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# Life events, barriers to care, and outcomes among minority women experiencing depression: A longitudinal, mixed-method examination

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# Abstract

The long-term course of depression is not well-understood among minority women. We assessed depression trajectory, barriers to depression care, and life difficulties among minority women accessing health and social service programs as part of the Community Partners in Care Study. Data include surveys (n=339) and interviews (n=58) administered at 3-year follow-up with African American and Latina women with improved *vs.* persistent depression. The majority of the sample

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reported persistent depression (224/339, 66.1%), 1 barrier to mental health care (226/339, 72.4%), and multiple life difficulties (mean 2.7, SD 2.3). Many barriers to care (i.e., related to stigma and care experience, finances, and logistics) and life difficulties (i.e., related to finances, trauma, and relationships) were more common among individuals reporting persistent depression. Results suggest the importance of past experiences with depression treatment, ongoing barriers to care, and negative life events as contributors to inequities in depression outcomes experienced by minority women.

# Keywords

Depression; Mental health services; Socioeconomic factors

# Introduction:

More than one in ten African American or Latina women in the U.S. has depression (Brody et al, 2018). Depressive disorders are associated with increased morbidity and mortality, and studies show racial and ethnic disparities in screening, access to care, quality of care, and outcomes (Miranda et al, 2008). Racial/ethnic minorities are less likely to be assessed by their health care providers for depression (Kato et al, 2018), and are less likely to receive depression treatment (Alegria et al, 2008; Lee et al, 2014; Simpson et al, 2007). Female minorities face intersectional stressors that impact mental health, including workplace discrimination (Pavalko et al, 2003) and experiences of discrimination (e.g., related to race, gender, language, social status) in healthcare settings (Burcusa et al, 2007; Burgess et al, 2008; Hausmann et al, 2008; Mays et al, 2017; Progovac et al, 2020). These barriers to mental health care (Hines-Martin et al., 2003a; Hines-Martin et al., 2003b; Snowden, 2001) have been well-characterized in cross-sectional studies and impact depression outcomes (Wells et al, 2008). Studies have shown that effective depression interventions can lessen barriers to care for minorities (Wells et al, 2008). However, the impact of barriers to care and life events on the long-term course of depression is not well-understood (Burcusa et al, 2007), particularly in low-resource and minority populations.

Major goals of treatment for depression include recovery from symptoms, experience of positive mental health, and regaining of functioning (Zimmerman et al, 2006). While recurrence or persistence can occur along different trajectories of depression, long-term improvement or remission is the ultimate goal of recovery (Bakish, 2001). Studies of lived experiences with depression (Ward et al, 2014) substantiate the significance of stigma in limiting psychosocial functioning and access to care among individuals with depression (Bromley et al, 2016; McNair et al, 2002), influencing trajectories of recovery for women, including minority women. Increasingly, there are efforts to consider personal experience of social risks (e.g., financial strain, housing instability) in guiding the development of U.S. recommendations for the delivery of care, including that for depression (Davidson et al, 2021). It is recognized that the number of stressful life events predict depression recurrence and that hardships predict depression and its maintenance over time (Butterworth et al, 2009; Lincoln et al, 2010; Roca et al, 2013; Skapinakis et al, 2006).

The goal of this study was to examine in-depth perspectives of life events, depression trajectory, and barriers to mental health care among African American and Latina women with depression. We used data from the Community Partners in Care (CPIC) study which enrolled participants with depressive symptoms served by a variety of health and social service programs within low income communities in Los Angeles. In order to describe how barriers to care differed by depression trajectory, we described differences in barriers to help-seeking, experiences of care, and life events assessed from surveys and interviews with women who experienced improved or persistent depression over a period of three years.

### Methods:

# **Study Overview:**

We explored depression experiences among African American and Latina women who participated in the Community Partners in Care (CPIC) Study from 2010 to 2014 (Sherbourne et al, 2017). We used quantitative data from telephone surveys (n=339) and qualitative data from in-depth interviews (n=58) collected from African American and Latina female CPIC participants at 3-year follow-up.

# **Community Partners in Care (CPIC) Study:**

The CPIC Study is a longitudinal community-partnered, participatory cluster-randomized trial comparing the effectiveness of two community-based interventions (Community Engagement and Planning [CEP] vs. Resources for Services [RS]) to address depression among African American and Latino clients of health and social service programs within low income communities in Los Angeles (Wells et al, 2013). Participants were recruited by study staff in-person in waiting rooms of or at events hosted by 60 participating local agencies that provided health (outpatient primary care), mental health (outpatient mental health, substance abuse), or community-based (e.g., senior, housing) services. From March to November 2010, study staff screened 4,440 individuals and enrolled 1,246 participants who met criteria for moderate to severe depression, defined as a score of at least 10 out of 24 on the Patient Health Questionnaire (PHQ-8) (Kroenke et al, 2009). Individuals who were unable to answer screening questions due to cognitive impairment were excluded from participation. Study design and protocols were approved by the RAND Human Subjects Protection Committee.

### Quantitative Data Analysis – 3-Year Follow-up Questionnaires (n=339):

CPIC staff administered telephone questionnaires to study participants at baseline, 6-, 12, and 36-month follow-ups. The quantitative analysis for this paper focuses on a descriptive comparison of measures of health care utilization, barriers to mental health care, and life difficulties at 3-year follow-up.

**Baseline Questionnaire:** The baseline questionnaire included measures of demographic characteristics (age, gender, race/ethnicity), socioeconomic status, health conditions, depression severity, functional limitations, use of health and social services, use of medications, and beliefs surrounding depression. Baseline questionnaires were completed with 981 participants.

