Partner Perspectives of Tailoring Technology-Assisted CBT Depression Treatment for Perinatal People Served By Head Start

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ABSTRACT

Background: 10-15% of pregnant and postpartum people experience perinatal depression (PND). Despite high PND prevalence, limited access to treatment remains. Barriers to care are exacerbated in under-resourced, rural communities. Technology-assisted PND treatments can increase access to care; however, treatment tailoring is critical to enhance engagement and improve outcomes.

Objectives: Explore partner perspectives of a technology-assisted cognitive behavioral therapy-based PND treatment to identify tailoring needs and increase treatment acceptability among perinatal clients served by a rural Michigan Head Start program.

Methods: Through a community-university partnership, partners were invited to participate in six focus group sessions. Partners reviewed the technology-assisted treatment and were asked to: 1) share perspectives and reactions, 2) identify gaps in content, 3) provide suggestions for modifications of visual and text-based elements. Research team members facilitated focus groups and took detailed field notes during each session. Thematic analysis of field notes was conducted by two independent coders.

Results: Two core themes were identified: 1) connection between treatment and lived experience and 2) power of positive affirmations and motivational statements. Partners identified the need for the intervention to reflect and incorporate content related to these core themes to be relevant and acceptable for perinatal clients in this community.

Conclusions: Findings are consistent with existing research suggesting treatment tailoring is essential to enhancing engagement. Community-engaged research is critical for meaningful treatment tailoring that maximizes relevance and acceptability for underserved perinatal people.

Study implications suggest the importance of designing technology-assisted treatments that allow for low-cost, efficient tailoring while retaining core, evidence-based content.

KEYWORDS: Community-Based Participatory Research, Social Work, Mental, Rural Health, Mental Health Services, Perinatal Depression, Mental Health Access Disparities

Introduction

Perinatal depression (PND) is common, with 10-15% of pregnant and postpartum Americans experiencing PND.[1] This is a substantial public health concern, as PND has negative consequences for perinatal people and their children.[1] Suicidality in pregnancy and postpartum is rising in the U.S. and mental health concerns contribute to almost one-quarter of maternal deaths.[2,3] Further, people experiencing PND are less likely to take their children to well-child visits, immunize them, or follow recommended safety practices.[4] PND among pregnant and postpartum people is also associated with poor cognitive outcomes for their children and higher rates of emotional and behavioral problems, compared to children of perinatal people who do not experience depression.[1,5,6] The COVID-19 pandemic was associated with decreased mental health screenings, increased isolation, and increased parenting stress, which increases risk for PND and associated negative outcomes.[7–9]

Despite research showing PND as a significant mental health challenge with negative outcomes for perinatal people and their children, it often goes untreated.[10–12] Low-income and rural individuals are less likely than high-income and non-rural individuals to receive PND treatment due to barriers related to availability, accessibility, and acceptability of care.[13] Additionally, these individuals often experience stigma associated with mental health and therefore seek informal mental health care, if any. It is critical to build capacity to deliver evidence-supported depression treatment that is accessible and acceptable to perinatal people in these communities.

Cognitive behavioral therapy (CBT) is an evidence-based depression treatment, shown to be effective when delivered in person as well as via technology-assisted approaches.[14] Technology-assisted CBT (t-CBT) has potential for increasing access to care among low-income

and rural populations,[15] however, research suggests that engagement and adherence with t-CBT presents a challenge.[16,17] Most t-CBT programs are text heavy and academic in nature, inhibiting user engagement and follow-through.[18–21] Additionally, despite consistent evidence suggesting that treatment tailoring is associated with increased treatment engagement, acceptability, and improved outcomes, most t-CBT programs are designed to offer a one-size-fits-all model, making tailoring difficult and substantial in time and cost.[22–25]

Treatment tailoring, critical to enhancing engagement and adherence, requires direct input from community partners using and/or supporting treatment. Community-University partnerships are imperative for guiding treatment tailoring processes that reflect community needs and experiences. Community-based participatory research (CBPR) principles, provide a framework to support community members' and researchers' ability to collaboratively engage with the shared goal of identifying treatment modifications to increase relevance and acceptability for specific client groups, community settings, and contexts.[26,27] This study explored partner perspectives of a t-CBT for PND to identify tailoring and modifications needed to increase treatment engagement and acceptability among clients with PND served by a rural Michigan Head Start program.

