Title
Supporting Low Income Women Experiencing Perinatal Depression: A Qualitative Study

Author
Murthy, Snehal G

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Supporting Low Income Women Experiencing Perinatal Depression: A Qualitative Study

By

Snehal Ghatare Murthy

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Committee in charge:
Professor Cheri Pies, Chair
Professor Melanie Thomas
Professor Colette Auerswald
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In the US, about 1 in 5 women experience perinatal depression, making it one of the most common complications during pregnancy and postpartum (Gress-Smith, Luecken, Lemery-Chalfant, & Howe, 2012). However, the burden of perinatal depression is greatest among low-income women (Gavin et al., 2005; Hobfoll, Ritter, Lavin, Hulsizer, & Cameron, 1995; Segre, O'Hara, Arndt, & Stuart, 2007). In addition to pregnancy and parenting-related stress, such as low maternal self-esteem and childcare stress, women experiencing poverty are exceptionally vulnerable to depression (Beck, 2001; Belle & Doucet, 2003). Psychosocial factors including low socioeconomic status, inadequate social support, chronic stress, and negative life events are associated with increased rates of perinatal depression (Beck, 2001). In fact, one study found that depression rates in both homeless and housed low-income mothers are about twice as high as in the general population of women (Bassuk, Buckner, Perloff, & Bassuk, 1998).

Untreated depression poses a health risk to mothers, their infants, and society overall. In the US, suicides from perinatal depression exceed the number of deaths from other obstetric medical conditions, including hemorrhage and hypertensive disorders (Gynecologists, 2015; T. Pearlstein, Howard, Salisbury, & Zlotnick, 2009). Maternal depression may also diminish a mother's attachment and bonding with her infant, resulting in increased risk for behavioral, cognitive, and social impairments among children (Gress-Smith et al., 2012). Perinatal depression is associated with missed pediatric outpatient appointments and increased pediatric emergency service utilization (Flynn, Davis, Marcus, Cunningham, & Blow, 2004).

Despite the effectiveness of a variety of both pharmacological and non-pharmacological treatment options, only 1 in 4 women diagnosed with maternal depression actually attends their first mental health appointment (Byatt, Levin, Ziedonis, Moore Simas, & Allison, 2015). Given the prevalence and associated adverse outcomes, perinatal depression among low-income women is a significant and under-recognized public health issue. Effective prevention, screening, and treatment for perinatal depression are crucial in improving maternal and child health (Siu et al., 2016). Because of the stigma associated with seeking mental health services as well as the limitations of standard approaches to treating maternal depression, innovative interventions with community partners are needed.

A San Francisco Bay Area community-based organization (CBO) partnered with a safety-net hospital and academic center to address the prevalence and consequences of perinatal depression among low-income women utilizing their services. We employed qualitative methods during the needs assessment phase of our partnership to 1) identify sources of distress for pregnant and postpartum women, 2) identify barriers in recovering from perinatal depression, and 3) identify examples of successful support for perinatal depression. We engaged directly with our community partners (both providers and clients) to gather their perspectives on how to better address the intersection of basic needs and psychological distress that often accompany perinatal depression, especially among socially and financially disadvantaged women.

Methods

We conducted focus groups with pregnant and postpartum women, as well as their providers in our partner CBO. We chose focus groups as the most appropriate methodology to explore their varying and shared explanatory model of the risks for perinatal depression and experiences securing access to care. Because perinatal depression can be stigmatizing topic, we felt that a focus group setting would allow participants to share more than they would in one-on-one interviews. The group discussion would also allow collective brainstorming of solutions and possible interventions (Kitzinger, 1995).

Study Setting

The CBO in this study is a social services organization that serves low-income and homeless families in a dense, urban setting. Their mission is to end childhood poverty with supportive, nonjudgmental case management to empower families, especially mothers, to support their children's success and healthy development. This CBO is unique in being one of the first agencies in the San Francisco Bay Area to hire previous clients to become case managers and community health workers. About half of the pregnant and postpartum clients identify as Hispanic or Latino, and a quarter identify as Black. About one third of the client base speaks Spanish as their primary language.

Case managers and community health workers provide information and resources for stable housing and economic self-sufficiency. Additional case managers are available for support regarding interpersonal violence and Child Protective Services (CPS) cases. Wellness services, like prenatal classes, mother-baby bonding activities, support groups, and parenting classes, are provided to empower families to support the healthy development of their children. Some on-site psychological therapy is available as well.

Data Collection

We conducted a total of eight focus groups, four with CBO providers and four with CBO clients. This study was approved by the Institutional Review Board at the University of California, San Francisco.

Providers were invited to participate in audio-recorded focus groups during team meetings. We recruited community health workers, case managers, and therapists from our partner CBO. Providers verbally provided consent and demographic information about age and race/ethnicity. Each provider focus group was conducted in English for one hour and was co-facilitated by two research team members.

CBO clients were primarily recruited to focus groups through wellness services. Flyers were also posted on organization billboards and handed to clients in case management meetings. Women were informed that the focus group topics were 1) "stressful experiences for pregnant women and new moms," and 2) "how to improve services for pregnant women and new moms." We used generic terms like *stress* and *anxiety* rather than *depression* to reduce the stigma of participating in focus groups and to recruit women across the spectrum of psychological distress. Prior research with at-risk, low-income women has shown that women prefer to use abstract terminology to describe their own distress rather than *depression* (Bilszta, Ericksen, Buist, & Milgrom, 2010; Guy, Sterling, Walker, & Harrison, 2014). Lunch, childcare, and a $50 Visa gift card were incentives for participation. Eligible participants for our study were pregnant or the mother of a child 0-3 years of age, at least 18 years old, and able to read and write in English or Spanish to complete self-administered surveys.

