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Disclosure of Depression in Primary Care: A Qualitative Study of Women's Perceptions

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Abstract

Background: Health care providers are better able to diagnose depression and initiate treatment when patients disclose symptoms. However, many women are reluctant to disclose depressive symptoms. Little is known about the experience of disclosing depression symptoms in primary care among racially and ethnically diverse women across the life course. We qualitatively explore experiences of disclosure of depressive symptoms to primary care providers among self-identified African American, Hispanic and non-Hispanic White women.

Methods: Twenty-four women with depression were recruited for open-ended interviews. We recorded, transcribed, and coded interviews using inductive content analysis.

Findings: Two distinct domains emerged: participant factors that hinder and facilitate disclosure and provider cues that encourage and dissuade discussing depression. Participants described perceptions about primary care not being the appropriate place, fear of not having a choice in treatment decisions, and the emotional cost of retelling as impediments to disclosure; perceiving an increased likelihood of getting help was described as a facilitator. Women identified provider behaviors of asking about depression and showing concern as facilitators, and provider time constraints as a barrier to disclosure.

Conclusions: Women perceive that primary care is not the appropriate place to disclose depression symptoms. Increased public education about behavioral health management in primary care, as well as more robust integration of the two, is needed. Efforts to improve depression disclosure in primary care must also encompass systematic use of depression screening tools and implementation of targeted interventions to cultivate provider empathy.

Depression disproportionately affects women ([National Institute for Health Care Management Foundation, 2010](#)) and adversely affects their health and well-being ([Pan et al., 2011](#), [Song et al., 2012](#) and [Zhang et al., 2005](#)). Despite existing effective treatments, many do not receive adequate depression treatment ([Young, Klap, Sherbourne, & Wells, 2001](#)), and disparities in the receipt of adequate treatment persist ([González et al., 2010](#) and [Witt et al., 2011](#)). Women may not receive treatment because they are not screened by health care providers or because they do not disclose symptoms ([Cepoiu et al., 2008](#)). Missed depression diagnoses are an important problem given that the cost of treating depression is far less than societal costs associated with lost productivity or suicide ([Goldman, Nielsen, & Champion, 1999](#)).

Research shows that health care providers are more likely to initiate treatment when patients disclose depressive symptoms or directly request help ([Kravitz et al., 2005](#) and [Tylee et al., 1995](#)). However, disclosure of depression occurs infrequently during medical

encounters ([Robinson and Roter, 1999](#) and [Sleath and Rubin, 2002](#)). Although studies examining depression symptom disclosure among women have identified barriers including stigma, lack of time, and lack of trust in providers ([Dennis and Chung-Lee, 2006](#), [Goodman, 2009](#) and [Jesse et al., 2008](#)), these studies have focused on postpartum depression. Little is known about women's experiences when disclosing depressive symptoms outside of the perinatal period. Although a large number of adults seek depression care in primary care ([Marcus and Olfson, 2010](#) and [Substance Abuse and Mental Health Services Administration, 2009](#)), few studies have focused on depressive symptom disclosure in this setting. Those focused on this disclosure found that 43% of adults reported at least one reason for nondisclosure of depression symptoms ([Bell et al., 2011](#)) and that perceptions of primary care providers' mental health-related capabilities and interests ([Kravitz et al., 2011](#)) are barriers to disclosure among predominantly White samples.

Although these studies highlight important barriers to disclosure in the primary care setting, little is known about the experience of disclosing depression symptoms in this setting among racially and ethnically diverse women across the life course. To address these gaps, this study uses qualitative methods to explore the experience of depression disclosure in primary care settings among self-identified African American, Hispanic, and non-Hispanic White women.