This innovative collaboration was guided by the CBPR principles with emphasis on 1) building on strengths and resources within the community; 2) facilitating a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities; 3) integrating and achieving a balance between knowledge generation and intervention for mutual benefit of all partners; and 4) involving systems development using a cyclical and iterative process.[26] Each of these CBPR principles was carefully considered throughout the study's progression and guided the collaboration between

community members and the research team, which resulted in a tailored t-CBT PND treatment program to maximize relevance and acceptability for one population of underserved perinatal people.

Methods

Community-University Partnership

Head Start is a federal program, supporting low-income children and their families to enhance support, social, and cognitive development as well as healthy family systems.[28] Our community partner, a Head Start program located in rural Michigan, identified PND as a common problem experienced by their clients. However, this Head Start program is located within a designated mental health provider shortage area,[29] therefore, their perinatal clients experience limited access to mental health resources. The Head Start program reached out to researchers from the University of Michigan School of Social Work about the possibility of partnering to provide accessible, acceptable treatment to their perinatal clients. This led to a Community-University partnership aimed at building capacity for addressing PND within this Head Start program.

The creation of our partnership structure centered around a shared goal of building on strengths and resources within a community to develop further capacity for supporting perinatal people experiencing PND. The partnership was created to respond to a community-identified need via a community-identified solution for enhancing access to PND treatment via Head Start. Our partnership structure identified the unique strengths and contributions all team members brought to the study and clearly delineated how community (i.e., Head Start clients, family services workers, and administrators) and university partners would actively contribute to each phase of the work. Further, community partners received financial compensation, with 45% of

the research funds supporting this project going to the community. The partnership structure specified that the tailored t-CBT developed as part of this project would be made available to Head Start at no cost with evaluation and technical support from research partners.

The expertise and local knowledge of community partners was centered and emphasized in the tailoring process. Tailoring focused on images, quotes, examples, and program look and feel. Decisions around treatment tailoring were based on community partners' feedback and suggestions, as community partner perspectives were essential to tailor a t-CBT for PND that would be relevant and acceptable to perinatal Head Start clients and could be integrated into standard practice within Head Start settings. Group agreements guiding focus group sessions included a commitment to intentionally considering and valuing all ideas for tailoring as well as a commitment to maintaining core elements of the t-CBT program to ensure fidelity to the evidence-supported treatment.

An iterative process was utilized to ensure intervention changes were reflected accurately based on community partner feedback and suggestions related to treatment tailoring. Sessions were held to review changes that were made based on community partner feedback and obtain additional input on the changes and the need for further modification or refinement before intervention implementation within the Head Start setting.

A key aspect of this partnership, and the aim of this study, was to explore multiple partners' perspectives of an entertaining t-CBT treatment housed on the Entertain Me Well (EMW) online treatment platform. The partnership structure outlined above supported the teams' ability to identify treatment tailoring and content modifications needed to enhance treatment relevance and acceptability for perinatal people served by this rural Head Start program.