Four focus groups were conducted with clients, two in English and two in Spanish. Client focus groups were held for 1.5 hours at the CBO in spaces utilized for health classes and support groups. Study personnel and CBO staff co-facilitated these groups. After providing verbal consent to be audio-recorded, clients completed a brief survey collecting demographic information including age, race/ethnicity, birth location (inside or outside of US), marital status, pregnancy status, if they were first time mother, and if they ever received mental health care. They also completed the Edinburgh Depression Scale (EDS), a well-validated 10-item screening tool for perinatal depressive symptoms (Bergink et al., 2011; Yawn et al., 2009). Scores on the EDS range from 0 to 30, with a score of 10 or greater indicating strong diagnostic evidence of perinatal depression (Gibson, McKenzie-Mcharg, Shakespeare, Price, & Gray, 2009).

Participants

A total of 26 CBO providers participated. Providers included 9 community health workers, 2 therapists, and 15 case managers. Participants identified as Latina (54%, n=14), African American (19%, n=5), White (19%, n=5), and Asian or Pacific Islander (8%, n=2). About 54% of providers were 25-35 years old (n=14), and 46% were older than 35 years (n=12).

Table 1 shows the demographic characteristics of pregnant and postpartum women participating in the focus groups. There were 39 client participants (Spanish-speaking participants n=24, English-speaking participants n=15). However, participants in the Spanish-speaking groups did not all complete the surveys in their entirety. Percentages shown in Table 1 are based on number of survey respondents.

All participants who completed the survey in the Spanish-speaking focus groups identified as Hispanic or Latina, and 18 of the 19 participants were born outside of the US. In contrast, English-speaking participants identified as African American, Asian or Pacific Islander, or white. While participants in the Spanish-speaking focus group were predominantly married (71%, n=15), English-speaking participants were mostly single (73%, n=11). Of the 34 survey respondents, 58% were pregnant (n=20), 44% were first time mothers (n=15), and 92% have received prenatal care (n=33). 35% had previously received mental health services (n=12).

Of the 34 pregnant and postpartum women who completed the EDS, 40% participants scored 10 or greater (n=14), indicating that they are at increased risk of having depression. Figure 3 depicts the distribution of EDS scores in the Spanish and English-speaking focus groups. As shown in in the figure, 47% of English-speaking participants scored 10 or higher on the EDS, versus 29% among Spanish-speaking participants.

Focus Group Topics

The aim of the provider focus groups was to understand the social service provider perspective in supporting pregnant and postpartum women experiencing social disadvantage and at high risk for perinatal depression. Provider focus group topics are illustrated in Figure 1.

The aim of the client focus groups was to understand the client experiences of perinatal distress and experiences in receiving professional and personal support for stress and anxiety. Client focus group topics are shown in Figure 2. Many of the client focus group questions were based on input from CBO providers and administrators. CBO providers were most interested in women's experiences of stress and depression, parenting expectations, experiences receiving treatment and support, barriers in seeking care, and preferred treatment options.

Data Analysis

All focus groups were audio-recorded and transcribed by a third-party professional service. Spanish language focus groups were translated to English before coding and analysis.

We used a grounded theory approach to qualitative research in our data collection and analysis (Charmaz, 2006; Saldana, 2016). The unit of analysis was the focus group transcript. Focus group transcripts were analyzed by two study personnel, the first author and another coder (GH for provider focus groups, and AB for client focus groups). We conducted three rounds of coding in total.

In the first round of coding, we used line-by-line, process coding, and in-vivo coding. Process coding emphasizes gerunds, such as "sacrificing physical needs for her child" or "paying more for childcare." This first cycle was conducted manually on only one transcript for each set of focus groups (provider and client). Each coder created a list of emerging themes. Based on these themes, both coders met and created a common list of codes and subcodes. The first author created a codebook with the discussed codes, definitions, and examples. The partnering coder modified the codebook and provided feedback. Both coders collaborated and edited the codebook until a consensus was reached. Separate codebooks were developed for the provider and client focus groups.

In the second round of coding, both coders coded all focus group transcripts with the codes generated in round one using MAXQDA software (http://www.maxqda.com). We continued to note emerging concepts that were not included in the original codebook. Then, both coders met again to determine intercoder agreement. We discussed coded segments until consensus was reached. Based on emerging themes from the second round, more codes were added to the codebook.

In the third round, both coders returned the data to recode all of the focus group transcripts with the final codebook. Coders then met to determine intercoder agreement for this final round of coding.

In order to provide immediate feedback to the CBO, we shared raw code reports of the provider focus groups shortly after those groups were conducted. We created concept maps of the codes from the client and provider focus groups. We iteratively composed memos to reflect on reports and our discussions of them. Based on these memos, we determined frameworks to analyze these data and answer the three research questions. We gave oral presentations of these data to CBO providers to validate the identified patterns and frameworks.

Results

Overview of Findings

Three main themes emerged in our data analysis: vulnerability factors for perinatal distress, barriers to recovery, and facilitators to recovery. Figure 2 summarizes our themes and subthemes.

Vulnerability Factors

Providers suggested that multiple stressors synergistically contributed to perinatal distress. One provider described her understanding of mental health:

> "[For] mental health, what I hear people say all the time [is that a] woman is stressed, independent of what the cause is. It could be homelessness, it could be lack of resources. But when they get to us, most of the time it's 'I'm stressed,' [or] 'I'm having difficulty navigating the system, some difficulty in parenting…' There are a lot of people with primary anxiety and depression or PTSD, but then there is a large group of people that are just having a really hard time with things."

This provider identified three key sources of stress in pregnancy and early parenting. Some women may be vulnerable because of an underlying psychiatric diagnosis, such as anxiety, depression, or PTSD. Others are experiencing stress from the new experiences of pregnancy and parenting. Finally, the financial stress and challenges to seeking help affect the mental health of these women.

Clients identified a range of stressors in their lives. These included financial stress, challenges to working in the perinatal period, housing instability, past trauma, and inadequate social support. In addition to these psychosocial stressors, women cited stressors specific to being pregnant and parenting. These included the fear of not being a good mother, physical and emotional changes, being a new mother, trauma from previous miscarriages, and changing relationships with partners, family, and friends.