Methods

Study Participants

We conducted semistructured interviews with a convenience sample of English-speaking African American, Hispanic, and non-Hispanic White women. Women were age 18 and older and reported a current or previous diagnosis of depression or met diagnostic criteria for current depression (score ≥ 10) based on the eight-item Patient Health Questionnaire depression scale (PHQ-8; [Kroenke et al., 2009](#)). The PHQ-8 includes eight of the nine DSM-5 diagnostic criteria for the diagnosis of depression. It is different than the PHQ-9, in that it omits a question which assesses suicidal or self-injurious thoughts. We used the PHQ-8 because the study interviews were conducted in public non-

clinical settings thereby limiting our ability to provide adequate follow-up if the women expressed suicidal or other harmful ideation. The PHQ-8 is a valid measure of depression ([Kroenke et al., 2009](#)) and research has shown that identical scoring thresholds could be used for both the eight- and nine-item scales ([Kroenke & Spitzer, 2002](#)). To focus on the experience of disclosure independent of access to care, we excluded women who had not seen a health care provider in the previous year.

The local institutional review boards approved this study. Over a 6-month period, we recruited participants from a Midwest city in the United States through online postings on Craigslist, flyers in local clinics, and letters sent to African American and Hispanic patients from a local women's internal medicine clinic. Our goal was to recruit 10 women within each group. Participants each received a \$50 stipend.

Data Collection

The principal investigator conducted all interviews using a semistructured interview guide ([Appendix](#)). Interviews lasted an average of 56 minutes and were recorded and professionally transcribed. The coding team (A.O.K., R.J.S.) reviewed transcripts for accuracy.

Data Analysis

We examined transcripts for patterns and key content-related categories using inductive content analysis. Inductive content analysis uses open and unstructured coding to allow for identification of previously unidentified or unexpected thematic categories ([Elo & Kyngas, 2008](#)). The coding team independently reviewed the first three transcripts line by line and generated initial codes. They then met to discuss similarities and differences in code definitions. After reaching consensus on the definition and meaning of each code, a revised code list was created by collapsing codes that were similar into broader higher order categories ([Elo & Kyngas, 2008](#)). The first three interviews were recoded using the agreed upon codebook. The coding team continued to modify codes and add codes and thematic categories throughout the analysis process. All transcripts were coded

with the final code list. Additionally, a co-investigator not involved in the initial phases of the analysis (E.A.J.) audited the final codes for consistency, clarity, and comprehensiveness.

As part of our analyses, we separated the transcripts by White, African American, and Hispanic patient groups and assessed similarities and differences in codes and thematic categories by race and ethnicity. This was based on previous research demonstrating that there are often meaningful differences in the substantive content of themes emerging from qualitative analyses about preferences and experiences of care across diverse racial and ethnic groups ([Mulvaney-Day et al., 2011](#) and [Tucker et al., 2003](#)). We used QSR International's NVivo 10 qualitative data analysis software ([NVivo qualitative data analysis software, 2012](#)) for managing codes and themes.

Results and Discussion

Study Participants

Thirty-four women responded to recruitment efforts; 31 were eligible, 28 were scheduled for interviews, and 24 interviews were completed (10 White, 9 African American, and 5 Hispanic). Participants were between the ages of 18 and 58 years (mean, 40), and their PHQ-8 scores ranged from 3 to 24 (mean, 14.7; scores ≥ 10 identify current depression; [Table 1](#)). Of the 24 women interviewed, 20 (83%) met the diagnostic criteria for current depression using the PHQ-8. The PHQ-8 scores for the four women who did not meet the criteria were 3, 9, 9, and 9; all four of these women reported a previous depression diagnosis.

Table 1. Demographic Characteristics of Participants Overall and by Race and Ethnicity

	Overall (n = 24)	African American (n = 9)	Hispanic (n = 5)	White (n = 10)
Average age, y (range)	40 (18–58)	42 (21–55)	43 (35–54)	38 (18–58)
Average PHQ-8 score, (range)	15 (3–24)	16 (11–22)	14 (9–24)	14 (3–20)
Average no. of doctor's visits past year, (range)	5 (0–10+)	4 (0–10+)	5 (3–10+)	6 (1–10+)

	Overall (n = 24)	African American (n = 9)	Hispanic (n = 5)	White (n = 10)
Insurance type (n)				
Private	11	2	3	6
Public	9	4	2	3
None	3	2	0	1
Education level (n)				
<High school	3	3	0	0
High school/GED	11	5	3	3
Technical school	2	0	0	2
College degree	8	1	2	5
Self-rated health (n)				
Excellent	1	0	0	1
Very good/good	17	7	4	6
Fair/poor	6	2	1	3
Receiving depression treatment (n)				
Counseling	16	3	3	10
Medication	18	6	5	8

When women spoke about disclosure, two distinct domains emerged: participant factors that hinder and facilitate disclosure and provider cues that encourage and dissuade discussing depression. We present the themes that emerged within each domain. Differences by race and ethnicity are discussed when present.