Three-Year Follow-up Questionnaire: At 3-year follow-up, participants were reassessed for depression using the PHQ-8. They reported their use of health care services in the previous 6 months, including: hospitalizations, outpatient visits, emergency room visits, case management services for health or mental health services, mental health hotlines, substance use services, or self-help meetings (See Table 1). Participants were asked to assess whether they experienced 19 barriers to mental health care, comprising four types of barriers (Stigma and Care Experience, Financial, Logistical, Discrimination) elicited with reference to "times when you didn't get as much help as you needed or had delays in getting care for emotional or personal problems" in the previous 6 months (See Table 2). The quantitative results for this study focus on all 339 minority women who had a PHQ-8 10 at baseline and completed the 3-year follow-up. Participants were categorized as having improved (PHO-8 10 at baseline, PHO-8 < 10 at 3-year follow-up) vs. persistent (PHQ-8 10 at baseline, PHQ-8 10 at 3-year follow-up) depression based on the presence of depression symptomatology at 3-year follow-up. Outcomes of interest for descriptive analysis included the proportion of participants reporting various types of health care utilization, and prevalence of barriers to seeking mental health care at 3-year follow-up. When respondents did not answer specific questions, data was treated as missing (not imputed).

### Qualitative Data Analysis – 3-Year Follow-up Interviews (n=58):

We sought to assemble a diverse sample for interviewing of approximately 100 out of 600 CPIC clients completing 3-year follow-up surveys. We designed a sampling strategy to ensure diversity among clients in terms of their depression status (improved at 3 years [PHQ-8 score<10] vs persistent at 3 years [PHQ-8 score 15] depression), ethnicity (African American and Latino), sex, and intervention status (CEP vs. RS) to better understand heterogeneity in priorities within this population (Anderson et al, 2018). We contacted 163 and recruited 104 (64%) clients (23 could not be reached; 20 had incorrect contact information; 14 initially agreed but could not be reached subsequently; and 2 refused). Among these, 60 were female and 44 were male participants. To ensure narratives addressed improvement or persistence in depression, we excluded one female participant from qualitative analyses with a baseline PHQ-8 score <10 and one with a PHQ-8 score=10 at 3 years, yielding a final qualitative subsample of 58 African American and Latina women (Khodyakov et al, 2018).

Semi-structured interviews were conducted in English and Spanish over the phone between February and July 2014 by trained study staff including community members (Anderson et al, 2018) and audio-recorded. Details on the interview methods have been previous reported (Khodyakov et al, 2018) and relevant questions from the interview guide are provided in Supplementary Table 1. Participants received \$25 gift cards for participating in the interview. Trained study staff transcribed the interviews conducted in English verbatim, and for interviews conducted in Spanish, translated and paraphrased to English. The goals of the interviews were to assess in-depth perspectives about overall well-being, life priorities, and experiences with mental health care. Participants were asked to identify the top 3 priorities or issues they wanted help addressing (e.g., housing, financial, employment, health, activities of daily living). For each issue, participants were asked to describe what

was working and not working for them in addressing those needs. In addition, participants discussed whether and where they had sought help to address the priorities, any progress or difficulties they had faced in addressing the issues, and potential ways for social and community organizations to better meet needs. Whether or not participants identified improving their mental health as a top priority, they were asked to discuss what was working and not working for them in addressing their mental health, whether and where they had sought help to address their mental health, any progress or difficulties they had faced, and ways for services to better meet needs. Analysis of top priorities at 3-year follow-up have been previously reported (Khodyakov et al, 2018).

Qualitative analysis was conducted by five coders (SMH, QW, EB, LT, TC) using Dedoose. The team conducted thematic analysis using a template analysis framework (Brooks et al, 2015) to allow a balance between deductive (as identified by a priori themes from the literature and interview guide topics) and inductive analysis of emergent themes. All coders read a subset of transcripts in their entirety before beginning analyses. Two coders (TC, SMH) conducted preliminary coding using both a priori categories (e.g., sources of help for mental health issues) and emergent ideas (e.g., life experiences shaping depression). Then, coders (EB, SMH, QW) organized codes into meaningful clusters and identified integrative themes (e.g., impact of prior depression care experiences) that seemed to span clusters of codes as well as subthemes (e.g., types of barriers) that differentiated aspects of each theme. A coding template was then developed and refined through comparison against data. The template was reviewed with the coding team, and then applied to all data by two coders (SMH, LT). The comprehensiveness and consistency of the application of the coding template was checked by three coders (EB, LT, QW). Results were compared against quantitative results from questionnaires completed by the 3-year follow-up sample.

# **Results:**

Among the 339 African American or Latina women who completed questionnaires at 3-year follow-up, mean age was 48 (range 22–76, SD 11.9; Table 1). The sample included 187 (55.2%) African American women and 152 (44.8%) Latina women. One quarter (81, 23.9%) reported being married or living with a partner. Almost half (157, 46.7%) reported having completed less than a high school education. Three quarters (248, 75.8%) reported a family income from work of less than \$10,000, which was more prevalent among participants with persistent (177, 81.2%) vs. improved depression (71, 65.1%; p=0.001). A larger proportion of individuals with persistent vs. improved depression reported being at risk for or experiencing homelessness (35.9 vs. 22.6%, p=0.013), while fewer reported working for pay (21.4 vs. 39.1%, p<.001). Almost half (146, 43.6%) reported having no health insurance, which was similar between individuals with persistent and improved depression. The qualitative sample included a subsample of 58 participants (Figure 1).

### I. Life Course

**Depression Course**—Among the 339 women who completed questionnaires at 3-year follow-up, 224 (66%) had PHQ-8 scores indicating persistent depression. Among the 224 participants with persistent depression, mean PHQ-8 score was 15.3 at baseline and 15.8

at follow-up. Among the 115 participants with improved depression, mean PHQ-8 score was 13.2 at baseline and 5.1 at follow-up. Among the qualitative sample (n=58), of those who had improved depression (n=29), PHQ-8 score decreased from an average of 12.9 at screening to 3.8 at follow-up. Among interview participants with persistent depression (n=29), average PHQ-8 score increased from 16.6 at screening to 19.8 at follow-up.