Women discussed the interconnected impact of psychosocial and perinatal stressors on their mental health. For example, this client feels afraid that she has forgotten how to care for her child, but also feels limited in providing the best for her child's future because of her socioeconomic status and unpredictable negative events:

> "This is my second child. I am scared as hell…Will I be able to change the diaper still? If he is crying, am I going to know [if] he wants a bottle or maybe the baby wants me to pick [him up]? And the high expectations. Yes, we do want our kids to do this and be that…We do not want them to see what we have seen growing up. We cannot predict, things happen so unexpectedly in our life every day. It is hard to just be like 'When I turn 18, I am going to college. Then after college, I am going to this place and I am going to get a full-time job'… When they always be like 'What are your goals?' I can tell you my goals. I can write on this paper. I can try to reach them goals but who is to say I am going to get there in five years?" (English-speaking participant)

Financial Stress & Challenges Working

The financial stress described by women included paying for childcare, diapers and formula, and the need to continue work. Many women felt the pressure to continue working to make ends meet, but found it difficult to do so while pregnant or with young children. Other women described the effects of hormones during and after pregnancy that affected their mood and concentration. One woman recounts her challenges in working while being a new parent:

> "Because I want to work and I cannot because, it is like I have to separate work from home, keep home at home and work at work. I cannot do it. I [feel] too emotional during the day. So, usually I cannot stay focused." (English-speaking participant)

For many women, financial stress also means that they cannot prioritize caring for their mental health because they need to make ends meet. One English-speaking participant said, "I do not really use any services [at this CBO] because I do not have the time as I am working full-time. Well, I was working full-time but there are other services [and] needs that need to be met." As a community health worker explained, "[Mothers] don't prioritize [the need for therapy] because they are more focused [on] what they are going to eat for that day or [where] they [will] sleep, so, it's not their priority."

Financial stress also served as a barrier for accessing care and working towards recovery. This community health worker describes how financial stability can become a competing priority with leaving an abusive relationship.

> "Some of the clients, they tend to stay in the domestic violence relationship because they don't have money to pay for their rent or for food and that makes an impact in their mental health because they feel stuck."

Homelessness & Housing Instability

Another key stressor was housing instability, a stressor described more often by participants in the English-speaking focus groups. One woman described the impact of stable housing on her mental health:

> "If you have a roof over your head and you have a safe place to go, then pretty much things in life are miniscule in scope in terms of not being so difficult or maybe worrisome." (English-speaking participant)

Another client revealed that her family would not let her stay at home with them when she became pregnant. She described the physical and psychological manifestations of homelessness and inadequate social support.

> "When you get in a rough situation as far as becoming homeless or having to stay with other people, it's like who do I have to run to? Who can I tell my story? Or, how do I feel right now? …I don't feel normal. I don't feel okay. I feel like something is going on in my body. What is going on? Who do I have to talk to? …I don't have anyone to express my feelings or express what I'm going through right now." (English-speaking participant)

One mother described the difficult events in her life that contributed to her homelessness and subsequent trauma:

> "I had visions of a completely a different life than what I dealt. Before my pregnancy, I was homeless…for almost three years. I had gone through five different miscarriages. I was diagnosed with PTSD. During that time, I had a severe drug addiction. As a child, I was on a lot of medications. When I got older, and my grandparents passed away [and] I lost insurance. The medications that were keeping me balanced were taken away. I had to find a way to self-heal. It was actually the [Homeless Outreach Team] that came around at the tents, a year and a half ago, and helped me. Because I was pregnant, they got me into shelter. I have now been clean a year and a half. I moved into a transitional housing. I expected pregnancy to be like this overall wonderful thing. But like, it really saved my life." (English-speaking participant)

Challenging experiences of homelessness and resulting miscarriages contributed to this client's distress. To cope, she turned to methamphetamine as a way to "self-heal" when she was uninsured and lost access to her medications. However, being placed into transitional housing provided her with the opportunity to address her addiction.

Inadequate Social Support

Women highlighted the inadequacy of their social support in facing the new experiences of pregnancy and parenting. Most Spanish-speaking participants had immigrated from outside of the US. Many participants described their distress resulting from being far away from family and friends. This participant explained how her loneliness affected how she took care of herself and her son:

> "I don't have family here. I cried every day. I cried all the time. I mean, I didn't eat because I was crying. So, it was very hard, because instead of moving forward you get down and down and down… You think, 'Well, what am I doing with my life? This isn't living!' Instead of getting past it, you sink lower. You'll hurt yourself. And not just yourself, but it might also rub on your child because he's with you all the time." (Spanish-speaking participant)

On the other hand, participants in the English-speaking focus groups highlighted different reasons for inadequate social support than the Spanish-speaking participants. These included incarceration or separation from their partners, and not receiving help from family and friends. This mother described feeling alone in taking her of premature child:

> "Everybody wanted to [take care of] the baby…[but] when she came out, she was premature. A lot of people like distanced themselves from her…because she was going to die because she was on a ventilator…. Her dad was in jail at the time so he could not help. So, I just did not have no support…with me being a first time mom." (English-speaking participant)

However, proximity to family and friends did not always translate to adequate support. One Spanish-speaking participant describes living with her mother in law:

> "His mom says things all the time: that we don't let her sleep, that nobody ever does anything for her… She loves to fight with me. She [tells me] that I have to get [my daughter] out because she makes a lot of noise, to shut her up. I tell her, 'I can't put tape on the girl's mouth. She's little. She has to yell, she has to cry, she has to talk.' [My husband] never says anything… I live there, [but] I don't live well. I have to be quiet. I have to limit myself to everything that I have to do and, honestly, that isn't very good." (Spanish-speaking participant)

Barriers to Recovery

When asked about barriers in achieving recovery for perinatal depression, both clients and providers emphasized their difficulties in getting access to social and mental health services. Participants suggested that psychosocial stressors significantly influence these women's mental health. They highlighted the reality of long waitlists and limited mental health and social services. They described how eligibility criteria both limited and enabled access care. Finally, women also described being afraid to disclose complete and accurate information to providers out of fear of consequences like reporting to CPS. CBO providers noticed this as well while screening clients for services.

