

Co-designing the FWP centered on how to improve caregivers' perceptions about mental wellbeing for themselves, their children, and their families. The project team met with the PAG one time, and several times with the FRC program director and staff to discuss preliminary ideas for a family program focused on mental health/wellbeing. During this stage of program development, the feedback gathered to inform the program centered on four questions: 1) How does mental health/wellbeing affect parents and how they parent? 2) What resources related to mental health/wellbeing are useful to help parents build their parenting skills and self-efficacy? 3) What challenges (e.g., language, literacy) exist accessing services and supports related to mental health/wellbeing for Latino parents? and 4) What difficulties, if any, do parents have finding and accessing services related to mental health/wellbeing for themselves or their children? Four themes emerged from these discussions: 1) the need for more knowledge about mental health/wellbeing, 2) the need to normalize behaviors related to emotions and feelings, 3) to need to learn about and engage in self-care activities, and 4) the need to engage in help-seeking behaviors to access mental health or behavioral health services. These themes informed the program goals to improve

caregivers' knowledge of mental health and wellbeing, increase caregivers' engagement in self-care activities, and reduce caregivers' stigma towards mental health.

Using this feedback, the project team gathered and selected evidence-based content on mental health/wellbeing that was culturally relevant and appropriate, and could be used for self-directed learning. Four packages were created for the FWP (see Table 1). Simultaneously, the program evaluation was created and integrated with existing programmatic activities (i.e., process of distributing materials to families, process related to check-ins with families). The co-design process involved weekly check-ins between the project team and the FRC director, which entailed reviewing and discussing the content, translating the content to Spanish, integrating the program in existing implementation processes to facilitate program sustainability, and co-designing the caregiver survey used for program evaluation.

A Shared Commitment to Health Equity

Based on both teams' experiences working with the Latino community, six strategies were applied to the FWP to address structural issues (i.e., language barriers, stigma, cultural beliefs, access) contributing to disparities in mental health among Latinos.²³ According to Kreuter et al. (2003) peripheral, evidential, linguistic, constituent-involving, sociocultural strategies, and cultural tailoring are implementation strategies critical for enhancing the cultural appropriateness of interventions for specific communities. Working with a translation team that used translations relevant to the Southwest Latino community, English and Spanish text were incorporated to make the content accessible (i.e., make caregiver comfortable with topic in native language) to bilingual and Spanish-speaking caregivers. Evidential materials (e.g., infographics) were used to elicit awareness about the prevalence of mental health in the Latino population and its effects on wellbeing. Constituents from the PAG reviewed the "evidence" and advised which materials to use for the program. The socioenvironmental context was considered to keep families safe (e.g., distribution of materials, engagement approach) during the Covid-19 pandemic. Cultural tailoring underscored *familismo*, which is a cultural value among Latinos that emphasizes family members' obligations to family wellbeing.²⁴ *Familismo* was integrated into the

program design by aligning the caregiver and child activities by topic based on the Circle of Security Parenting (CoS-P).^{25,26} CoS-P is an eight session, manualized, attachment-based intervention that aims to strengthen parent-child relationships which has repeatedly shown an increase in security of child-parent attachment.²⁶ To address stigma towards mental health, which is commonly perceived in the Latino community, materials were tailored to normalize feelings and emotions (e.g., stress, depression), and reinforce familiar behaviors (e.g., reaching out to friends, family, a family physician, or pediatrician). This was reinforced using monthly wellness checks in which staff directly engaged with caregivers about their mental health and facilitated timely access to mental health resources and/or a referral.

Implementation Activities and the Collaborative Processes

The FWP enrolled 110 families over the course of 12 months. Two cohorts of 55 families each received four activity packages over four months that were prepared and distributed by the staff (see Table 1). Packages included information for caregivers about mental health (e.g., what is mental health? Stress?), worksheets about expressing one's emotions and feelings, activities to engage in self-care, and resources on when and how to access mental health supports or services. The staff also administered monthly wellness checks using non-intrusive, non-diagnostic validated questions either in person or over the phone to assess caregivers' mental wellbeing and connect them to behavioral health resources and/or services. Collaborative decision-making during implementation involved weekly discussions between the FRC program director and staff, and the FRC program director and the project team. These discussions led to sharing ideas and information to work through implementation challenges, and developing and modifying implementation processes to achieve the program goals.

Program Evaluation

The project team obtained institutional review board approval to collect data from staff via videoconferencing (i.e., Zoom; STUDY00014038). A semi-structured question guide was developed along the RE-AIM dimensions to gather information on factors relevant to program implementation based on staff's perceptions. Six FRC staff participated in pre- and post-implementation focus groups conducted

in September 2021 and November 2022. A trained researcher conducted the qualitative focus groups and adhered to the research protocol (e.g., consent) before recording the focus group discussions and collecting demographic information from participants using an online survey. Focus groups were on average 60 minutes in length. Thematic analysis was used to code the focus group transcripts.²⁷ A priori codes created from the dimensions and operationalization of the RE-AIM framework informed the coding strategy resulting in subthemes related to factors of implementation. Two project team members individually reviewed and coded the transcripts. Codes were reviewed between both members and discrepancies were discussed to resolve any disagreements or discrepancies. Identified themes were discussed with the program director for additional feedback and clarification to ensure accurate interpretation of the findings and eliminate potential bias.