With regard to issues they wanted help addressing, interview participants with persistent depression more commonly reported that their top priority was mental health or depression. Among participants with persistent depression (n=29), the 4 issues most commonly noted as top priorities were mental health or depression (15, 52%), physical health conditions (5, 17%), relationships and caring for others (3, 10%), and housing (2, 7%). Among participants with improved depression (n=29), the 4 issues most commonly noted as top priorities were physical health conditions (6, 21%), financial help (5, 17%), having no current problems to address (5, 17%), and finding employment (4, 14%).

Interview content reflected changes in scores on the PHQ-8. One participant with improved depression noted: "...now I think I am doing a lot better....Like my attitude is now changing, you know, I am able to do a lot more than I was doing. I'm not just sitting in the house, watching TV or playing a game and things like that." (H4774) In contrast, a participant with persistent depression noted: "It was getting better but now it is back where it was, like I said, my anxiety and depression, where I just want to stay in and don't want to go out there in the world." (W7494)

**Health Service Utilization**—Among those who completed 3-year follow-up questionnaires, rates of health care utilization in the prior 6 months indicated high need for acute medical care; almost one fifth (18.6%) of participants reported being hospitalized for a medical or health reason, and two fifths (39.9%) reported visiting the emergency room (ER) for a health problem, with rates being even higher among participants with persistent depression (49.6%, p<.001; Table 1). While over three quarters (75.6%) reported visiting a primary care provider, fewer reported having at least one mental health outpatient visit (43.7%). Compared to participants reporting improved depression, individuals with persistent depression were more likely to report visiting the ER (16.1 vs. 5.3%, p<.001) for an emotional, mental health, alcohol or drug problem. In addition, participants reporting persistent depression were more likely to report any outpatient visit for primary care (79.9 vs. 67.8%, p=0.014), mental health (54.5 vs. 22.6%, p<.001), medication for a mental health issue (46.4 vs. 20.2%, p<.001), and counseling (42.4 vs. 18.8%, p<.001). Participants with persistent depression were also twice as likely to report depression-specific care, including having any outpatient primary care visit for depression (40.4 vs. 20.9%, p<.001) and meeting with a case manager for depression (30.4 vs. 12.3%, p<.001). Attendance of substance use self-help meetings (16.5 vs. 8.7%, p=0.048) or mental health support groups (32.1 vs. 13.9%, p<.001) was also more common among individuals with persistent depression.

Qualitative interviews revealed a range of sources of mental health care. While some participants noted that they discussed their mental health only with their primary care providers, others sought help from licensed therapists, psychiatrists, case managers,

transitional or supportive housing staff, and group therapy programs, predominantly in public health care or safety net settings (Institute of Medicine (US) Committee on the Changing Market, 2000) such as county hospitals and community clinics. One participant with persistent depression described her experiences with group therapy: "Well, counseling, I go to a group there like three days out the week and it's anywhere from about ten to fifteen people...I'm volunteering to speak out and telling people what I've been through and that's like a big old miracle right there." (B3524) In addition, participants with improved depression more prominently discussed receipt of counseling within their church: "Mostly my help comes from [Mental Health Clinic] and...I have a spiritual leader. I have my pastor at my church." (P9437) A few participants noted receiving outpatient substance abuse treatment.

**Life Difficulties**—At 3-year follow up, the prevalence of negative life circumstances was significantly higher among women with persistent depression (Table 2). Compared to participants reporting improved depression, participants with persistent depression were more likely to report being worried about food (59 vs. 41%, p=0.002), having a major financial problem (41 vs. 26%, p=0.008), avoiding calls due to bill collectors (36 vs. 22%, p=0.006), experiencing difficulty finding work (33 vs. 20%, p=0.011), and experiencing housing insecurity (13 vs. 3%, p=0.002). Women with persistent depression were also more likely to report experiencing several trauma-related life circumstances, including losing a loved one (44 vs. 17%, p<.0001) and witnessing violence (14 vs. 5%, p=0.02). Participants with persistent depression more commonly reported experiencing a serious problem with friends or relatives (42 vs. 21%, p<.001) or serious argument (25 vs. 13%, p=0.01).

In interviews, women described similar stressors (Table 3). Both participants with persistent and improved depression described difficulty finding work, food insecurity, housing insecurity, and stressful living situations. One participant with persistent depression reported that, "My job laid me off due to the fact that I had got sick and I went into the hospital for a couple of days...after I did everything [my boss] asked me, he still let me go." (W2263) Another said, "being afraid to go out the door and wondering who is going to get killed around me next. I think I have experienced about 20 murders since I've been down here. And I don't want anybody else to experience living down here like that." (W7494) Participants also described significant traumas, including the death of loved ones, abuse, and experiencing or witnessing violence. Participants also described the loss of romantic and family relationships (e.g., with siblings, children) due to separation or geographic distance as contributors to loneliness or depression.

Among interviewees, particularly among women with persistent depression, chronic medical conditions, acute illness, and chronic pain were prominent stressors. Overall, particularly among those with persistent depression, participants emphasized the ways that these kinds of life events exacerbated symptoms of depression, undermined a sense of security, and interfered with recovery from depression. For instance, one participant with persistent depression described a medical emergency as exacerbating her anxiety: "I wound [up] having a heart attack and stroke...I was in [the hospital] for 20 days...So most of the issues and the illness that I have are all from stress." (Y9172)

### II. Barriers to Mental Health Care

Barriers to Mental Health Care—Among participants who completed 3-year follow-up questionnaires, almost three quarters (72.4%) reported at least one barrier to mental health care, and almost two thirds (64.7%) reported at least 2 barriers of any type. The most common type of barrier reported related to Stigma and Care Experience; all 5 Stigma and Care Experience barriers were significantly more prevalent among participants with persistent depression (Table 2). Three Financial barriers to receiving mental health care were significantly more common among individuals with persistent depression, in particular the need to spend money on other necessities besides health care (53 vs. 33%, p<.001). Five Logistical barriers were also more common among individuals with persistent depression, including the inability to get an appointment soon enough (39 vs. 21%, p<.001) and not knowing where to go for help (39 vs. 16%, p<.001). Rates of three barriers related to Discrimination were similar between participants with persistent and improved depression; one tenth of all participants completing the 3-year follow-up questionnaire reported that no one spoke their language at their clinic (11%) or that they felt discriminated against because of their race or ethnicity (10%).