Waitlists & Limited Resources

Although various housing shelters are available, women found it difficult to find a stable place to stay, especially because they cannot live in shelters that they have stayed in before. One participant described the effort she put in to find a home:

> "I'm in [Shelter A]. Now, they're telling us that [Shelter A] might not even be a two-year transitional [program] anymore as of October. Am I now back to the day-to-day shelters? Because I have been now doing housing workshops for the last six months. I'm getting letters back from places. But they're telling me I have to wait. I'm on the list. I'm on every list you can be on…I can't go back to [Shelter B]. I have already done that. I can't go to [Shelter C] because they're full." (English-speaking participant)

Some women described that even when social service organizations provide concrete assistance, like diapers and hand pumps for breast milk, the quality of these products may not adequately fulfill these women's needs. Some clients were afraid to seek much needed support because they did not want to be told that they could not provide. This mother said,

> "I don't feel like I'm endangering anybody by saying [that] I can't afford groceries this week. I had to pay my service fees. I have a lot of like medications for myself and others that I have to pay for. Then, I worry about diapers. I mean, no offense. But, the government diapers give him butt rash like there is no tomorrow. I have got to buy my diapers. I can't go and just put any diaper on him…He [also] never stuck to any formulas. I have to breastfeed. I needed a pump, [but] the little hand pump wasn't doing it. There are things that you get afraid to ask for…Are they going to think that I can't provide?" (English-speaking participant)

CBO providers also described their challenges in making referrals for their clients. One case manager expressed concern for pregnant women and mothers who had to "wait in line at 6:00 in the morning" to receive emergency, walk-in therapy provided by the county. Case managers noted particularly long waitlists for Spanish-speaking clients. One case manager supporting women with open IPV cases noted that therapy referrals for Spanish-speaking clients are one to two weeks longer than for their English-speaking counterparts. Another case manager noted,

> "The only successful referrals [I've had] were in house referrals…when staff is available to see them and they are here… They [see] the client and they'll continue to see them on a weekly basis, that's successful. An unsuccessful [referral] is [when] we put them on a waitlist and that's been really it, wait until they come to that person's name."

Eligibility Requirements

Both clients and providers described how eligibility requirements limited their access to services. They related these difficulties to eligibility requirements for welfare programs that provide food, housing, and childcare. For instance, one woman described being ineligible for certain welfare programs because of income requirements:

> "I don't have such a high income, but I also don't have a very low income. So, I don't qualify for anything, not even for housing… For a family of three, you need to make $2,000 a month without deductions… And rent alone is close to $2,000." (Spanish-speaking participant)

Providers expressed their concern that these services are not being offered early enough to women. One community health worker said, "we are in desperate need of more preventative support before families even get to the crisis point."

For example, this English-speaking participant couldn't get emergency assistance for housing because she "wasn't pregnant enough yet." She had to be seven months pregnant to qualify for emergency housing assistance. Another client found she was more eligible for housing and therapy after having an open CPS case.

> "CPS was in my life for two years…I [had] to do parenting counseling. I [had] to do abuse counseling. I [had] to do anger management. All through those, I learned a lot... I think it is a very good thing. Because you do learn different things in different steps that you can carry on for the rest of your life." (English-speaking participant)

Other clients described accessing therapy only after an interpersonal violence incident. One Spanish-speaking participant described first getting access to therapy when she filed a domestic abuse report. An English-speaking participant described entering group therapy and counseling after a domestic violence experience:

> "I like group therapy. I have been to counseling for seven years after I got my first [domestic violence case]. So I had to do 52 classes, graduated from that and ever

since I did that, I kept going to see him. So, I have been seeing him for nine years and recovered from drugs."

Another case manager highlighted the short-term nature of therapy for most women after resolution to the immediate crisis.

> "A lot of [therapy] is usually a year, which I understand because a lot of them are non-profits [and] more than the year is a lot of time to spend with someone. But I think if someone has a deep trauma, a year is really… it's not enough time. It takes about a month or two or three months to really connect with your therapist. And then you start making progress, and then they start preparing you to close out towards the end. So [in] that year, someone has really only 5 months of that break through. And then they start to feel disconnected again because they know that their time is ending. So, I think [it's] a big issue [that] longer term [therapy doesn't] seem to be an option."

Fearing Consequences of Disclosure

Providers at this CBO noticed that many women were not willing to disclose all information during screenings, especially in written documentation. One community health worker described her experience with clients completing registration forms:

> "So, they'll mark no, but once you go in and give them information on why there are here, they start disclosing, 'I just lost my child, I'm going through domestic violence, I fear my life.' But none of that was put on the registration form and it happens on a daily basis."

Similarly, case managers who lead prenatal classes found that women were not disclosing their stress levels accurately on the Edinburgh Postpartum Depression Scale.

> "'Cause sometimes we will do like a depression scale with them, I mean some of them…. [we] can clearly see, you know, they're feeling some type of way, but they'll put zeros down. You know when it's time to score, they'll say, oh, I got zeros, I'm fine, and it's like, really?"

Through the client focus groups, women described the reasons for being afraid to disclose substance use, homelessness, and medication compliance because of adverse experiences with medical providers and fear of CPS. Many women felt that providers did not trust them once they revealed a history of substance use or homelessness. One participant said,

> "I was very picky and cautious on what I told any doctor that I saw for prenatal care. Because the worst thing for a doctor to do is write down that you use drugs. Because every single medical provider that I have ever encountered… looks at you instantly [and] assumes that you're going to relapse… [They don't] care that it has been four, or five, or six years since you ever did anything... It doesn't matter what you have worked on. What you've accomplished in your life. It doesn't matter if you have a career. You're a drug addict.

> The same is when they put no home on that piece of paper. All of a sudden, you are inadequate to provide for a child. Because you live outside. It doesn't matter if you have a vehicle, or a tent, or live in the climates [where you] don't necessarily have to be inside. There's so much stereotyping for what they expect you should have to have to live [and] provide for a child. Legitally, you need clean clothes, a way to clean your child, or change their diapers, and a way to feed them, and keep them warm at night, and a cozy place to sleep. The kid doesn't really need much more than that except for happiness." (English-speaking participant)

Another participant described similar discrimination by health care providers because of choices around taking psychiatric medications during pregnancy.

