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Locally contextualizing understandings of depression, the EPDS, and PHQ-9 among a sample of postpartum women living with HIV in Malawi

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Abstract

Background: The Edinburgh Postnatal Depression Scale (EPDS) and Patient Health Questionnaire-9 (PHQ-9) are widely used depression screening tools, yet perceptions and understandings of their questions and of depression are not well defined in cross-cultural research.

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Contributors

Bryna J. Harrington proposed the study, designed the protocol and interview guide, coordinated interviews, analyzed qualitative and quantitative data, and led manuscript drafting and revisions.

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Brian W. Pence, Joanna Maselko, Bradley N. Gaynes, William C. Miller, and Mina C. Hosseinipour provided important feedback on the study design and assisted with manuscript drafting and revisions.

All authors contributed to and have approved the final manuscript.

Conflicts of interest

No authors have conflicts of interest to declare.

Institutional Review Board

The Institutional Review Board of the University of North Carolina at Chapel Hill, and the National Health Sciences Research Committee in Malawi approved the parent (S4) and qualitative studies.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jad.2020.10.063.

Methods: 30 postpartum women living with HIV in Malawi were recruited from a cohort study and participated in in-depth cognitive interviews. Transcripts were evaluated following an inductive approach to identify common themes.

Results: Participants most frequently described looking sad or different than usual, self-isolation, ‘thinking too much,’ and anger as key symptoms of being depressed. HIV-associated stigma was commonly identified as a cause of depression. The EPDS and PHQ-9 were generally well understood but did not capture all the important symptoms of depression that women described. Participants sometimes requested clarification or rephrasing of certain EPDS and PHQ-9 questions when asked to explain the questions’ meanings in their own words, and requested rephrasing more often for EPDS questions than PHQ-9 questions. Few women believed either tool was sufficient to detect depression.

Limitations: Our results may not be generalizable, but are locally contextualized. Women suffering with depression may have been more or less likely to agree to the qualitative interview depending on their comfort level discussing any current depressive symptoms.

Conclusions: Researchers and practitioners who use the EPDS and PHQ-9 should be aware of the tools’ limitations in their context and population. New instruments may need to be developed or adaptations to existing tools made to improve accuracy of depression screening and diagnosis in different cultural contexts.

Keywords

Perinatal depression; Cognitive interview; EPDS; PHQ-9; HIV; cross-cultural

Introduction

Numerous depression screening tools exist and have been translated into several languages, yet validation efforts have focused on linguistic comparison of a translation to a reference standard (often based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)) and have not documented participants’ interpretations of the tools (American Psychiatric Association, 2013; Shrestha et al., 2016; Sweetland et al., 2014). Though depression symptoms across cultures have commonalities, the DSM-5 states ‘all forms of distress are locally shaped, including the DSM disorders’ (American Psychiatric Association, 2013). Thus, validating screening tools for cultural relevancy by potentially including local expressions for depression and not relying solely on the Western-based DSM-5 criteria may improve depression identification and treatment in cross-cultural settings (Cork et al., 2019; Fabian et al., 2018; Green et al., 2018; Haroz et al., 2017; Hines, 1993; Jayawickreme et al., 2017; Mayston et al., 2020; Sweetland et al., 2014).

Two well-established depression screening tools are the Patient Health Questionnaire-9 (PHQ-9) and Edinburgh Postnatal Depression Scale (EPDS). The PHQ-9 is used in adult men and women, including in the perinatal period of pregnancy and 12 months postpartum (Kroenke et al., 2001; Moraes et al., 2017), and is appealing in resource-limited settings where having a single tool for all adult patients is more efficient. The EPDS is specifically for perinatal women for two reasons: it includes questions about anxiety which may differentiate depression during the perinatal period from other times (Lee et al., 2007); and

omits somatic symptoms (changes in appetite, weight, and energy level), which may be less diagnostic of depression during perinatal-related physiologic changes (Cox et al., 1987). At least 10% of mothers suffer from perinatal depression (Gaynes et al., 2005), and its consequences include increased risk of adverse outcomes for both mothers and infants, including preterm birth (Field et al., 2006; Wisner et al., 2009), malnutrition (Anoop et al., 2004), and maternal impaired functioning and suicide (Aaron et al., 2015). Importantly, perinatal depression is treatable if women are identified and linked to care.