Entertain Me Well

Entertain Me Well (EMW) is a t-CBT platform that delivers treatment for depression in an entertaining, flexible way.[17] EMW is delivered through a character-driven storyline, video-based educational content, and tailorable text and image-based educational content. The program consists of eight sessions with an accompanying workbook that includes in-session and between-session activities and exercises.[17] EMW supports quick, easy, and low-cost treatment tailoring while maintaining core CBT principles, concepts, and treatment elements. Preliminary studies utilizing EMW have demonstrated high treatment adherence and efficacy across diverse populations and settings.[30–32]

Study Design

This study used a phenomenological qualitative research approach to understand the lived experiences of Head Start partners and the meaning they assign to those experiences in order to identify treatment tailoring needs. Exploring and understanding partners' lived experiences related to PND directly informed the treatment modifications related to the client group of perinatal people served by Head Start as well as the Head Start delivery setting. CBPR principles directly informed the study design by having a research team comprised of both community and university members. Our phenomenological study design was intentionally selected to emphasize community knowledge, strengths, and resources, and all aspects of our study design centered on creating balance between idea-sharing and maintaining the core of the t-CBT program while engaging in an iterative process with multiple partners.

Participants and Recruitment

Purposive sampling was utilized to invite Head Start clients, administrators, and family service workers (FSWs) who had personal and/or professional experience with PND to participate in a series of focus groups centered on their perspectives of the t-CBT platform. Oral

informed consent was obtained from each participant at the start of each focus group session. A research team member described the purpose of the study, potential risks and benefits, and human subjects' protections. Researchers explained that participation was voluntary, participants did not have to answer any questions that they did not feel comfortable answering, and that they could stop participation at any time without impact on their services and/or employment with Head Start. Head Start client partners received $50 incentives for each focus group session they attended. The Head Start site as a whole received grant funding for their participation at the organizational level. This study met the University of Michigan's Institutional Review Board (IRB) guidelines[33] for non-regulated status and was exempt from ongoing IRB review as long as the study remained within the reported scope.

Focus Group Sessions

Participants were invited to attend six focus group sessions held between June and October 2022. Focus groups were conducted via Zoom and lasted 60-90 minutes. Focus group sessions were not recorded, however, master's and doctoral-level social work researchers facilitated all focus group sessions and took detailed field notes. The decision not to record focus group sessions was made by the community-university partners given concerns about confidentiality within the context of a small, rural community.

Partners first reviewed the t-CBT housed on the EMW platform and then were asked to: 1) share their perspective of and reactions to the program; 2) identify gaps in content; and 3) provide feedback on visual and text-based program elements. During focus group sessions, researchers facilitated discussions on each program element (e.g., videos, text, images, quotes, examples) to understand participants' perspectives, preferences, and suggestions related to tailoring required to address the lived experiences of this perinatal population. As each treatment

element was presented, focus group participants were asked to specifically consider whether: 1) images accurately reflected their experiences, realities, and community context and 2) text-based content applied to their lived experiences during the perinatal period and with PND (clients, family advocates) or supporting people experiencing PND during the perinatal period (staff, administrators). The team engaged in an iterative process to tailor each panel based on partner feedback. See Table 1 for examples.

Analysis Plan

Thematic analysis of field notes was conducted by two independent coders, following Strauss and Corbin's (1990) approach.[34] Independent coders were master's and doctoral-level social workers. The coding process began with line-by-line, open coding of field notes, followed by relating open coded passages to form axial codes, then further categorizing, identifying core codes with broad applicability. Once the coding process was completed, member checking occurred, presenting thematic analyses to community partners for additional feedback before platform changes were made. After platform changes were made, community partners reviewed the tailored content and provided feedback to ensure an equitable, iterative process and verify that changes adequately reflected their community's specific needs related to both the experiences of perinatal people with depression and delivery in the Head Start setting.

Results

Two administrators, six FSWs and three Head Start clients participated in focus group sessions. Each session had six partners present: three Head Start clients, two administrators, and one FSW. All three client partners participated in five of the six focus group sessions. One session included two client participants. Thematic analysis of field notes resulted in two core themes: 1) Connection between treatment and lived experience and 2) Power of positive

affirmations and motivational statements. Table 1 shows examples comparing original content to tailored content based on these two core themes.