> "I have a bipolar disorder, PTSD, and anxiety disorder. They put cotton balls in my son's diaper. I looked up [and] they were pushing him out of the room. I am like where are you guys taking my baby? The social worker came up — they were trying to kick us out… I was like 'Okay. Well, I'm not leaving it without my baby. It's either you give me back the baby. Or, you have the cops come down here'… Because the whole thing was over the fact that I should have been on a [psychiatric] medication. But [I] stopped taking the medication because it is harmful during the pregnancy. [My psychiatrist] told me while I was on it, because I was on such an allotment of drugs, that they didn't want me taking my medication…I was willing to stop as long as they provided therapy for me. I did the therapy. I [see] three different therapists a week…They still were like, "Oh well, she's not on her medication. She is a harm to herself." Well, I have never wanted to hurt myself." (English-speaking participant)

As a result of this mistrust, some women do not seek services, or travel for services elsewhere. One mother experiencing homelessness delivered her child in Oregon because she would have an open CPS case in any hospital in San Francisco. One case manager said,

> "I had one client, she didn't want to apply for [child support] because she was afraid that, because she wasn't stable, the husband is going to take the child away. She has some mental issue [and] she didn't want to address it because [of] the fear that her child will be taken away."

Facilitators to Recovery

Both providers and clients also described examples of successfully accessing mental health care or other forms of support for a client's mental health. These included therapy, peer support, mother-child support groups, social tools, and non-judgmental, structurally competent providers.

Preference for Therapy

Women in both Spanish and English focus groups overwhelmingly preferred therapy to medication as treatment for depression.

In the Spanish-speaking focus groups, women disliked the side effects of some psychiatric medications, such as suicidal ideation, but seemed more open to therapy. One participant attended therapy after her first pregnancy because she felt lonely since her friends and

family were not in the US. Another woman described attending therapy because she had depression in the past and wanted to prevent postpartum depression. This participant described how receiving tools in therapy kept her engaged:

> "What has helped me is that I tell my therapist about my situation and she gives me solutions. So, then I feel okay to tell her because then I know how to work with that situation. That's what makes me tell her the problem." (Spanish-speaking participant)

English-speaking participants expressed fears of becoming dependent on medication. Some clients argued that medication only temporarily relieves symptoms without actually addressing underlying causes of depression. One participant said,

> "I was on a lot of medications. All it ended up doing was kind of making me unbalanced; which led me into other aspects of my life like my drug addiction and stuff like that. Now that I have had a long period without medication and without drugs; it's been about a year and six months now. I don't want to go back on the medication. I'm sticking with my therapy… I am able to learn to control my own emotions without having to feel sedated." (English-speaking participant)

Many participants were open to using therapy if they felt the need for it, based on previous experiences of others who utilized it, or in this case, the experience of those who did not engage in therapy.

> "I think if I ever got to a serious point that I would feel comfortable going and I would definitely recommend it to everyone because three years ago, my boyfriend at the time committed suicide and I just think that counseling is really helpful… I think when you really talk about it, you get it out, it is really helpful." (English-speaking participant)

Peer Support & Support Groups

Women noted that peer support is helpful to normalize experiences and to share information about pregnancy and parenting. One Spanish-speaking mother described becoming "very heavy" during pregnancy and experiencing sexual discomfort with her husband:

> "I feel very heavy… it makes me feel odd. And the sexual part too. The couple changes a lot…So, we're talking with friends, my friends' husbands, and I ask them if the same thing is happening to them. And they say it is, that the pregnancy is also affecting them a lot, because they don't feel comfortable. They think they'll hurt the baby. And, at first, I thought it was because of physical appearance that sexual activity had gone down. But it's also something psychological that, inevitably, affects them as well." (Spanish-speaking participant)

Another Spanish-speaking participant described the relief she feels when her experience is normalized when hearing from other women:

> "It honestly helps me a lot to see there are people who always offer us opportunities to ask for help, to take care of us, to know that I'm not alone, because many women go through the same things or different things we all go through. It helps me, it relieves me. Because sometimes you make a big deal out of nothing and you think you're the only one going through a situation." (Spanish-speaking participant)

Peers often provided practical support as well. One woman says,

> "It got to the point that I was depressed and I wouldn't go out anymore because of my depression. I got a lot more -- I'm plump now, but I got very fat, until I met a neighbor and I started going out. She started motivating me. She'd tell me I was pretty and young. She started to say, 'I'll look after your kid. Go to the gym…' Family and friends are important too." (Spanish-speaking participant)

Providers who lead support group and classes noted that Spanish-speaking, Latina women had high participation. One case manager says,

> "[In groups], Latina women are more willing [to] tell something that's not easy. They are more willing to put themselves out there and they look for support. Like with the parenting playgroup right now, they've been coming [for] so long together that now, they are kind of a community and they help each other and they are willing to accept help from each other."

During the English-speaking focus groups, participants demonstrated support for one another, although no expectations were set for group support by the facilitators. For example, one woman responded to another participant with the following:

> "I wanted to touch up on perspective. And when I met you, I felt your soul, it was just so beautiful and happy and they say you are your own worst critic but yet perhaps if you look at it through a different perspective where you are thinking these things only because you are going to be that much of a better mother, you already have so much apparently from what you have experienced in life and what you have gone through that you know, some people do not. Just look at it as a building block and bodyguard that they can experience. It is going to be beautiful. You already are." (English-speaking participant)

From the provider perspective, group settings are also helpful ways for screening women. One case manager who also led support groups noted that women were more willing to disclose in group settings:

> "In one-on-one [case management], you [ask] general questions, [like] how are things going with you and the baby? They say 'Oh, I'm getting no sleep but you know…' Like [they] brush it off. [They] really want to say everything is fine… Whereas in group, they get to see other women who are going through what they are going through. Or they hear them say things that they might have been scared

to say… Like sometimes I want to go right in the room and hide. And sometimes I just want to cuddle [my baby] up, I can't take this, I'm going crazy. And then they'll look around [and realize] it's not just me."