Assessing depression in cross-cultural resource-limited settings such as Malawi, a country in south east Africa, can be challenging. Depression assessments need to be culturally valid for the local context, and a prevalent comorbid condition may impact depression measurement if its symptoms overlap with those of depression. Human immunodeficiency virus (HIV) is one such example, and is the focus of this study. The somatic symptoms of both HIV and depression can include changes in appetite, sleep, and energy level, thus, it may be important to adapt depression screening tools to persons living with HIV (Simoni et al., 2011; Treisman and Angelino, 2007; Wierzbicka, 1999). In Malawi, where 11% of adult women have HIV (UNAIDS, 2018), both the EPDS and PHQ-9 have been validated in the predominant local language (Chichewa) for linguistic equivalence but not formally for cultural relevance (Stewart et al., 2013; Udedi et al., 2019). The current study evaluated what a sample of postpartum women living with HIV in Malawi understood of depression symptoms and of the questions on the EPDS and PHQ-9. Women's qualitative interview responses are analyzed to highlight important considerations for using the screening tools, particularly in non-Western cultures and contexts different from those in which the tools were developed.

Methods

Parent study

All qualitative sub-study participants were recruited from women enrolled in the “Safety, Suppression, Second-Line and Survival” (S4) cohort study ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02249962) identifier: [NCT02249962](https://clinicaltrials.gov/ct2/show/study/NCT02249962)) on long-term safety and efficacy of Malawi's Option B+ prevention of maternal to child transmission of HIV program at Bwaila District Hospital in Lilongwe, Malawi. Women establishing antenatal care at Bwaila, the busiest government antenatal clinic with over 15,000 deliveries annually, were eligible for S4 enrollment if they were: living with HIV, pregnant, at least 18 years of age or an emancipated minor, intending to give birth in Lilongwe, and willing to provide informed consent.

At enrollment into the parent cohort (S4), women answered a series of demographic questions and the Chichewa versions of the EPDS and PHQ-9, both which had slight wording adaptations from the prior studies to improve cultural relevance (e.g., “participating in a meeting” was substituted for “reading the newspaper” in PHQ-9 question #7 on ‘trouble concentrating on things’) (Malava et al., 2018; Stewart et al., 2013). All S4 participants answered the PHQ-9 and then the EPDS at multiple postpartum visits.

Qualitative sub-study

S4 study nurses and coordinators recruited a convenience sample of S4 participants for an in-depth interview between August and November 2017. Resources and time limited the feasibility of more sophisticated sampling, and the first 30 women who agreed to participate in one-on-one interviews were selected. Staff explained that the qualitative interview was separate from their routine medical care, voluntary, and in addition to normal S4 study visits. Participants were consented specifically for the qualitative sub-study, and all were postpartum at the time of qualitative sub-study participation.

A semi-structured interview guide was developed based on the author team's knowledge of the Option B+ and postpartum depression literature, as well as the team's and local partners' experience working in the Malawian antenatal context (see supplemental files). The guide was created in English and then translated into Chichewa, with back-translation to English for verification. A bilingual interviewer from Malawi (AT) trained in qualitative methodology and specifically on administering the EPDS and PHQ-9, conducted the interviews in Chichewa (n=28) or a combination of Chichewa and English (n=2), based upon participant preference. During the interviews, participants answered both the EPDS and then the PHQ-9 for a score, then answered a series of cognitive interview style questions on their interpretations of the wording of each tool's questions (Beatty and Willis, 2007; Godderis et al., 2009; Willis and Miller, 2011). Additionally, interviews elicited information about the woman's recent pregnancy, HIV diagnosis, antiretroviral therapy (ART) experience, knowledge about depression, and stigma surrounding HIV and depression. Interviews lasted approximately 60 minutes and were digitally audio recorded.