Connection Between Treatment and Lived Experience

Partners discussed the importance of their unique experiences reflected in the platform. They shared aspects of their lived experiences that they wanted to see represented through text, images, quotes, and examples, including their realities as parents living in a low-resourced, rural community. Partners also identified the need to integrate content specific to experiencing depression during pregnancy, the postpartum period, or when parenting young children. They shared the importance of normalizing PND and validating perinatal people's depressive symptoms, rather than dismissing them. Additionally, partners shared that perinatal people parenting young children who experience depression often have a hard time doing things for themselves and asking for help, therefore, participants emphasized the importance of offering examples, images, and text focused on self-care.

Finally, as Head Start serves families with a range of structures and environments, partners felt that the platform should provide diverse reflections of what family looks like. For example, partners identified the importance of family structures reflecting one-parent and two-parent households, as not every family that Head Start serves has two caregivers. They also identified the need to exemplify diverse family structures, specifically with representation of multigenerational families and families parenting multiple children at different developmental stages. One specific example they gave was for the treatment program to showcase examples of parents caring for multiple young children and how that experience can be overwhelming and exacerbate thinking and behaviors that lead to feeling down and depressed.

Power of Positive Affirmations and Motivational Statements

Partners identified the need to incorporate positive affirmations and motivational statements as key elements throughout the platform due to them being powerful tools to enhance engagement and provide support. Partners connected the importance of affirmations and motivational statements to the challenges perinatal people may experience in asking for help and prioritizing their own needs, and they expressed strong preferences for including positive affirmations across all treatment sessions.

For example, participants indicated that positive affirmations could be used to encourage and remind clients to 1) give themselves credit for accomplishments; 2) recognize their value as a person with multiple identities beyond being a parent; and 3) prioritize their own mental health needs and self-care. Partners provided examples of challenges individuals with PND experience in their communities, including feelings of inadequacy and isolation, as well as a loss of sense of self. Partners also viewed positive affirmations as a helpful tool to support empowerment, normalization of PND symptoms and experiences, and treatment engagement.

Motivational statements were also identified in empowering participants to address their needs and engage with treatment, even when it is difficult. Partners felt that incorporating motivational statements throughout the treatment provides validation and emphasizes the importance of individuals addressing and prioritizing their own needs. Partners acknowledged the difficulty of adhering to a treatment program while pregnant and/or parenting young children and shared that they viewed motivational statements as powerful tools to enhance treatment adherence and follow-through by reminding clients that they were making progress and that by engaging in treatment, they were prioritizing their own needs and the needs of their children.

Discussion

Findings from this study provide critical insights into treatment preferences and needs of perinatal Head Start clients with PND living in this low-resourced, rural community. Depression treatment engagement among perinatal clients is low across a range of settings but it is particularly a challenge in rural areas.[35,36] Although t-CBT is effective for PND and has potential to reduce a myriad of barriers to care, existing literature suggests content modifications, tailored to both setting and psychosocial challenges specific to the perinatal period, are necessary to engage this population effectively.[36]

This study reiterates the importance of designing technology-assisted interventions that allow for low-cost, efficient tailoring, as participants consistently shared their preference for treatment that aligned with their lived experiences. This is also consistent with existing literature suggesting that intentional treatment tailoring driven by community input maximizes intervention acceptability and feasibility.[23–25,27,30–32,37] Treatment tailoring that incorporates community preference and feedback while retaining core elements of evidence supported treatment modalities offers a promising solution for bridging the gap in accessing mental health care.

This study's findings also align with O'Mahen and colleagues' study indicating that internalization of the "myths of motherhood," self-sacrifice, and managing social support are key elements to incorporate within CBT treatment for PND.[36] Furthering this concept, rural contexts specifically often hold more traditional values regarding gender roles that model self-sacrifice as a part of being a parent. Participants in this rural context shared that sentiment and emphasized challenges they faced prioritizing their own needs and engaging in self-care. Further, participants discussed the importance and need to normalize asking for help during the perinatal period and their desire to see content that differentiated PND from "normal" feelings and experiences.