Mother-Child Bonding Services and Social Tools

When we asked clients to describe services that have been helpful for stress and anxiety, they named activities for self-care, such as yoga and massage, as well as mother-child bonding activities, like play groups. One mother described a service where she could dance with her baby:

> "They call it Zumbini… Your baby is months old and you start dancing with him, do movements with the baby with music, you sing, you give him something to play with and that's nice too. I feel that, in addition to stimulating the baby, it would stimulate us too." (Spanish-speaking participant)

Some mothers in the English-speaking focus groups felt that spending time with their children was a form of self-care. One mother emphasized the importance of spending undistracted time with her children:

> "When you really just stop everything you're doing. You sit down. You just talk to them. You will be amazed about what the hell will be going on with your child. What they know. Or, what they don't know. It makes you feel better about it. I never knew you even knew that…I feel like that would be a big help for me, too. Why don't we just do something with our kids. I feel like I ain't took them nowhere. Let me go to Chuck E. Cheese's …or, let me just go to the park. We would be there for four or five hours. I feel like that's a big help, your children." (English-speaking participant)

Other clients noted unique services that taught social tools, like English classes and parenting classes, or empowered women to work and be independent. A Spanish-speaking participant described a program she found supportive:

> "You meet a lot of people. You know more resources and make new friends. There are others who help us single moms or only for women, to motivate women and make them independent and give them the courage to work or do -- because we do a lot of crafts we make at this center. So, sometimes we think we're not capable, but we have the ability to do a lot of things." (Spanish-speaking participant)

Often, these services also provided childcare onsite. One woman described having childcare at the location as her English classes:

> "I went specifically for the English lessons, because it's a place where you can take classes and have your kids looked after…The teachers also teach them to paint and color. I had a good experience because my daughters went in real small, they grew up there and, honestly, they came out smart because of the teachers -- they knew how to write their names, they already knew a lot of things. I'd said,

> ‘Well, I’m learning, but I left my children in good hands and I know they're also learning something new.’” (Spanish-speaking participant)

Reliable, Patient-centered, and Non-Judgmental Providers

When we asked clients to describe qualities of providers who they trusted the most, they described three qualities being reliable, patient-centered, and non-judgmental.

Many participants valued reliability highly in all types of providers, including case managers, social workers, and clinicians. A Spanish-speaking mother described how she could depend on her case manager for breastfeeding support:

> “[My case manager] helped a lot and I feel that she listens to you and helps you. But, when the baby was born, I had a lot of problems breastfeeding and I called her and she immediately said, ‘I'm coming over. I'll bring you some things and everything.’ And she sent me someone else from here to help me with lactation.” (Spanish-speaking participant)

Some clients described how clinical professionals provided support that their friends and family were unable to provide. One client’s case manager was able to provide her with rental assistance programs and grocery resources that her friends could not have helped her with. Another client described feeling that doctors and therapists were able to provide her an outsider perspective, while her friends and family were sometimes nosy and gave her “empty information.”

For other participants, providers were most supportive when they helped clients define their own goals. One woman said,

> “I talk to my doctor. These are the only people I feel comfortable with judging me because everybody else has all these ideas and praying and all this stuff. Sometimes you just need somebody to kind of just help you line up your thoughts in the right way.” (English-speaking participant)

Another mother with previous methamphetamine use discusses support for her physician in taking a controlled substance as a medication for her narcolepsy:

> “[My doctor] was okay with giving it to me. He was like, ‘We'll monitor it…’ It didn't red flag him at all that I had previous history and abuse. He was willing to listen and know that…I was asking for it to make my life better, not as an opening to make it worse.
>
> When that didn't work out because of the current environment situation…I quit taking it. I was able to just call him up really easy…He was really open to hearing what I was comfortable with…Then, we were able to discuss other options that weren't going to be a controlled narcotic…I think it can depend a lot on who you see to seek medication. Because you have to have that comfort that they really want what you want in medication, and not what they think is just going to fix it all.” (English-speaking participant)

This client most appreciated that her doctor centered his treatment plan around her own comfort and goals for medications. He provided her care without judging her for her previous substance use and respected her wishes to not necessarily "fix" her addiction.

Other clients echoed similar appreciation for non-judgmental support. This mother appreciated that her case manager connects her with resources without judging her for not being able to afford child care necessities:

> "If I say like, hey, I can't afford to get a new bottle this month, [my case manager] is not going to be looking at me like I can't afford my kid. She [is going to say], 'Maybe we can find you a bottle.'" (English-speaking participant)

Some clients greatly appreciated when their providers had had similar life experiences. This client describes the trust and nonjudgmental support she receives from her case manager who was also previously a client at this CBO.

> "I feel like I could go to [my case manager] for anything... Believe it or not, like she was on the streets at one point. Like there is no judgment. When I go and I talk to her, I am like, 'Dude, I'm feeling like this today. I swear to God. I'm going to pull my hair out.' She understands that I'm not at a standpoint of where I'm hurting. Where I'm a danger [to myself]; like I could tell her honestly how I feel." (English-speaking participant)

Discussion

Clients and providers in our partner CBO described sources of distress for pregnant and postpartum women, as well as barriers and facilitators to receiving support for their mental health. Although we were focused on access to mental health services, focus group participants emphasized that psychosocial factors and access to social services significantly impacts mental health. We found that lack of basic needs such as housing and social support for low-income women increased their vulnerability to mental illness during pregnancy and early motherhood. Many of these women are resilient and strive to meet the increased demands of pregnancy and parenting. However, insufficient services, long waitlists, and competing priorities prevent them from meeting their mental health and basic needs. Navigating services is complicated for both the women and the referring providers, compounded by inconsistent and ever-changing program eligibility requirements. Our participants feel the pressure of individual responsibility to be a good mother and to provide for their children, but feel trapped by their limited socioeconomic means.