All recordings were transcribed in Chichewa and translated into English. Each transcript was read in its entirety (by BJH and LLK) to identify salient themes and construct a code book, following an inductive approach (Thomas, 2006). To ensure intercoder reliability, the initial two transcripts were coded by 3 researchers (BJH, LLK, LMR) for consistency and all discrepancies were discussed and resolved as a team. An additional 8 transcripts were each coded by two researchers (BJH, LLK, or LMR), with discrepancies explored and the coding framework iteratively refined to maintain responsiveness to the data. For example, the initial coding schema was organized by question stem (e.g., EPDS question 1), but many women's responses to a given question included information that was relevant to other questions in the interview, thus the authors refined the coding approach to be able to consistently categorize data under relevant themes throughout interviews. The remaining 20 transcripts were coded by one researcher and reviewed by another (BJH, LLK, or LMR), with any discrepancies discussed and resolved as a team. NVivo Version 12 (QSR International, 2017) was used for all coding. The coders wrote and discussed analytic memos on intriguing or surprising aspects of an interview, and on recurring themes (Saldana, 2009). The coding framework synthesized consistencies and variabilities across transcripts.

A positive screen for probable depression was an EPDS score ≥ 6 (out of 30 possible points) per the recommended threshold to discern major depression in the original validation study of the EPDS in Malawi (Stewart et al., 2013), with a corresponding comparable threshold of ≥ 5 (out of 27) on the PHQ-9. Women who screened positive or endorsed suicidal ideation

were seen by a study clinician for assessment and/or counseling and referred to mental health services as appropriate given that no psychiatrist was immediately available on-site.

The Institutional Review Board of the University of North Carolina at Chapel Hill, and the National Health Sciences Research Committee in Malawi approved the parent (S4) and qualitative studies. Participants received a transport stipend of \$5 USD equivalency and refreshments.

Results

Participant characteristics

At enrollment in the parent study, qualitative interview participants (n=30) had a median age of 24 years (interquartile range (IQR) 21–31) (Table 1). About half of women had finished primary school or more (53%). During the qualitative interviews, about one in five participants screened positive for probable depression on the EPDS (20%) or PHQ-9 (23%) (scores ranged 0–11 on both tools).

Understandings of depression and depression symptoms

When asked, ‘Have you heard of “depression?” What does this term mean to you?’ (see supplemental files for Chichewa), most women (73%) had heard of depression generally, yet upon further probing, about one third stated that they had never heard of depression as a diagnosable disease or illness condition. To help clarify, the interviewer provided additional words related to depression in Chichewa (e.g., sadness (kukhumudwa), stress (nkhawa), worrying (kudandaula)), but often women framed these symptoms as reactions in response to specific situations such as being told something hurtful, having a conflict with a partner, family member, or friend, or living with HIV. About three-quarters of the women who initially responded that they had never heard of depression were able to describe a time when they either directly experienced or observed another person experiencing symptoms of being depressed upon further probing and explanation:

‘Have you ever heard of depression as a disease or condition?’ “*No, I have never heard of that.*” ‘But have you ever seen someone depressed?’ “*Yes.*” ‘What are the signs?’ “*The person is very quiet, they prefer to stay alone and they are easily agitated.*” (age 33 years; EPDS score: 7; PHQ-9 score: 3)

General beliefs about being depressed included its negative effects on overall health, like weight loss and high blood pressure (Table 2).

When asked for signs of being depressed, most women (80%) named at least one symptom consistent with diagnostic criteria (being sad, miserable, or hopeless; adverse changes in sleep or appetite; disinterest in usual activities; feeling unimportant; or suicidal ideation). Looking sad or different than usual, self-isolation, and anger were the three most frequently mentioned symptoms of depression.