Perspectives on barriers to mental health care from interviews reinforced those reflected in the questionnaire (Table 4). Overall, participants with persistent depression more prominently described experiencing barriers to the receipt of mental health care. We elaborate on barriers to mental health care described in interviews as they correspond to the four domains in the questionnaire: Stigma and Care Experiences, Financial, Logistical, and Discrimination.

Stigma and Care Experiences.: In questionnaires, this domain included experiences of feeling able to get over problems by yourself, being afraid of what others would think, embarrassment, thinking you could not be helped, and anticipating a lack of compassionate care. Participants did not elaborate in interviews on embarrassment or a fear of what family or friends would think about their depression. However, several participants said that they had experienced judgment from mental health providers, including one participant with improved depression who discussed her difficulty in "finding someone that doesn't try to tell you what's wrong with you without getting to know you." (D5878) Among participants with persistent depression, some noted not currently seeking care for their depression out of a sense that they could manage their mood best on their own or that mental health care would not be effective. One said, "I don't have anyone to really turn to help me with these things. I'm just dealing with it, as, you know, like, I do the best I can. You know, day-by-day." (W2263) Another said, "I don't want to do anything. I can't change it. I don't know, it's just sad. It's just sad, sad, and bad- taken me and flipped me and tossed me in a place where I just don't want to be bothered." (B3654)

Some participants discussed their satisfaction with the care they had received, including one participant with improved depression who discussed their experiences with their psychiatrist: "...they ask you how you're doing and everything, and work with you. They do activities. They help you a lot." (C2783) While all were asked about care experiences, few interviewees with improved depression elaborated on these types of barriers. Some

participants with improvement in their depression continued to seek regular care, and others noted they would return if needed: "I don't really have a low mood...But if I do, I know where to go. I can go back to the clinic where I always go to." (E2866) Two participants with improved depression expressed dissatisfaction with the types of mental health care available or past negative experiences with mental health care, as well as numerous instances of mistreatment within medical settings. Additionally, a few participants described aversion to medication, including one participant with improved depression who noted: "I don't mind getting it [mental health care], but I am the type of person right now—I don't like to take a bunch of medication. But if it was just like maybe talking to someone about my feelings, I don't have a problem with that. But as far as taking medication I don't want that. I really don't." (J6347)

Many interview participants with persistent depression described negative care experiences. Some said that medication was helpful in managing their condition, but many described negative experiences with mental health providers. They described providers being disrespectful or not caring about their progress and described not receiving information or advice they could act on. For example, one participant with persistent depression said her mental health provider "never asked me anything and if I told him something, he would tell me 'Hold on let me write that down,' and he would be sitting there writing and at the end of the session here, he is just grading my medication and stuff, but he never really did any counseling. He never gave me no suggestions or tried to help me in any way." (Y9172) Another participant with persistent depression acknowledged that some providers were helpful but overall felt likely to receive a provider who would not help: "they have great psychologists who will help you live a healthy successful life, and they have those who don't care, and I've been to them all. They just come in, you have your medicine, and then you leave, and that is what a lot of the mental health care providers do also—they don't listen to you." (W7494)

While many participants with persistent depression expressed negative past experiences of mental health care, some were satisfied with the care they received because providers took sufficient time to understand participants' circumstances and establish strong relationships. One participant with persistent depression said her therapists "actually work with me, probably more than they would anywhere else....That's how they make it seem, that's how they make it look to me: like I'm just having a conversation with someone. And it helps. It makes me feel more comfortable. They don't hold back. We kind of get to know each other well and, that's what is helping me open up." (K4952) Another participant with persistent depression expressed that feeling like her provider truly cared about her was an important aspect of continuing their care: "She cares about the way I feel, she cares about what I go through and that really sits a long way with me, you know it goes a long way with me." (X9240) Although many participants shared preferences for one-on-one counseling, others noted finding this type of connection in group therapy. One participant with persistent depression said it was helpful, "Just being able to speak to other people that were having the same issues you were having...and feeling like I wasn't a total stranger, that they were other people in the room that had problems sometimes greater than mine, but at least I felt like we were equal." (Y9172)

Financial barriers.: Financial stress was commonly discussed by both participants with persistent or improved depression. Descriptions of financial stressors often indicated extreme poverty and difficulty receiving services. One participant with improved depression noted, "I get food stamps, but sometimes at the end of the month, you know how it goes. You go short with food." (Z4505) Financial hardship impaired many participants' ability to seek care for their depression. One participant with persistent depression said, "I was looking for a therapist...I don't have any insurance right now—it's been kind of difficult, and I've been getting passed around." (Z4119) Another participant with persistent depression described multiple barriers to access and continuity of care, saying, "I've been trying to change healthcare plans [and] I don't think I can see my therapist much longer... they're contracted to [County Health Plan]. And when I went there for my first doctor's appointment...you gotta wait for about 65 people [to] go in before you." (Q7680)

<u>Logistical barriers.</u>: Few participants with improved depression endorsed logistical barriers to accessing mental health care. In contrast, logistical barriers to care were extensively discussed among those with persistent depression, including difficulty getting to the care setting, difficulty getting an appointment or referral, or not knowing where to get help. One participant with persistent depression said, "I have been trying to get in for mental health for four months now and after I got the referral, I couldn't get an appointment for two months even to get in there...So it is the waiting thing just trying to get in to see somebody." (Y9172)

Discrimination.: Interview participants with persistent and improved depression described numerous experiences of discrimination within healthcare settings due to their race, ethnicity, preferred language, or social status. Discrimination-related barriers were discussed by participants of both Black or African American and Latina race/ethnicity. One participant with improved depression said, "I hate to say it but it's a silent racism going on here with the doctors and the nurses" (M8580). Another participant with persistent depression described experiencing racism in the neighborhood where she sought mental health treatment, saying, "I did have an experience--they didn't turn around and say anything to me but I can tell by the way I was looked [at] that I was not—by the color of my skin, I was not too welcome in that neighborhood." (Q7860) Latina participants whose preferred language was Spanish reported experiencing discrimination in healthcare settings, including feeling ignored, not receiving interpretation services, and being reprimanded for not speaking English.