Despite most client participants receiving social services from our partner CBO, many still experienced the negative effect of their inability to meet basic needs. Financial challenges, unstable housing, and inadequate social support are all risk factors for maternal distress (Dennis et al., 2009; Lange, Dáu, Goldblum, Alfano, & Smith, 2017). The challenges in meeting basic needs is consistent with quantitative studies showing that increased diaper need and increased food insecurity correlates with mental health disorders in mothers (Austin & Smith, 2017; Whitaker, Phillips, & Orzol, 2006). Our study found that low-income women prioritized working to financially support their family. As a result, women were unable to spend as much time with their children as they would have wanted to. These results are similar to those from a mixed methods study that showed that poverty negatively impacts mothers' ability to provide the quality of parenting they wanted to give because they have to restrict time spent with their children (Lange et al., 2017).

Many participants described their experiences of the mistrust of medical providers, including a fear of being reported to CPS. This is consistent with literature showing that women are afraid of losing custody of their infant if their mental health status was revealed (McComish, Groh, & Moldenhauer, 2013). Other studies have shown that clients avoid prenatal care visits if they have a history of substance use (Roberts & Pies, 2011). Participants also identified key qualities in providers they trusted, including being reliable, patient-centered, and nonjudgmental. These competencies can inform trainings and supervision of health care professionals and social service providers.

Clients in Spanish and English-speaking focus groups doubted the efficacy of medication as a permanent solution, and some clients were afraid of addiction or side effects. This echoes findings in the literature that pregnant and postpartum women are afraid antidepressants as a "quick fix" solution with addictive properties and associated personality change (Chew-Graham, Sharp, Chamberlain, Folkes, & Turner, 2009; Guy et al., 2014; T. B. Pearlstein et al., 2006).

Clients in our focus groups enjoyed and benefited from mental health treatment alternatives, including peer support and support groups. A study on the group-based CenteringPregnancy model found that participants had increased self-esteem, decreased stress and social conflict in their third trimester, and decreased social conflict and depression after one year postpartum (Ickovics et al., 2011). Group settings allow women to normalize symptoms through mutual empathy, especially when others in the room have also experienced and recovered from depressive symptoms (Nicole et al., 2007; Scrandis, 2005).

Our study has several limitations. First, our findings are limited in their generalizability to all low-income women experiencing perinatal depression because our participants were all clients receiving significant social support from our partner CBO. Furthermore, clients were mostly recruited from support groups and prenatal classes which may bias their preference for these types of services. Additionally, some clients already knew one another from attendance in groups together, which may have limited and facilitated disclosure regarding sensitive topics.

Our study also has notable strengths. Because of our partnership with a well-regarded CBO, we were able to gain perspectives from and give voice to a highly vulnerable population, specifically low-income women of color experiencing housing instability. The substantial diversity of race, ethnicity, and age range among the study participants contributed a variety of perspectives to our results. Although participants were recruited with convenience sampling, the client focus group findings were triangulated with feedback from a majority of our partner CBO providers. Finally, most studies on perinatal depression have been limited to a focus on barriers to accessing mental health services without including perspectives on potential successful solutions. The solution-oriented discussion we elicited can inform future intervention development and implementation. The trusting, near-peer relationships between patients and providers in the context of a safe environment with multiple on-site services are especially notable at this CBO. Other organizations can focus on these successful qualities when modeling their care after this CBO.

Conclusions

Given providers' challenges in making referrals and client frustrations with accessing inadequate and fragmented social and mental health services, integration of social and mental health services can likely improve patient satisfaction and health outcomes. This conclusion is supported by prior research documenting that pregnant and postpartum women had higher rates of mental health care utilization with the implementation of additional interventions, such as resource provision, perinatal care provider training, on-site assessment, and access to mental health consultation for perinatal care providers (Byatt, Levin, Ziedonis, Moore Simas, & Allison, 2015). Another program called Massachusetts Child Psychiatry Access Project for Moms (MCPAP) developed a cost-effective model that leveraged limited resources to address perinatal depression among a large population of women. Through trainings and toolkits for depression screening, assessment, and treatment, phone consultations for frontline providers, and care coordinators to link individuals to psychiatrists and support groups, MCPAP was able to develop a sustainable model that effectively identified and addressed perinatal depression among thousands of women in Massachusetts (Byatt et al., 2016). Logistically, however, the most successful referrals occurred when multiple services were provided in the same location.

We should attempt to address the mistrust of providers that many of our study participants described and that is well documented elsewhere. As in our CBO, increased support for hiring and training providers who have similar backgrounds to patients being served may increase trust and utilization of existing services. Structural competency trainings can equip all providers with tools to deliver nonjudgmental and patient-centered care. Structural competency is the trained ability to discern how upstream, structural factors such as institutional, political, and economic forces, shape clinical presentation, such as symptoms, attitudes, or diseases (Metzl & Hansen, 2014). For example, many health care providers can receive more extensive training to sensitively handle trauma, familial experience, substance use during pregnancy with an emphasis on how pregnancy can re-trigger past experiences of trauma. Furthermore, providers may develop trusting, collaborative relationships with their patients by empowering their patients to address their parenting insecurities, as well as openly communicating with their patient before making a CPS referral.

Given the variety of patient preferences regarding mental health treatment, researchers have argued that interventions should be individualized to consider a woman's age, cultural and linguistic differences, circumstances, and needs in order to be effective (Leger & Letourneau, 2015). Group care models, such as CenteringPregnancy, can be additional options for mental health screening and treatment, given the preference for group support, increased disclosure of depressive symptoms in group settings, and the growing evidence of their benefits to mental health (Shaw, Levitt, Wong, & Kaczorowski, 2006). Other group care models include group prenatal classes, group early pediatric care, group parenting classes, and mother-baby bonding activities (Benediktsson et al., 2013; Walker & Worrell, 2008).