“*[Being depressed] is when somebody is feeling abnormal, abnormal in a bad way. Your heart is not the same as it normally is, you find that you cannot do anything and it makes you feel as though you are losing your mind. You cannot concentrate in doing things, you find*

yourself sad over every little thing. Even if you are a happy person, you find it difficult to be happy.” (age 40; EPDS: 7; PHQ-9: 3)

Understandings of EPDS and PHQ-9 questions

Overall, most participants were able to state the EPDS and PHQ-9 question meanings in their own words, but had more difficulty doing so for the EPDS than the PHQ-9. Common interpretations and specific points of confusion are outlined below for each depression screening tool and in Tables 3a and 3b.

EPDS

Interpretations of ‘been able to laugh and see the funny side of things’ (EPDS1) featured ‘being happy’ for two-thirds of participants. A third of women needed clarification from the interviewer, and rephrasing ‘the funny side of things’ to ‘the good side of things’ was helpful to participants. One common difficulty was being unsure how to respond if the participant agreed with, or only understood, one portion of the statement, such as: *“I laugh but I don’t really see the funny side of things”* (age 26; EPDS: 3; PHQ-9: 1).

For ‘looked forward with enjoyment to things’ (EPDS2), common interpretations included waiting for a happy thing to occur and hope for the future. Participants named weddings, trips to the lake, their child testing negative for HIV or being happy that they receive ART medicine as hopeful future events. Some women (10%) took issue because: *“You don’t know what good thing is coming in future. Once the thing has happened, you can be happy”* (age 33; EPDS: 7; PHQ-9: 3).

More than one in three (35–40%) women requested clarification on each of the three anxiety subscale items (EPDS3–5) prior to describing the question in their own words. Most interpretations of ‘I have blamed myself unnecessarily when things went wrong’ (EPDS3) focused on self-blame related to having caused or experienced a bad outcome (70%), and feeling unimportant or inferior to others (30%). One quarter of women equated self-blame with thoughts of self-harm or suicide:

“If the troubles are beyond what you can handle, you can start to think that it is better I just hang myself and die...I am facing what I am facing because I am a bad person” (age 33; EPDS: 3; PHQ-9: 6).

While women generally understood ‘unnecessarily’ to mean without need or cause, when explaining the question’s meaning in their own words, fewer than 20% included the concept in their responses, and about 10% simply stated “this [question] is difficult.”

Interpretations of the other two anxiety subscale questions (been ‘anxious or worried for no good reason’ (EPDS4), and ‘scared or panicky for no good reason’ (EPDS5)) overlapped considerably. Common interpretations of EPDS4 centered on being sad, disappointed in one’s self, and withdrawn from friends or family. Interpretations of EPDS5 often featured being afraid, withdrawn, or having no peace of mind. One-fifth of women believed that they had already answered whether they had ‘been scared or panicky’ (EPDS5) with their prior response to ‘been anxious or worried’ (EPDS4). Despite featuring ‘for no good reason,’ women usually listed a specific reason for being worried or afraid (e.g., theft, debt, or their

HIV status). A few women struggled to interpret ‘been scared or panicky for no good reason,’ stating: “*You cannot panic without a reason*” (age 26; EPDS: 0; PHQ-9: 0). When asked whether their responses would change if ‘for no good reason’ were removed, replies were mixed. Those who said ‘no,’ that their answers would not change, described one of two rationales: “*Being worried or anxious whether for a good reason or not is just the same, it is all worry*” (age 40; EPDS: 7; PHQ-9: 3); or ‘no,’ their responses would not change because they had nothing that made them anxious, worried, scared or panicky recently. Those who would change their response stated they would do so “*because there was a reason for me [to be worried]!*” (age 31; EPDS: 1; PHQ-9: 1).

Across the anxiety subscale (EPDS3–5), women mentioned HIV and its associated stigma in one-third of responses. Women described their fear and worry about anticipated or experienced stigma related to their HIV diagnosis, including attending the HIV clinic or taking ART in secrecy, being discriminated against if their HIV status was known, or dying if they did not take ART.