# **Discussion:**

Among a sample of African American and Latina women with depression seeking care at social service agencies in Los Angeles, we found that depression persisted among 66% after a period of three years. A similar rate of persistent depression was observed among the full CPIC study sample at 3-year and 4-year follow-up (Arevian et al, 2019; Ong et al, 2017). In previous analyses comparing two methods of depression care dissemination among a subsample of largely low-income, minority women from CPIC, we found that a multi-sector, community-engaged approach vs. a technical assistance approach resulted in few differences in mental health care use by intervention group, but was effective at improving numerous outcomes at 6- and 12-month follow-up, including increased mental health quality of life

and reduced experience of structural and logistical barriers to depression care (Ngo et al, 2016). However, our study found that a high proportion of minority women continued to suffer with life difficulties, social stressors, and barriers to care at 3-year follow-up. Consistent with literature noting the association of social stressors with indicators of mental health among minority women, we found that many life difficulties were more prevalent among participants with persistent depression (Holden et al, 2013; Holden et al, 2012; Perry et al, 2013). These findings are consistent with results within the parent study indicating the association of social stigma, lower income, and experience of chronic medical conditions with fewer periods of remission during 3 years of follow-up (Arevian et al, 2019), as well as other studies linking the experience of socioecological factors and stressors with depression outcomes (Poleshuck et al, 2019; Starkey et al, 2013).

In addition, although seeking help for depression or mental health was reported as the top priority for many female participants with persistent depression, outpatient mental health care was recently accessed by only half of the sample, and fewer reported seeking treatment specifically to manage their depression. These rates were similar to those found in previous studies (Alegria et al, 2008). Quantitative and qualitative findings from this sample elucidate the barriers to mental health care that may explain this gap between prioritization of and access to mental health care. Barriers including uncertainty regarding the value of care, financial stressors, structural barriers to care access, negative past experiences, and the stigma of help-seeking were particularly high. Despite these barriers, qualitative findings revealed that many participants planned to initiate or were currently accessing care for their depression, and highlighted sources of social support (e.g., friends, family, religious and social organizations) and self-care activities (e.g., physical activity, hobbies) that were helpful for participants in managing their depression. To address these barriers, our findings support interventions to improve accessibility (e.g., improved care coordination and referral, expanded coverage or affordability), care experiences (e.g., emphasis on counseling or mentorship vs. medication management or documentation of symptoms alone), and concordance of care (e.g., by provider background, experiences, and language) for women with depression.

Interview findings both substantiated barriers identified in questionnaires and provided further information about the nature of barriers to care among minority women. Women in both the questionnaire and interview samples reported multiple interfaces with healthcare and social service settings but still faced a lack of care options or coverage, difficulties receiving referrals or appointments for care, and a lack of compassionate care in accessing treatment for mental health. This suggests these mechanisms may be important drivers of disparities in access to mental health care (Alegria et al, 2008; Lee et al, 2014; Simpson et al, 2007). In particular, participant perspectives illustrated negative experiences with mental health providers – including judgment, lack of caring and listening, and disrespect – and numerous experiences of discrimination (Nicolaidis et al, 2010). These interpersonal aspects of care were central to participants' perceptions of the value of care, suggesting these features are important to assess in studies of the quality of behavioral health care and to target as strategies to lessen disparities.

Past studies have noted perceived need for mental health care was less common among racial/ethnic minorities compared to whites (Breslau et al, 2017; Green et al, 2020). In our study, quantitative results indicated that the most common barrier to accessing mental health care among participants was a perception that participants could overcome their problems by themselves. Yet qualitative perspectives revealed that this perception was due neither to inexperience with mental health care nor to high levels of self-efficacy with regard to managing depression. Instead, participants who may have reported that they preferred to manage problems on their own had sought care in the past or were currently seeking treatment but had endured negative past experiences with care or were struggling to access treatment that felt valuable. This suggests lower levels of perceived need for mental health care may reflect inadequacies in care quality and care access for minority women.

This study has several limitations. To elaborate on quantitative findings from the CPIC 3-year follow up sample, we use qualitative data from a non-random subsample designed to increase diversity of perspectives. Qualitative findings may not provide comprehensive accounts of barriers and life events due to differences in samples. Our quantitative findings are limited to descriptive analyses of the prevalence of barriers to care, life difficulties, and health care utilization. Causal inference could also be bidirectional, such as life difficulties leading to or resulting from persistent depression. In addition, we do not interrogate the directionality in the relationship between utilization of mental health care and depression outcomes, such as the extent to which participants' help-seeking is driven by more severe illness or receipt of less effective treatment. Future studies may benefit from model-based analyses to assess relationships between these factors, such as the effect of barriers on rates of utilization or racial and ethnic differences in report of barriers to care. While we assessed utilization of various types of mental health care, we did not assess the type or quality of services delivered at health care visits, limiting our ability to ascertain rates of depression screening, psychotherapy, medication management, or other evidencebased practices for depression. Finally, data focus on outcomes and barriers to long-term improvement in depression reported at 3-year follow-up; they may not capture the range of dynamic depression experiences across the entire 3-year follow-up period and may not reflect outcomes or barriers that would have been reported at other points in time (e.g., 24 months). However, consistent with recommendations to include a focus on personal experience of social risks in guiding clinical practice (Davidson et al, 2021), our study describes the personal perspectives of women with a history of at least moderate depression during a 3-year follow-up period.