Additionally, there is a small body of research suggesting intentional integration of positive affirmations within PND treatment is associated with improved mood and anxiety among perinatal people.[35,38–41] Participants' recommendation to include positive affirmations and motivational statements aligns with existing work,[35,40] where participants also shared their desire to have positive affirmations included in PND treatment.

Although this work led to important elements with treatment tailoring and a customized intervention for our rural Head Start partner site, there are limitations of the study that need to be acknowledged. Because treatment tailoring was only identified in this one, small, rural community, tailoring identified for this context might not have broad applicability across other low resourced communities, which further reinforces the need for additional t-CBT platforms that allow for quick, easy, low-cost tailoring. Due to the small sample size and variability in the number of focus group sessions attended by participants, there is potential that certain themes or concepts could have been over emphasized by individual participants raising the same theme across different sessions. In future iterations of tailoring, having a more diverse attendance at focus groups and limiting the number of sessions each partner attends could give more accurate results. Additionally, focus group sessions were not recorded, therefore transcription coding for analysis was not feasible.

Despite these limitations and barriers, treatment tailoring that was identified by this group of partners was imperative to increasing relevance and acceptability of the program. This study reinforces research indicating the importance of treatment tailoring, as partners identified key changes to improve treatment acceptability and relatability. This work also provides a model for community-engaged treatment tailoring that centers the voices and experiences of potential treatment end users as well as providers who would support treatment. Finally, results suggest

the need for t-CBT that supports low-cost tailoring for client groups, settings, and contexts while retaining core, evidence-based content.

Future research testing the tailored treatment among perinatal Head Start clients is needed and has begun as next steps in this community-university partnership. Our community-university team has continued collaborating to implement our tailored t-CBT for PND within our partner Head Start site. Community-university partners collectively developed a training for FSWs, procedures for introducing clients to the treatment program and support them as they complete program, and an evaluation plan to assess the impact of the treatment program on clients' depressive symptoms. FSWs have started to deliver and support the tailored intervention with Head Start clients and our evaluation is in progress. Finally, we have continued engaging in an iterative process with community partners by further refining the intervention as we gain additional feedback from FSWs and clients about their experience using the program.

The methods and results of this study are particularly novel and important, as individuals in rural communities and those in economically disadvantaged areas have been underrepresented and largely ignored in mental health intervention and implementation research. Our work demonstrates the importance of including and centering community voices to increase access to PND treatment and ensure intervention acceptability in rural, economically disadvantaged communities.

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TAILORING T-CBT FOR PERINATAL DEPRESSION

Table 1

Examples of new and tailored panels based on partner feedback.