Domain 1: Participant Factors that Hinder and Facilitate Disclosure

Participants commonly brought up four factors that hindered disclosure of depressive symptoms: 1) the perception that primary care providers were not the right people to talk to about depression, 2) being afraid of not having a choice in treatment decisions, 3) the emotional cost of retelling their story, and 4) difficulty recognizing and accepting symptoms. They described one facilitator to disclosure: perceiving that they would likely get help.

Primary care providers are not the right people

Women emphasized the distinction between physical and mental health and talked about how primary care providers were not the appropriate people with whom to discuss their depressive symptoms. One White woman described this distinction by saying, "I feel like the [primary care doctor] should be working on stomach hurts, you know, stitches kinda thing, not really mental. I think they're more with the physical." Additionally, a White woman said: "You don't really want to necessarily talk about something like that to your [primary care doctor] because all your life you've associated them with just, Oh, I'm going in there for a broken arm, or I've got the flu."

Both of these quotes illustrate that, although women made the assumption that primary care providers were only concerned with physical health, they were uncertain, as evidenced by their tentative language of "You don't really want to necessarily talk about [mental health]," and "I think they're more with the physical." Rather than clarifying this assumption with providers, women chose not to engage in this type of clarification, suggesting that other factors may be involved in their intentions to disclose.

Being afraid of not having a choice in treatment decisions

Women described being afraid that they would not be included as active participants in decisions about treatment. A Hispanic woman spoke about how she did not trust that her provider would respect her choices if she fully disclosed her feelings.

If I tell them exactly that, the feelings that I've had lately where I'm feeling so overwhelmed, then they'll wanna step in and either medicate me.... And I don't wanna be at that point. I think what I want is the choice, the choice to go in and get the help without having it forced on me, which is why I don't really tell her everything.

As this quote suggests, even when women disclose symptoms, they may not share the severity of their symptoms owing to the fear of not being included in decision-making processes.

Emotional cost of retelling

Even in cases where women perceived the initial disclosure of symptoms to be beneficial, having to change providers and go through the emotional process of retelling their story was a barrier. An African American woman explained,

It was helpful. You know it made me feel a little bit better. But then going through the whole initial thing again and having to explain why you're feeling this way—you know kinda feels like, mm, maybe I don't want to go through this again because you don't.

This suggests that women treat each opportunity to disclose symptoms as discrete and emotionally burdensome events. Even if they benefited from disclosing symptoms in the past, the need to repeatedly retell their story, often caused by discontinuity in care, can deter disclosure of recurrent or persistent symptoms.

Recognizing and accepting

African American and White women, but not Hispanic women, spoke about having difficulties identifying the way they were feeling as symptoms of an illness. One White woman described the difficulty in this way, “[women] are not gonna recognize it a lot of times. I mean that's the first thing is they're not gonna know what's happening. They're not gonna know this isn't normal.” An African American woman described an experience where she did not accept her depression diagnosis. “And I told [the doctor] how I was feeling, and he pinpointed it as being depressed. I didn't see it as being that.” Women often described the increasing severity of symptoms as what ultimately led them to disclose symptoms to their primary care provider. One White woman described her reasons for disclosure by saying, “The only reason I finally told somebody about is, I mean I was just absolutely against the wall, could not do it anymore.”

Women seemed to be more willing to disclose when the severity of their symptoms exceeds their individual coping resources. However, if they did not believe in the biomedical model of the etiology of depression held by most clinicians, they may be less likely to believe

that a clinician is the person to talk to and therefore not initiate or continue treatment.