### Conclusion:

Among a sample of African American and Latina women with depression recruited from health and social service organizations in low-income communities in Los Angeles, we identified substantial barriers to accessing mental health treatment which participants often linked to past salient experiences of disregard, disrespect, and racism in receipt of mental health care. We also identified suboptimal rates of utilization of depression treatment and substantial financial and logistical challenges to accessing mental health care. Particularly women with persistent depression report high levels of negative life circumstances, and they describe these as making recovery from depression substantially more difficult. In addition

to efforts to improve quality of depression care, addressing issues of violence, trauma, food and housing insecurity, and under- and unemployment are crucial to facilitating women's recovery from depression. Programs and policies to expand options for mental health care in low-resource settings and interventions to improve personalized care are likely to improve treatment among women facing depression.

# **Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

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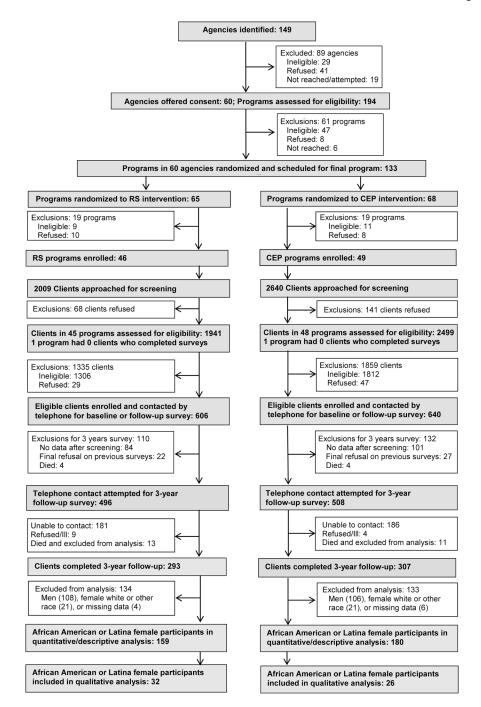
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**Figure 1.**Trial Profile: Community Partners in Care, African American and Latina Female Substudy Sample, Los Angeles, CA, 2010–2014

 $\label{eq:Table 1.} \textbf{Table 1.}$  Participant Characteristics and Healthcare Utilization, n=339

Characteristic a	Total n=339	Persistent Depression N=224	Improved Depression N=115	P-value
Age, mean (sd)	48.2 (11.9)	49.0 (11.6)	46.6 (12.5)	0.074
Race/ethnicity <sup>b</sup> , n (%)				<.001
African American	187 (55.2)	140 (62.5)	47 (40.9)	
Latina	152 (44.8)	84 (37.5)	68 (59.1)	
Less than high school education $^b$ , n (%)	157 (46.7)	97 (43.9)	60 (52.2)	0.149
Married or living with partner, n (%)	81 (23.9)	39 (17.4)	42 (36.5)	0.194
Working for pay, n (%)	93 (27.4)	48 (21.4)	45 (39.1)	<.001
Family income from work <\$10,000, past 12 month, n (%)	248 (75.8)	177 (81.2)	71 (65.1)	0.001
Experiencing homelessness or 2 risk factors for homelessness, n%	106 (31.4)	80 (35.9)	26 (22.6)	0.013
Depression self-efficacy, mean (sd)	6.4 (2.5)	5.8 (2.5)	7.7 (2.1)	<.001
No health insurance $^b$ , n (%)	146 (43.6)	99 (44.6)	47 (41.6)	0.6
PHQ-8 score, mean (sd)				
At study screening	14.6 (3.9)	15.3 (4.2)	13.2 (3.0)	<.001
At 36-month follow-up	12.2 (6.3)	15.8 (4.0)	5.1 (3.0)	<.001
Have 3 chronic medical conditions $^b$ , n (%)	183 (58.7)	140 (68.3)	43 (40.2)	<.001
Healthcare utilization, past 6 months, n (%)				
Hospitalizations				
Hospitalized for medical/health reason	63 (18.6)	48 (21.4)	15 (13.0)	0.06
Hospitalized for emotional, mental health, alcohol or drug problems	13 (3.8)	8 (3.6)	5 (4.3)	0.725
Emergency room (ER) care				
Visited ER for health problem	135 (39.9)	111 (49.6)	24 (21.1)	<.001
Visited ER for emotional, mental, alcohol, or drug problems	42 (12.4)	36 (16.1)	6 (5.3)	0.004
Outpatient care				
Visited primary care provider	257 (75.8)	179 (79.9)	78 (67.8)	0.014
Had any mental health outpatient visit	148 (43.7)	122 (54.5)	26 (22.6)	<.001
Had any visit to mental health provider where received advice about medication for emotional or mental health problems	127 (37.6)	104 (46.4)	23 (20.2)	<.001
Had any mental health outpatient visit in which received counseling	108 (34.1)	87 (42.4)	21 (18.8)	<.001
Had any outpatient primary care visit for depression	114 (33.7)	90 (40.4)	24 (20.9)	<.001
Met with case manager for depression	82 (24.3)	68 (30.4)	14 (12.3)	<.001
Substance abuse treatment				
Stayed in residential treatment facility for substance abuse problems	10 (2.9)	7 (3.1)	3 (2.6)	0.79
Visited substance abuse agency or self-help meeting	47 (13.9)	37 (16.5)	10 (8.7)	0.048

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Improved Depression N=115 Persistent Depression N=224 **Total**  ${\it Characteristic}^a$ n=339 P-value Other mental health services 16 (13.9) Attended self-help or family support groups for emotional or 88 (26.0) 72 (32.1) <.001 mental health problems Called hotline for emotional, mental, alcohol, or drug 0.064 16 (4.7) 14 (6.3) 2 (1.7) problems

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<sup>&</sup>lt;sup>a</sup>Variables with missing responses were not imputed. Variables had no or low missingness, with the exception of Depression self-efficacy (n=319/339), Working for pay (315/339), and Number of chronic conditions (n=312/339).

b Race/ethnicity, educational attainment, chronic medical conditions, and health insurance status were only assessed at baseline. All remaining variables reflect assessment at 3-year follow-up.