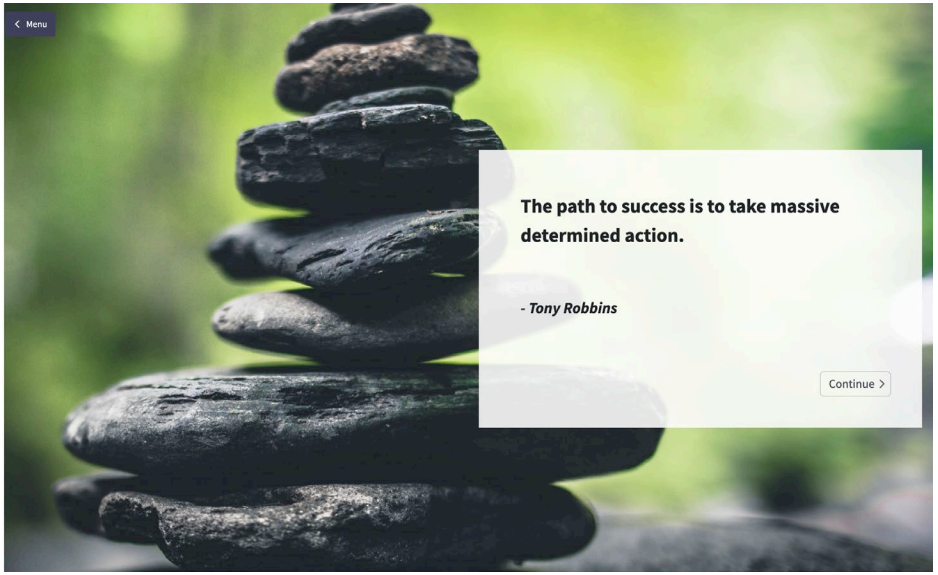
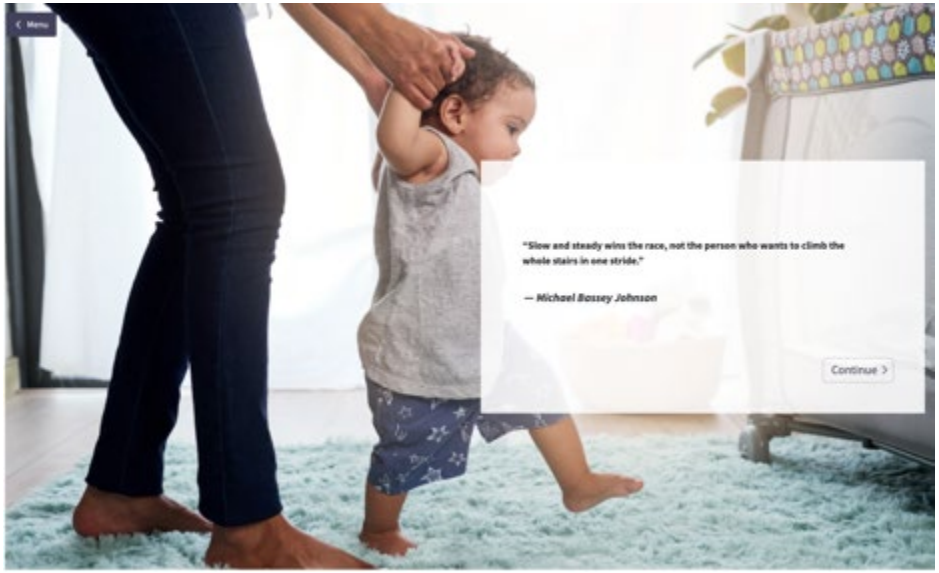
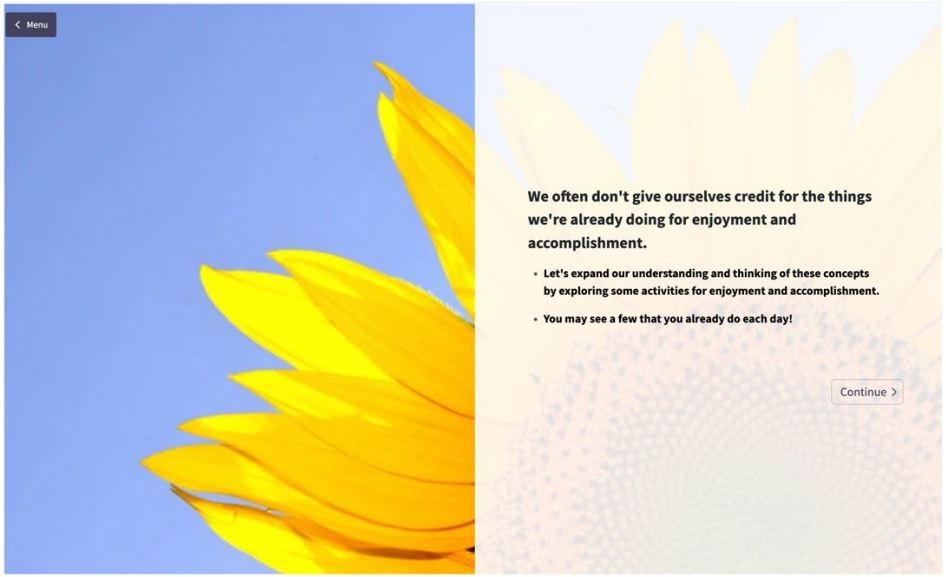
Original Panel	Tailored Panel
	
	

Table 1 (*continued)*
Examples of new and tailored panels based on partner feedback.