Likelihood of getting help

Although women doubted the appropriateness of talking about depression with their primary care provider, women were more likely to do so if they perceived that disclosing symptoms would ensure receiving help. One African American woman said, "I would want them to offer the whatever it is—medication they offer... I would expect them to do that or recommend you to like a therapist or something." A White woman described her expectations of her provider the following way:

It has always been hard for me to open up to people, and I think for that to happen with someone who's kind of a complete stranger, I need to feel some kind of, I don't know if connection is the right word, but to feel confident that telling them will actually do something.

This quote suggests that the perception of getting help may result from a sense of connection and trust with the provider, suggesting that provider cues are important in influencing patients' beliefs about disclosure.

Domain 2: Provider Cues that Encouraged and Dissuaded Discussing Depression

Perceptions about the appropriateness of disclosing to primary care providers were likely reinforced by provider behaviors during disclosure attempts. Specifically, women identified the behaviors of asking about depression along with showing sincere concern as facilitators to disclosure and provider time constraints as a barrier to disclosure.

Asking questions

One Hispanic woman described not telling her provider how she feels unless she is asked directly.

If you really wanna know what's going on, I'll tell you. But if I don't get asked those questions then I kinda shut down because I- I'm like, 'It's fine,' and then I don't tell them exactly what's really going.

Additionally, a White woman said, "I know if my medical doctor would have asked me something I would have—I would have told them something. Like it's um—people are looking for that opportunity to get help."

Both of these quotes illustrate the importance of providers initiating direct conversations about depression in women's disclosure process. Along with asking about depression, women wanted providers to create a safe space where they felt that the information shared would be protected. Specifically, they described the need to keep that "very fragile piece of you in a protective stance" and that without assurances of such protection, they were less willing to disclose.

Sincere concern

Although a critical component of women's willingness to disclose, asking about depression in and of itself was not enough to encourage women to disclose their feelings. Questions about depression needed to be combined with a demonstration of sincere concern. One Hispanic woman described a situation where she was asked questions about her mood, but the provider did nothing to address her response and therefore she determined the provider was not actually concerned about her well-being.

And I think they, they tried asking me, 'How are things at home?' And when I would say, 'Well, they really suck,' They'd be like, 'Oh, okay,' and then they would just move on. [laughter] So I'm like, 'Okay, you didn't really wanna know about that. Um, why did you ask me about that?'

Women perceived that their provider was sincerely concerned about them when providers listened to them and made them feel comfortable through a positive connection. One African American woman noted the importance of feeling comfortable in the following terms: "It has to be someone that's—makes you feel comfortable and have to go that little extra yard of asking you more questions about

yourself and about them, and relating to you is real important too." A Hispanic woman described how her provider showed concern by listening: "This particular doctor, she's real open. So, like when you talk to her, you get the feeling that she's really concerned that she really wants to listen." Similarly, a White woman stated, "you need somebody who listens to you and who understands what you're trying to say."

One mechanism that women used to evaluate their provider's level of sincerity was through the provider's listening behaviors. As evident by their desire for providers "to go that little extra yard of asking you more questions" and demonstrate that they "understand what you're trying to say," women valued providers who were actively engaged in both listening and probing so they could explore patient statements about symptoms in greater detail and reflect back what was said. When providers seemed to be genuinely concerned and engaged, women were more willing to share information.

Time

A main barrier to disclosure was lack of time with providers. Time was described as both length of visits and frequency of contact with providers. One African American woman described how she does not see her provider enough to feel comfortable talking about her depression symptoms.

I go to a doctor it's maybe, you know, it might be for the yearly, you know, pap smear or something like that, or breast exam, just little stuff or I might go to the doctor for if I get sick in the wintertime. You know, I feel like I don't see her enough to know—actually tell her what—how I'm feelin' or ask for help because I'm only there for, you know, maybe three or four times out of the year and I don't feel comfortable with talking to her or asking her could she help me with this.

Women also expressed concerns about visits not being long enough. One Hispanic woman said:

My experience has been that doctors don't really want to get into the nitty-gritty of it because of their time managed as it is...