**Table 2.**Barriers to Mental Health Care and Life Difficulties among African American and Latina Women with Persistent and Improved Depression at 3-Year Follow-up, n=339

	Total Sample n=339	Persistent Depression N=224	Improved Depression N=115	P-value
Barriers to Mental Health Care				
Stigma and Care Experience Barriers, n (%)				
You thought you could get over your problems by yourself	166 (49.1)	123 (54.9)	43 (37.7)	0.003
You were afraid of what others would think	118 (34.8)	95 (42.4)	23 (20.0)	<.001
You didn't think you could be helped	116(34.2)	91 (40.6)	25 (21.7)	<.001
You were embarrassed to discuss the problem with anyone	114 (33.6)	91 (40.6)	23 (20.0)	<.001
You did not think you would be treated with dignity and compassion	78 (23.1)	60 (26.9)	18 (15.7)	0.02
Financial Barriers, n (%)				
You needed to spend the money on other things like food, clothing, or housing	156 (46.2)	118 (52.7)	38 (33.3)	<.001
You worried about the cost	95 (28.2)	72 (32.3)	23 (20.2)	0.019
Your health plan wouldn't pay for treatment	82 (24.8)	64 (29.6)	18 (15.8)	0.006
The provider wouldn't accept your health insurance	67 (20.1)	48(22.0)	19 (16.5)	0.234
You would lose pay from work	50 (14.9)	31 (14.0)	19 (16.5)	0.542
You needed someone to take care of children	51 (15.0)	33 (14.7)	18 (15.7)	0.822
Logistical Barriers, n (%)				
You couldn't get an appointment soon enough	111 (32.8)	87 (39.0)	24 (20.9)	<.001
You could not find out where to go for help	105 (31.1)	87 (39.0)	18 (15.7)	<.001
It takes too long to get to the office from home or work	93 (27.7)	76 (34.4)	17 (14.8)	<.001
You couldn't get to the provider's office when it was open	79 (23.6)	66 (29.9)	13 (11.4)	<.001
You couldn't get through on the telephone	80 (23.8)	62 (28.1)	18 (15.7)	0.011
Discrimination-related Barriers, n (%)				
No one spoke your language at clinic	38 (11.3)	25 (11.3)	13 (11.3)	0.991
You felt discriminated against because of your race or ethnicity	34 (10.1)	25 (11.2)	9 (7.9)	0.339
You were afraid you would get deported	19 (5.6)	13 (5.8)	6 (5.2)	0.824
Total Barriers, n (%)				
1 barrier to mental health care	226 (72.4)	165 (81.7)	61 (55.5)	<.001
2 barriers to mental health care	202 (64.7)	150 (74.3)	52 (47.3)	<.001
Life Difficulties				
Financial Difficulties, n (%)				
Worried about food	178 (52.7)	131 (58.7)	47 (40.9)	0.002
Had major financial problem	121 (35.7)	91 (40.6)	30 (26.1)	0.008
Avoided answering the phone due to bill collectors	106 (31.4)	81 (36.3)	25 (21.7)	0.006
Tried to find work but gave up because hard to find	97 (28.7)	74 (33.2)	23 (20.0)	0.011

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Improved Depression N=115 Persistent **Total Sample** Depression N=224 n=339 P-value Work hours involuntarily reduced 42 (12.4) 30 (13.5) 12 (10.4) 0.425 35 (10.3) 21 (9.4) 14 (12.2) 0.423 Lost health insurance coverage 32 (9.4) 29 (12.9) 0.002 No place to stay for at least 2 nights in a row 3 (2.6) Laid off or fired from work 31 (9.2) 22 (9.9) 9 (7.8) 0.538 Evicted or had house foreclosed 12 (3.5) 10 (4.5) 2(1.7)0.199 Trauma-related Difficulties, n (%) Someone close died 118 (34.8) 98 (43.8) 20 (17.4) <.001 Witnessed someone getting beaten/abused/killed 36 (10.7) 30 (13.5) 6(5.2)0.02 9 (2.7) 8 (3.6) 1 (0.9) 0.143 Arrested or on probation Lost custody of any children 7 (2.1) 5 (2.2) 2 (1.7) 0.762 Relationship Difficulties, n (%) 93 (41.5) 24 (20.9) <.001 Had serious problem with friends/relatives 117 (34.5) 71 (20.9) 56 (25.0) 15 (13.0) 0.01 Had serious argument with someone 22 (9.8) 0.379 Had arguments or other difficulties with people at work 30 (8.8) 8(7.0)Total number of life difficulties, mean (SD) 2.7 (2.3) 3.2 (2.3) 1.9 (2.0) <.001

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 $\label{eq:Table 3.} \textbf{Life Difficulties among Interview Participants}, \, n = 58$ 