Due to participant confusion, the interviewer often had to rephrase the question stem ‘things have been getting on top of me’ (EPDS6) to “you have had many things to do but you have had trouble managing.” While a few women described “*you get worried why you are failing to complete [the tasks]*” (age 23; EPDS: 5; PHQ-9: 0), a more matter-of-fact interpretation predominated that focused on noncompletion of needed tasks due to financial constraints and household chores rather than a feeling of inadequacy:

“*Maybe you were thinking that I will wash then I will go to the maize mill, but that day there is no money to buy soap or to go to the maize mill*” (age 25; EPDS: 5; PHQ-9: 6).

‘Being so unhappy that I have had difficulty sleeping’ (EPDS7) was easily understood. Women described how troublesome daytime events can negatively impact sleep at night, and they attributed sleeplessness to depression, anxiety, and thinking too much: “*[It means] misery...you have many questions without answers*” (age 22; EPDS: 0; PHQ-9: 0). About one in five women described that quarrels with friends or spouses, their health, and having HIV could contribute to poor sleep.

The EPDS questions on depressed mood or tearfulness (EPDS8: ‘felt sad or miserable’; EPDS9: ‘been so unhappy that I have been crying’) infrequently required clarification. All interpreted EPDS8 as asking about being sad, ‘having no peace of mind,’ or ‘thinking too much,’ which then resulted in difficulty concentrating on tasks or conversations. Twenty percent connected sadness with being angry: “*She is failing to be happy because she has no peace of mind. When you are sad you become angry and sometimes you can’t talk back at someone because you are tearing up*” (age 26; EPDS: 0; PHQ-9: 0). A few had difficulty interpreting ‘felt sad or miserable’ in their own words if they had not felt that way recently. Multiple women described unhappiness leading to tearfulness (EPDS9) due to bereavement (33%), strained personal relationships (27%), HIV (diagnosis, partner disclosure, or discrimination) (10%), or financial constraints (13%): “*Maybe the husband has left you without money; so you become sad to say ‘what does he think I am going to eat?’*” (age 26; EPDS: 0; PHQ-9: 0). A recurring theme was reaching a tipping point into hopelessness:

“When this sorrow becomes unbearable, it makes you cry; tears flow because your thoughts go beyond a certain limit and make you to lose faith, and finally you think that it is better I should die because I am suffering a lot” (age 35; EPDS: 4; PHQ-9: 1).

Women interpreted the question about thoughts of self-harm (EPDS10) without difficulty. Common reasons for considering self-harm included having unresolvable problems, being depressed, having no peace of mind, financial constraints, and feeling unimportant. *“If you are in pain, maybe you are going through tough times, you can start to think of doing bad things so that you shouldn’t feel any more pain”* (age 33; EPDS: 3; PHQ-9: 6). Ten percent of women’s responses were related to HIV, including that contracting HIV or not taking ART were self-harm.

In summary, five EPDS questions frequently required rephrasing or additional explanations (for 25% of women), including anhedonia (EPDS1), anxiety (EPDS3–5), and being unable to keep up with things (EPDS6). Participants seldom (<5%) requested rephrasing for questions about difficulty sleeping (EPDS7) or self-harm (EPDS10).

PHQ-9—Common interpretations of ‘little interest or pleasure in doing things’ (PHQ1) included disinterest or reluctance in doing usual tasks, such as chores or community projects, or having financial constraints.

“When you have concerns inside of you, it is difficult to carry out your daily activities or to even attend different events... it is difficult to be amongst other people” (age 33; EPDS: 3; PHQ-9: 6).

Though about three-quarters of participants easily interpreted PHQ1, 10% explicitly had difficulty articulating the meaning in their own words, stating *“that one is hard,”* and only provided responses after the interviewer asked, “How would you know if a person had little interest or pleasure in doing something?”. Overall, participants required rephrasing of PHQ1 more often than PHQ2.

Women generally described feeling ‘down, depressed or hopeless’ (PHQ2) as being disappointed and unable to manage: *“You say I cannot solve this problem, I cannot handle it...and then you think that things are just going to get bad”* (age 40; EPDS: 7; PHQ-9: 3). Commonly, women mentioned a person’s overall outlook: *“Hopeless means that you are taking the day as it comes, you do not have any hope for the future or plan for the next day”* (age 33; EPDS: 2; PHQ-9: 1). Ten percent of women’s responses related to HIV, including losing hope due to having HIV, worry about infecting their children, and being unable to take ART if a person is depressed.