I used to work at a clinic, too, so I know how pressed for time you are.

Women with depression value having "face time" with primary care providers; therefore, lack of time with providers as a result of infrequent visits, short visit times and/or rushed providers prevents women from being able to fully present and discuss their feelings.

Our participants shared with us factors that hinder and facilitate disclosure of depression symptoms. Similar to previous work ([Kravitz et al., 2011](#)), this study found that women doubted the appropriateness of disclosing symptoms to primary care providers. Recent health policy efforts have focused on improving depression recognition in primary care; most notably, the U.S. Preventive Services Task Force now recommends screening for depressive disorders in the general adult population ([U.S. Preventive Services Task Force, 2015](#)). To increase compliance with U.S. Preventive Services Task Force guidelines, investigators have focused on developing depression screening tools that are minimally burdensome to both patients and providers ([Blozik et al., 2013](#) and [Corson et al., 2004](#)). Our study suggests that women are reluctant to disclose depressive symptoms to primary care providers, but that they are more open to discussing how they feel if providers ask directly about depression and show sincere concern for their responses. Empathy, "an understanding of the emotional states of others and expression of this understanding" ([Kelm, Womer, Walter, & Feudtner, 2014](#)), is not expressed in clinical encounters as often as patients would like ([Levinson, Gorawara-Bhat, & Lamb, 2000](#)). Efforts to improve depression disclosure in primary care will need to encompass increased use of depression screening tools and implementation of targeted interventions to cultivate provider empathy ([Kelm et al., 2014](#)).

We also found that women's decision to disclose often depended on the severity of symptoms and the anticipated benefit of disclosure. Even when concerned about her mood, a woman may not disclose concerns until they become severe and a threat to her well-being. Although the severity of symptoms and the desire to avoid consequences of depression might be powerful enough to encourage disclosure, we also heard that decisions about where and to whom

they will disclose their distress are driven by perceptions of the type and amount of help they will receive. Yet, confidence in the provider's ability to initiate a treatment plan was often tempered by the fear of not being included in the treatment decision-making process. Specifically, women shared their desire to have choices and not feel forced to accept a specific treatment. The desire to be an active participant in the treatment decision-making process is not unique to our study participants. Previous studies have found that the majority of individuals with mental illness desire greater participation in treatment decisions ([Adams, Drake, & Wolford, 2007](#)), particularly through shared decision-making interventions ([Deegan, Rapp, Holter, & Riefer, 2008](#)). Shared decision making creates an environment that not only encourages symptom disclosure, but may also improve the likelihood of treatment adherence, as depression treatment plans that are consistent with patient preferences have been shown to have increased initiation and adherence rates ([Raue, Schulberg, Heo, Klimstra, & Bruce, 2009](#)).

Lack of time with providers was a barrier to symptom disclosure. One potential approach to overcoming this barrier is a team approach to providing patient care ([Hopkins & Sinsky, 2014](#)). Although team-based care does not necessarily increase the amount of time patients spend with providers, by including structured interactions with other care team members this model of care encourages establishing relational ties with team members aside from the provider. Additionally, purposefully involving other health care workers in the care delivery process increases the number of health care contacts patients experience, which may result in more opportunities for disclosing symptoms. To ensure that individuals who disclose depressive symptoms are appropriately evaluated and treated, health care teams may benefit from evidence-based strategies for optimizing performance and communication, such as TeamSTEPPS ([Agency for Healthcare Research and Quality, 2016](#)).

Although the two large thematic categories identified in the study were similar between the three diverse racial and ethnic groups, there were some differences for Hispanic women. These women did not experience difficulty with recognizing and accepting depressive symptoms as a barrier to disclosure; however, Hispanic women discussed interpersonal factors, such as showing concern and time

with the provider, more frequently than their White and African American counterparts. These findings are consistent with the Hispanic cultural values of *simpatía* and *personalismo*, where emphasis is placed on politeness and pleasantness ([Triandis, Lisansky, Marin, & Betancourt, 1984](#)), and suggest that the need for a positive relationship and feeling connected with a primary care provider may be a particularly important facilitator for disclosure among Hispanic women. Future research using a larger sample of Hispanic participants is needed to know whether these differences hold.