Category	Theme	Sample Quote(s)		
Financial Difficulty finding work or financial support		It all falls back on a job. Everything that I am saying that I need help in fall right back in the job. If I had a job, I could go further. (Participant with improved depression, Z4505)		
	Lack of stable or safe housing	The paint peels off the tub, peels off the sink, and peels off the walls. I was in here 21 days with no heat and they didn't want to put a heater in here and this was during the winter time (Participant with persistent depression, Y9172)		
	Food insecurity	I get food stamps. But sometimes at the end of the month, you know how it goes. You go short with food. (Participant with improved depression, Z4505)		
	Sexual or physical abuse	My mother says 'it wasn't your fault.' My nephew says the same thing. You know, when you are raped, you feel so dirty. Your insides feel so dirty no matter how many times you take a bath, you still feel so dirty. (Participant with persistent depression, X9291)		
	Experiencing or witnessing violence	I'm constantly dodging it whether I'm out on the street trying to find somewhere safe to be. Or whether I'm actually back visiting relatives, you know? (Participant with improved depression, S5682)		
Relationship	Loss of loved one or relationship	I had a brother that died, I think it was from alcoholism. (Participant with persistent depression, W5306)  Me and my husband separated. That was really, really bad I just—I wanna be close with my kids and—I miss that. (Participant with persistent depression, N7618)		
	Lack of social support	I have a lot of anger issues and I have um trauma issues and um so I just it's kind of hard to get alongwith others. So I stay isolated and I don't have to deal with a relationship too much. (Participant with persistent depression, Z4119)		
Medical	Chronic conditions	it's just the pain I have everyday. I have so much pain in my knee. It's swollen and it's hard for me to walk. (Participant with improved depression, T4837)		
	Hospitalizations	I wound having a heart attack and stroke behind that I developed another issue with my heart where my heart rate just bottoms out. So most of the issues and the illness that I have are all from stress. (Participant with persistent depression, Y9172)		

 $\label{eq:Table 4.}$  Perspectives on Barriers to Mental Health Care among Interview Participants, n=58

Barrier Category	Theme	Sample Quote(s)
Stigma & Care Experience	Feeling that care would not help	I don't know what it is that I'm looking for that would balance out my feeling better. Cause I don't know what I'm looking for. I don't know how to tell you I'm getting the desired results because I don't know what the desired results are. (Participant with persistent depression, B3654)
	Not wanting to have a stigmatized condition	[My therapist] hasn't deemed it necessary that I should see a psychiatrist and see if I need a psychotropic, which I pray I don't I wasn't crazy like that kind of crazy likeI know I'm not crazy. (Participant with persistent depression, Q7680)
	Difficulty discussing feelings	I'm kind of a private person. I don't really like for everybody to know what I'm going through. (Participant with persistent depression, K4952)
	Negative past experiences with mental health providers	It took me a long time to get a therapist, one that actually understand me. Some of them seem like they were just doing it, they were just there because it's their job and they just want to get paid. (Participant with persistent depression, K4952) I've seen a lot of therapists and a lot of psychiatrists since I was very young and I've been betrayed by a couple of them. (Participant with persistent depression, Z4119) I think sometimes, I wish that [my psychiatrist] would understand me a little bit more. I still feel like there's no one there to help me, you know? Like they're not understanding me, and then so I start to cry. And um, I'm just another [person] walking in that door, you know? (Participant with persistent depression, B3524)
Financial	Lack of insurance	It takes a while to find a good therapistI just haven't in the last two years because I didn't have insurance. (Participant with persistent depression, W7494)
	Care not affordable	I can't afford to pay for no place to go. Everyone wants money and I don't have money to pay for all of these different services. (Participant with persistent depression, W5306)
Logistical	Difficulty getting to clinic/office	And then walking to Mental Health, there's no bus at all. I got to walk all the way—the whole walk, and I don't have no other support besides the cane. (Participant with persistent depression, N7618)
	Difficulty getting an appointment	It is the waiting period. I have been trying to get in for mental health for four months now and after I got the referral, I couldn't get an appointment for two months even to get in thereSo it is the waiting thing just trying to get in to see somebody. (Participant with persistent depression, Y9172)
	Difficulty getting a referral	[My provider] was supposed to refer me but she didn't." (Participant with persistent depression, B3654) Right now, I am just waiting on a referral to go to a new mental health provider. And it takes a while for them. (Participant with persistent depression, W7494)
	Not knowing where to find help	I need somebody to help me think about which way to go, to advise meI don't know. (Participant with persistent depression, B3654)
	Suboptimal care options	When I went there for my first doctor's appointment they all put you in a big room for cattle call, give you a number- 'you're number 20 and you're number 85' and you gotta wait for about 65 people go in before you. (Participant with persistent depression, Q7680)  I don't like none of the mental health offices I've been in, to tell you the truth. They are all overcrowded andits small. It's like 'write a script and wait.' (Participant with improved depression, M8580)
Discrimination	Racism	I did have an experiencethey didn't turn around and say anything to me but I can tell by the way I was looked that I was notby the color of my skin, I was not too welcome in that neighborhood. (Participant with persistent depression, Q7680)
	Discrimination	"Tuve una experiencia con un doctor que cuando entre a la consultael me dijo, 'porque no hablas inglés?' Y entonces le dije 'no puedo memorizar y eh tratado'. Pero siento que no puedo, que lo que aprendo hoy se me olvida al ratito. Entonces se molestó mucho y me dijo que saber el inglés porque vivía en América. Y este sentí que tenía ganas de llorar y me salí triste, me salí deprimida porque pensando por qué no puedo yo hablar inglés. Por qué me tratan así?" (Participant with persistent depression, A7016) * I felt like I was discriminated against a lot down there I felt like that these women who are in these positions who are—weren't trying to help me (Participant with persistent depression, Z4119)
	Lack of concordant care	It's like, where are the black group leaders? I can't sit in here and talk about my life. I need to talk to older black women in the group, not a young Latino in the group. (Participant with improved depression, M8580)

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Barrier Theme Sample Quote(s)

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It's like getting a drug counselor and she's never taken drugs before, but yet she's sitting there counseling you. What is she really gonna tell you? (Participant with persistent depression, B3524)

<sup>\*</sup>English translation: "I had one experience with a doctor, who when I came into the office ... he said, 'Why don't you speak English?' And then I said, 'I can't memorize and I have tried.' But I feel like I can't, that what I learn today I forget after a while. Then he got very upset and he told me to know English because I lived in America. And I felt like I wanted to cry and...I left [that visit] very sad, I left depressed because I was thinking why can't I speak English? Why do they treat me like that?"