Original Panel	Tailored Panel
	
	

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Examples of new and tailored panels based on partner feedback.

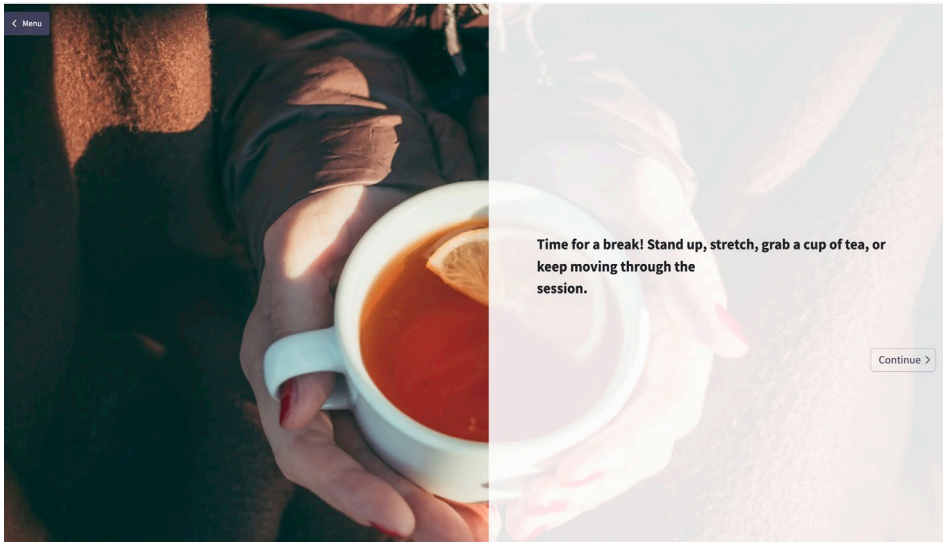
Original Panel	Tailored Panel
	
	

Table 1 (*continued)*
Examples of new and tailored panels based on partner feedback.