Several potential limitations of this study should be noted. First, we excluded women who had not seen a provider in the year before enrollment in the study; therefore, our findings may not capture experiences of women with depression who did not previously seek care. This population should be a focus of future research given that women with depression who have not sought care in the previous year may be at greater risk for negative outcomes. Second, although the study found more similarities than differences among these groups of women, our ability to explore this was limited by the small number of Hispanic women in the sample. Moreover, we did not explicitly ask about how their race or ethnicity influenced their experience with disclosing depression symptoms. Race and ethnicity can be very sensitive topics, and participants may have been reluctant to raise them. Our study results show that women may not disclose depression in primary care unless the provider asks; perhaps the same dynamic may apply to issues around race and ethnicity in qualitative studies. It should also be noted that only six women reported being in poor health. Women in poor health may have more contact with their providers and therefore their experience of disclosing symptoms of depression might differ. Finally, non-English-speaking women were not included in the study, which likely contributed to the difficulty in recruiting Hispanic women. Research has shown that limited English proficiency is a barrier to mental health service use ([Sentell, Shumway, & Snowden, 2007](#)) and receipt of adequate treatment ([Keller, Gangnon, & Witt, 2013](#)). Moreover, Spanish-speaking Hispanic and English-speaking Hispanic persons have been shown to differ in their beliefs about the etiology of depression and preferences for treatment ([Fernandez, Franks, Jerant, Bell, & Kravitz, 2011](#)). Future studies are needed to explore the process of disclosing mental health symptoms in primary care among this vulnerable population.

This study has important strengths. The sample included women from three racial and ethnic groups and allowed for the opportunity to compare content categories across groups. Although the history of depression diagnosis was self-reported, participants did complete the PHQ-8 at the time of enrollment, thereby providing valid information about their depression symptom status.

Implications for Practice and/or Policy

The perception that primary care is not the appropriate place to disclose depression symptoms persists. Increased public education about and more robust integration of behavioral health and primary care are likely necessary to foster women's willingness to disclose depression symptoms in primary care. Our study findings highlight how potentially modifiable aspects of the patient-provider relationship influenced women's willingness to disclose depression symptoms. Interventions that support providers asking about depression while augmenting their ability to demonstrate empathy and reflective listening may be key strategies for encouraging women to disclose depression symptoms in primary care settings.

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Abiola Keller had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. None of the authors have a conflict of interest with this research. The authors would like to thank all the women who participated in this study.

Appendix Semistructured Interview Guide for Participant Interviews

Introduction

Thank you for agreeing to take time out of your busy schedule to speak with me today. As I mentioned over the phone, this project is about women's experiences with getting care for depression.

Before we begin the conversation, we need to go over the consent form. This is a form that provides you with information about the conversation today. You will take a copy of it with you at the end of the day. We will take a couple of minutes for you to read it. Please let me know if you would like for me to read it.

[Complete the consent process]

I am going to ask you a few questions about your experience with depression or feelings of sadness and what makes it easier or harder for women to get the care that they need.

Ok, if you don't have any more questions, let's get started.

Q1: What do women need from their health care providers when they are depressed?

Q2: How well do health care providers meet those needs?

Q3: What makes a good provider when it comes to treating depression?

Q3a: Are there things about the provider that make it easier for women to talk about their mood? What are they?

Q3b: Are there things that the provider can do to make it easier for women to talk about their mood? What are they?

Q4: What kinds of things do you think health care providers should say to or ask a woman who is depressed?

Q5: Some people think health care providers should involve them in making decisions about treating their depression. What do you think about that?

Q6: Tell me about different types of health care providers or healers that you have encountered while seeking care for depression.

For each provider/healer mentioned:

Q6a: When did you encounter this provider?

Q6b: What prompted you to seek care?

Q6c: How did you find out about this provider/healer?

Q6d: How would you characterize the quality of your experience with this provider/healer?

Q6e: How did this provider/healer help you?

Q6f: What made their advice or suggestions helpful?

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