Results

All staff self-identified as cisgender female, Hispanic or Latino between 30 and 49 years old ($M = 37.17$ years, $SD = 6.79$ years). All but one FRC staff had a Master's degree. Staff worked between 1 and 15 years at Valleywise Health ($M = 5.17$ years, $SD = 5.64$ years), and worked an average of 4.5 years ($SD = 4.14$ years) at the FRC. Staff had an average of 11.5 years ($SD = 5.82$) working in early childhood education.

Thematic analyses of staff focus groups resulted in key factors related to reach (e.g., participant recruitment, participation), perceived program effectiveness, adoption, program implementation, and sustainability (i.e., maintenance).

Reach

Recruitment was characterized by the staff's bilingualism and biculturalism expertise working with Latino caregivers. Recruitment strategies for the two cohorts differed. For the first cohort, recruitment was based on one-on-one relationships staff had with caregivers or families already engaged with the FRC. The second round of recruitment was affected by social distancing measures that greatly limited staff's ability to recruit in-person or help them establish relationships with caregivers. Given these

limitations, the staff relied on contact lists, social media and their networks to recruit participants. This facilitated staff's ability to engage with many caregivers, expanding their recruitment efforts for the program.

Several factors affected families' participation in the program. Engagement in the program required families to pick up four packages over the course of 4 months, review materials, complete activities and participate in monthly wellness checks with the staff either in-person or over the phone. First, most families were not able to pick up the packages in a timely manner (e.g., first week of the month). Second, families were not able to differentiate the FWP from other activities they were enrolled in at the FRC. Third, the sociocultural context for families changed over the course of the pandemic (e.g., work schedules changed), which affected their participation. Fourth, the end-of-the-year holidays played a role in lower engagement among caregivers in the second cohort.

Effectiveness

Staff perceived caregivers gained new knowledge about mental wellbeing. Staff discussed how caregivers were willing to share their feelings on the call or talked about discussing their emotions with others (e.g., family, friends), and doing activities related to self-care. Although most caregivers did not ask for additional mental health resources or request a referral for services, staff did indicate that they perceived caregivers would seek services if they needed them.

Adoption

Although the program was intended for families in the Maryvale community, the program was expanded to include families across Maricopa County. The FWP was adopted by five FRCs in three different cities (i.e., Chandler, Peoria, Phoenix). Staff perceived the program was easy to adopt because it was in line with existing processes, similar to other programs they implemented, and easy to integrate into their existing workflows.

Implementation

Staff perceived the program was successfully implemented despite recruitment challenges and the onset of the pandemic. Although the materials were distributed at different points-in-time, the materials and the monthly wellness checks were delivered as intended.

Maintenance

Staff perceived program sustainability would require creating short videos for caregivers to access and reference after completing the program. For long-term outcomes, staff recommended creating a support group, either online, in-person, or both, so that caregivers could practice and share their experiences using the materials with group members over time. Funding, specifically to make the suggested changes (e.g., videos, incorporate the lessons learned from this evaluation) would be needed. In the interim, staff acknowledged ways to incorporate the materials in current and future programming.

Lessons Learned

Evaluating the FWP along the RE-AIM dimensions helped elucidate strategies for implementation affecting the participation of Latinos who are an underrepresented group in mental health disparities research.^{28,29} The staff's bilingualism and biculturalism were instrumental in recruiting Latinos. Latinos are a heterogeneous population who oftentimes maintain cultural values (e.g., Spanish language, *familismo*), and building relationships based on these values requires tailoring recruitment strategies.³⁰ However, several lessons were learned when active recruitment was not possible during the Covid-19 pandemic. For example, although the staff had extensive relationships with community providers and the Latino community, efforts to sustain recruitment efforts were limited due to social distancing measures.³⁰ Instead, the staff relied on approaches (e.g., social media, phone calls) which broadened the reach of the program. Although effectively expanding the reach of the FWP, staff also recruited caregivers who did not identify as Hispanic/Latino. Thus, tailoring recruitment strategies to better reach the Latino community were needed. For example, recruiting specific groups on social media sources (e.g., Facebook) is a way to recruit hard-to-reach populations.³¹ This takes time and effort, however, and recruitment through social media shows mixed results.²⁹ Along with recruitment, staff also explained that

Latino caregivers needed a better understanding of the program commitments (e.g., monthly wellness checks), timeline, and evaluation activities (e.g., pre- and post-surveys); and that a short video to explain these expectations could improve program participation. This highlights the need to tailor recruitment strategies that may also align with improving participation.^{29,32}