Because inability to meet basic needs contributed significantly to perinatal distress, creating structural interventions that reduce the risk in women's environments should be considered (Weiser et al., 2011). Upstream interventions to expand access to housing, food, diapers, formula, and other basic parenting needs shifts the focus away from the agency of mothers. Current interventions, such as reporting women to CPS, restrict women's autonomy by framing mothers' choices and limiting life options. This focus on structural vulnerability can "rectify misdiagnosis, blame, and maltreatment that accompanies the experience of poverty and cultural subordination" (Quesada, Hart, & Bourgois, 2012). Partnerships with community based

organizations rather than health service-based interventions may be more effective approaches to supporting low-income women with perinatal depression. Rather than having OBs and midwives screen and refer distressed women to multiple resources (such as psychiatrists, social workers, eligibility), they could refer them to an affiliated CBO that is cultural sensitive, trauma informed, and provides one-stop wrap-around multidisciplinary care for basic needs and peer support.

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Appendix

Figure 1

Abbreviated Focus Group Guide for CBO Providers
1. What are your clients' main concerns around mental health? 2. How have you supported clients with their mental health needs? 3. Describe your experience linking clients to mental health services. 4. What are some ways we can improve access to mental health services for clients at this CBO? 5. Are there any questions we should ask clients about their experience with perinatal distress?

Figure 2

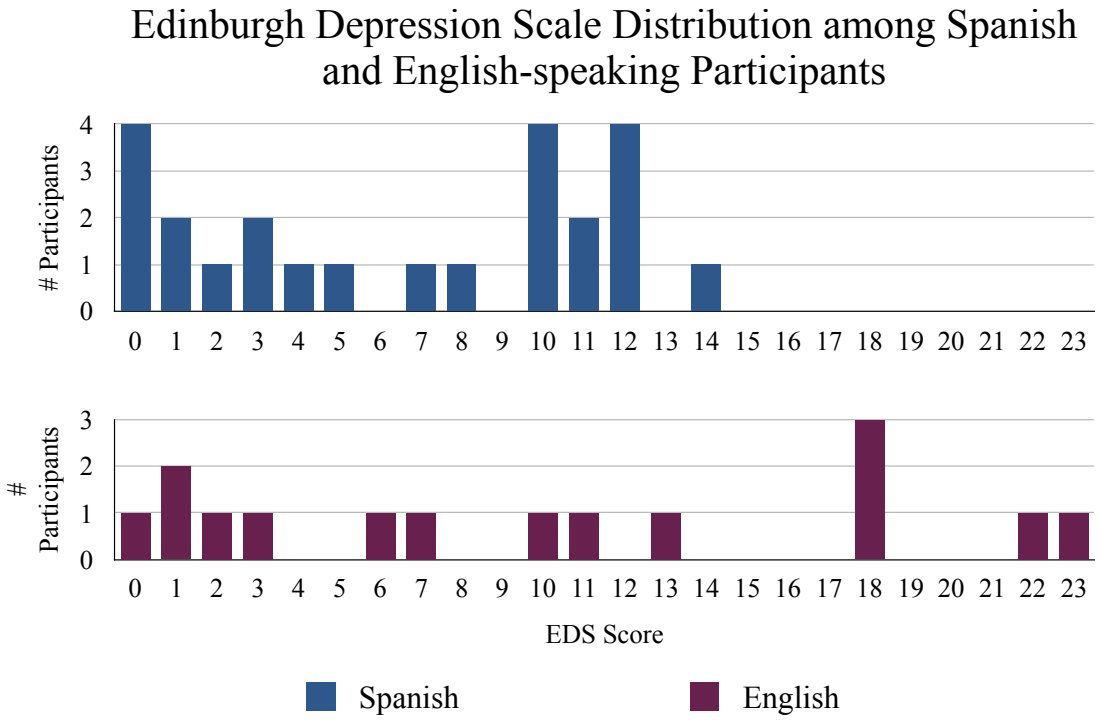
Abbreviated Focus Group Guide for Pregnant Women and Women with Children Ages 0-3
1. When you were pregnant with your first child, what were you looking forward to? What did you find surprising or unexpected after you delivered? 2. What are some thoughts or emotions that mothers may feel during pregnancy or as a new parent? 3. What are some things that make it hard to be a mother? 4. Who do you trust to help you when you are feeling down? How do they help you? Why do you trust them? 5. What services could you use at this CBO for support with anxiety or stress? What services could you use outside of this CBO? 6. Would you consider counseling or therapy if you felt down or stress or anxious? 7. How can this CBO do a better job supporting mothers?

Table 1 – Client Focus Group Demographics

	Spanish-Speaking	English-Speaking	All Client Responses
Age of Clients			
18-24	3 (15)	1 (7)	4 (12)
25-35	11 (55)	12 (80)	23 (68)
35+	6 (30)	2 (13)	8 (20)
No response	1	0	0
Race & Ethnicity			
Hispanic/Latina	19 (100)	0 (0)	19 (56)
Central American	17 (89)	0 (0)	17 (50)
Mexican	2 (11)	0 (0)	2 (6)
Asian & Pacific Islander	0 (0)	3 (20)	3 (9)
African American	0 (0)	10 (67)	10 (29)
Native American	0 (0)	1 (7)	1 (3)
White	0 (0)	3 (20)	3 (9)
No response	2	0	0
Birth Location			
Born in US	1 (5)	14 (93)	15 (44)
Born Outside US	18 (95)	1 (7)	19 (56)
No response	2	0	0
Marital Status			
Married	15 (71)	3 (20)	18 (50)
Single	5 (24)	11 (73)	16 (44)
Separated	1 (5)	0 (0)	1 (3)
Divorced	0 (0)	1 (7)	1 (3)

All values are shown as n (%). Percentages are by focus group category (Spanish-speaking respondents, English-speaking respondents, or all client participants). Percentages only include focus group participants who completed the survey question.

Figure 3



Spanish-speaking participants EDS scores: n = 20, mean = 6.9, standard deviation = 4.25
English-speaking participants EDS scores: n = 15, mean = 9.27, standard deviation = 8
Currently pregnant participants EDS scores: n = 20, mean = 8.9, standard deviation = 7
Not currently pregnant participants EDS scores: n = 15, mean = 6.6, standard deviation = 4.6

Figure 4 – Overview of Findings