Women had little confusion about sleep and energy symptom questions. All responded about decreased sleep, but when prompted, women saw a distinction between what causes ‘trouble falling or staying asleep’ versus ‘sleeping too much’ (PHQ3). Typically, failing to sleep resulted from ‘thinking too much,’ whereas oversleeping was always benign. A few women described that their ART compromised sleep. Over half of women listed more than one reason why a person could be ‘tired or have little energy’ (PHQ4), including physical illness or exertion, ART side effects, or worrying, though typically the fatigue was short-lived.

“Maybe there was something I was thinking about and in the end my joints just become weak and I don’t have energy anymore” (age 26; EPDS: 3; PHQ-9: 2).

Over one third of women (35%) requested rephrasing of ‘poor appetite or overeating’ (PHQ5). A third of participants initially assumed that food was unavailable due to financial constraints. After clarifying that food could be available but the person had no appetite, a common explanation was a physical illness such as malaria or pregnancy, though some associated eating less with being depressed or anxious. Overeating was commonly attributed to having skipped a meal recently, and only one person associated it with depression.

One in four participants asked for clarification on the wording of ‘feeling bad about yourself or that you are a failure’ (PHQ6). The interviewer found rephrasing to “feeling ashamed” was helpful, and women interpreted it as looking down on themselves and feeling useless or unimportant. Stigma from having HIV (30%), inability to take care of the family (23%), and financial constraints (20%) were the most common reasons women listed as causes for feeling like a failure. One woman misheard “feel” for “hear”, which are similar words in Chichewa.

For ‘trouble concentrating’ (PHQ7), about one-third of women directly commented on how a person may have difficulty concentrating: *“She cannot concentrate because she has no peace, she is in deep thought”* (age 23; EPDS: 1; PHQ-9: 0). Another third of women rationalized not attending a meeting due to logistics (e.g., lack of childcare), or disinterest. HIV was one reason for self-exclusion, though was not directly linked with impaired concentration: *“I may fail to participate in groups for fear that if they know I am HIV positive, they will start talking about me”* (age 34; EPDS: 9; PHQ-9: 0).

Most interpretations (87%) of ‘moving so slowly that others noticed, or been fidgety or restless’ (PHQ8) focused on slowness rather than restlessness. Though PHQ7 focuses on impaired concentration, in their responses to PHQ8, half of participants described that slowed movement was caused by ‘thinking too much’ which led to impaired concentration: *“You are walking and talking to yourself to the point that even your steps go slow because you are discussing things in your mind by yourself... You would definitely get in a car accident because in that state you cannot concentrate on where you are going”* (age 40; EPDS: 7; PHQ-9: 3). Physical limitations such as a stammer or being ill were also frequently mentioned (33%). About 15% of women did not understand the question, stating *“I’ve failed that one.”*

Women easily interpreted ‘thoughts of being better off dead or of hurting yourself’ (PHQ9) as meaning thoughts of self-harm, self-hate, and suicide. Causes for such thoughts included feeling depressed or like a failure. About one-quarter of participants’ responses about reasons for self-harm or suicidal ideation centered on anticipated or experienced stigma and discrimination from having HIV.

In summary, many participants (25%) asked for clarification on little interest or pleasure in activities (PHQ1), changes in appetite (PHQ5), and feeling like a failure (PHQ6), but less often (<15%) for the questions about sleep (PHQ3), fatigue (PHQ4) or suicidal ideation (PHQ9).

Utility of the EPDS and PHQ-9 to identify depression

While most women (83%) initially responded “yes” that the EPDS or PHQ-9 questions were sufficient to identify a depressed person, the majority of responses clarified that it was not the EPDS or PHQ-9 questions themselves, but rather, the person’s mood when interacting with the interviewer that would be revealing. About half of participants stated that “*the way she answers and the facial expressions can tell you that she is depressed*” (age 27; EPDS: 8; PHQ-9: 6). One fifth of women emphasized the importance of being familiar with the person, even if using the EPDS or PHQ-9:

“You cannot judge that a person has depression by seeing her only once. However, when you chat and see her for a couple of days, then you can realize that this person is depressed” (age 33; EPDS: 2; PHQ-9: 1).