Systematically assessing barriers staff experienced during implementation provided them ways to apply new strategies to better engage Latinos in the program. Challenges they experienced included ways to better emphasize program uniqueness, issues with caregivers picking up their package at a designated FRC location, the timing of implementation (i.e., year-end holidays), and considering sociocultural factors (i.e., work schedules) that affected participation in the FWP. Modifications to the program design were made in the following ways. Staff were able to support caregivers by mailing them the packages (e.g., when Latino caregivers could not pick them up due to their work schedules) or providing them with different pick-up locations when possible. Effectively, these strategies provided a way for staff to reach caregivers that needed extra support to participate in this program. In line with research, there is a need to consider the timing of implementation (i.e., avoiding holiday periods that delayed implementation), and how to better promote the uniqueness of a program or intervention.^{33,34}

Although the wellness checks allowed for staff to check-in with caregivers (i.e., when caregivers picked up their package or via phone call), and facilitated timely referrals to mental health resources, they experienced several challenges. Caregivers often times confused the FWP with other programs offered at the FRC (i.e., lack of perceived program uniqueness), needed repeated reminders about the materials in the package, and were not always available for a check-in. Accommodations were made to overcome these issues such as calling caregivers in the evening or at more convenient times. Staff also suggested texting a wellness check “link” to caregivers, and/or having caregivers initiate a monthly wellness checks on their own time. These suggestions underscore the need for multiple approaches characterized by requiring staff to be flexible and persistent, which is key to enhancing the participation of underrepresented groups in research.^{29,34} Despite these challenges, staff perceived that the monthly checks

were helpful in confirming their beliefs that the program had a positive impact and benefit on caregivers and their families. Interestingly, staff noted caregivers used the materials with the entire family rather than just with youngest child (i.e., enrolled child). This was an intentional but unconfirmed attribute (i.e., applicability to the family unit) of the program design. Overall, these findings suggest that systematically assessing the challenges of implementation are necessary for appropriately tailoring a program to meet the needs of underserved populations.^{34,35}

Next Steps and Future Directions

Findings based on staff's implementation experiences point to strategies that may inform program adaptation. However, a broader view of implementation consisting of participant level data (i.e., pre- and post-survey data, monthly wellness checks, and focus group data) are needed for an in-depth understanding of the interplay between the implementation process and program outcomes.^{36,37} For next steps, the convergence and the complementarity of these data via triangulation will elaborate and clarify which implementation strategies may be appropriate for participants and their social context.³⁸ These findings will inform future directions for the adaptation of the FWP and the continuation of the program at Valleywise Health.

Conclusion

By systematically assessing the FRC staff's delivery of the FWP, we discerned implementation strategies along the RE-AIM dimensions that could be used to improve the participation of Latino caregivers in future programming. The implications of this work could show promise for sustaining programs designed to address disparities in mental health among Latino caregivers.

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Table 1. Overview of activities by theme for caregivers and child

Month	Theme – Caregiver Activities	Theme – Child Activities
Month 1	<p>Learning about Mental Health and Wellbeing “Mental Health: What it is/what it is not” handout</p> <p>Learning about Emotions/Feelings “Learn to Express your Feelings” worksheet</p> <p>Learning about Self-Care “Learn to Care for Yourself” handout Mindfulness card activity</p> <p>Learning How to Seek Help and Support “Support Can Be...” handout</p>	<p>Quality time together Runaway Bunny (book) Making homemade playdough Bubbles with wand Georgie and the Giant Germ coloring book</p>
Month 2	<p>Learning about Mental Health and Wellbeing “Mental Health affects Everyone” handout “You are Not Alone” handout “5 Things You Can Do about Stress” handout “Things I Cannot Control” handout</p> <p>Learning about Emotions/Feelings “Iceberg Feelings” handout</p> <p>Learning about Self-Care “Types of Self-Care” worksheet Fitness dice Journal for writing exercises</p> <p>Learning How to Seek Help and Support “Talking to Your Doctor” handout “What to Ask Your Doctor” handout</p>	<p>Feelings The Way I Feel (book) Listening to My Body (book) “Feelings” Chart “Feeling masks” craft materials</p>
Month 3	<p>Learning about Mental Health and Wellbeing “Common Myths” handout “Health is Mental Health” worksheet</p> <p>Learning about Emotions/Feelings “Learning to express your feelings” handout “Learning to talk about depression” handout</p> <p>Learning about Self-Care Self-Care Wheel “Self-care plan” worksheet “Setting goals” worksheet</p> <p>Learning How to Seek Help and Support “Identify people that support you” worksheet</p>	<p>Supporting If You’re Happy and You Know It (book) Stuffed animal Child mindfulness cards Sensory scavenger hunt</p>

Month 4	<p>Learning about Mental Health and Wellbeing “I Need Mental Health Support” handout “Am I Stressed or Anxious?” handout “How Body Handles Stress and Anxiety” handout</p> <p>Learning about Emotions/Feelings “Coping with stress” worksheet</p> <p>Learning about Self-Care Journal for writing exercises</p> <p>Learning How to Seek Help and Support “What Can I do About My Mental Health” handout</p>	<p>Curiosity and Exploration Harold and the Purple Crayon (book) Edible finger paints Squiggle game Planting seed kit</p>
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*Bold text indicates a program theme.