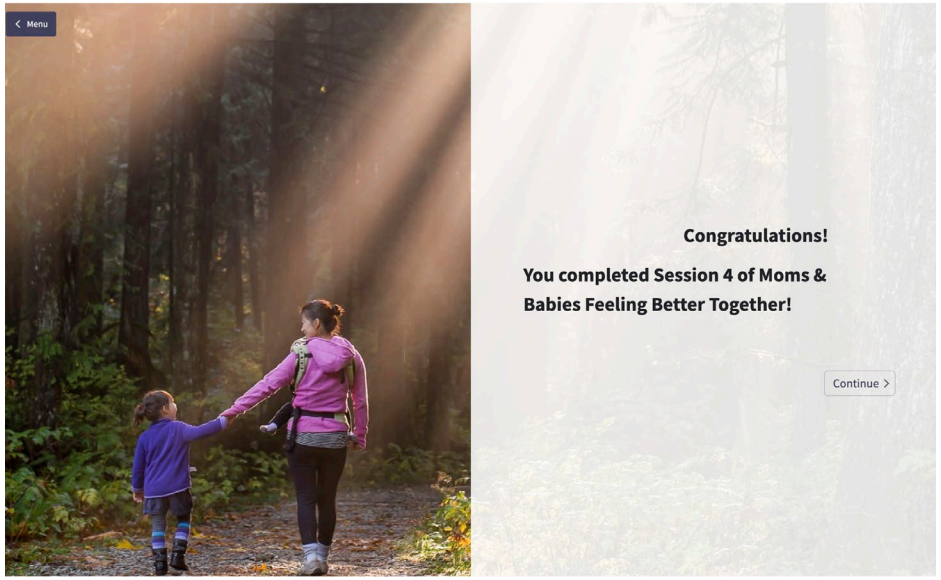
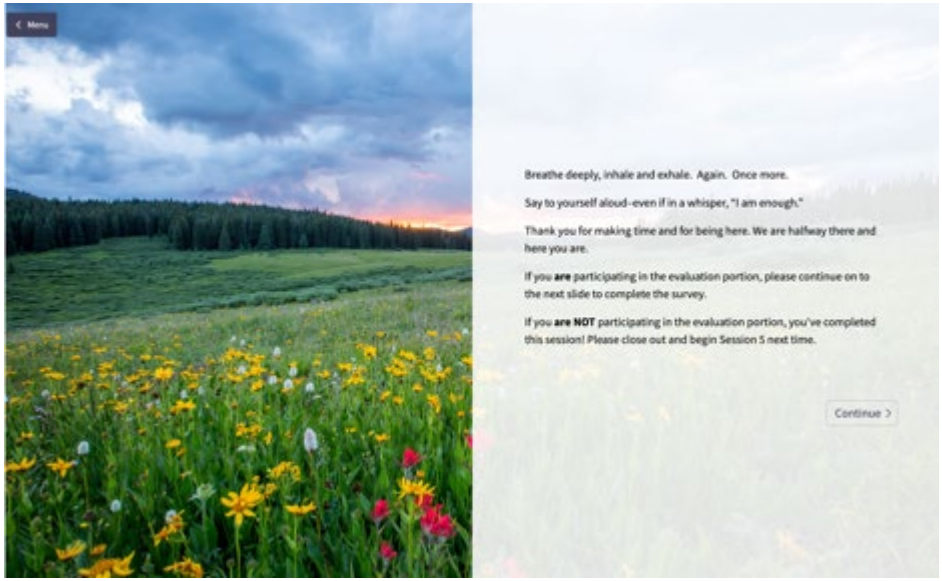
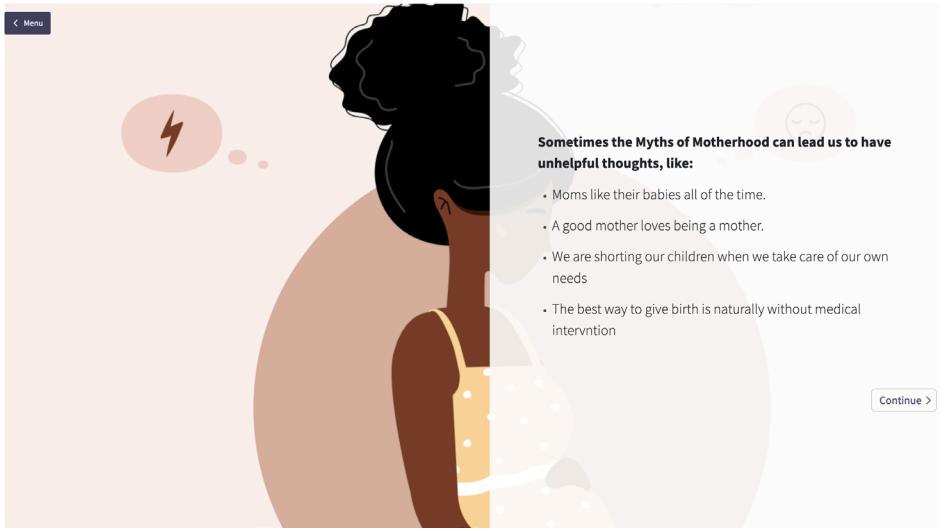
Original Panel	Tailored Panel
	
	

Table 1 (*continued)*
Examples of new and tailored panels based on partner feedback.

Original Panel	Tailored Panel