A few women described that a person could hide their feelings if desired: “*I can be depressed but you will not know, because what is depressed is in my mind. I may respond as though I am not depressed while in fact, I am*” (age 31; EPDS: 1; PHQ-9: 1). A quarter of participants stated that asking about self-harm (EPDS10 and PHQ9) or explicitly asking if one is depressed may be helpful in identifying a depressed person.

Discussion

The featured cognitive interviews summarize how a sample of women in Malawi living with HIV describes depression symptoms and interprets the EPDS and PHQ-9. Participants commonly identified HIV-associated stigma as a cause of being depressed and self-isolation. Though participants generally were able to describe the EPDS and PHQ-9 questions in their own words, women asked for clarification on questions in both tools, and more often for those on the EPDS. Participants most often asked for rephrasing about anhedonia (EPDS1 and PHQ1), feeling unable to keep up or like a failure (EPDS6 and PHQ6), and all three anxiety questions (EPDS3–5). Women seldom requested rephrasing or clarification about suicidal ideation (EPDS10 and PHQ9) and difficulty sleeping (EPDS7 and PHQ3). Participants’ difficulty with some wording on the EPDS and PHQ-9 illustrates challenges in capturing conceptual equivalence and cultural relevance with standardized tools in heterogeneous settings, even if validated, but also points to opportunities to improve the tools.

Depression as a disease exists across cultures, though specific contributors, manifestations, and terminologies for it may vary (Haroz et al., 2017; Kessler et al., 2009). In addition to naming at least one symptom that aligns with DSM criteria for depression, many of our participants described a form of rumination, ‘thinking too much,’ that leads to having ‘no peace of mind,’ a state of ongoing stress that could cause both somatic and affective consequences leading to depression. ‘Thinking too much’ is a concept of distress documented in multiple Western and non-Western cultures and may reflect elements of depression, anxiety and post-traumatic stress disorder (American Psychiatric Association, 2013; Kaaya et al., 2010; Kaiser et al., 2015; Mendenhall et al., 2019). The concept is included in the Shona Screen for Mental Disorders in Malawi’s neighboring country, Zimbabwe (Patel et al., 1997), but ‘thinking too much’ or any direct assessment of rumination is not featured on the EPDS or PHQ-9. Proposed depression screening

algorithms that include specific evaluation of local idioms of distress exist for multiple languages (Cork et al., 2019), though how commonly those tools are used is unknown, and no such resources exist for Malawi. It may be particularly important to evaluate ‘thinking too much’ during depression assessment in Malawi given that it was often discussed along with the most frequently described symptoms of depression: looking sad or different than usual, self-isolation, and anger.

The EPDS and PHQ-9 do not include all key symptoms of being depressed that our Malawian participants commonly described, a discrepancy noted in multiple cross-cultural studies of depression (Haroz et al., 2017; Jayawickreme et al., 2017; Psaki and Hindin, 2016). Anger was the third most frequently listed symptom of depression among participants, but is not directly evaluated with either the EPDS or PHQ-9. The EPDS does not ask about anger or irritability because during the tool’s development, authors found that an irritability subscale represented a “‘non depression’ factor,” and omitting it decreased time needed to complete the questionnaire and may have improved specificity for depression (Cox et al., 1987). The PHQ-9 content was based on DSM-III-R criteria for depression, which did not include anger (American Psychiatric Association, 1987; Spitzer et al., 1999). Depression and anger have been linked in multiple other global contexts (Haroz et al., 2017), including Ethiopia (Terasaki et al., 2009), Italy (Bruno et al., 2018), South Korea (Min and Suh, 2010), and the United States (Judd et al., 2013). Given our participants’ descriptions that anger is a marker of depression in Malawi, it could be informative to investigate the diagnostic and prognostic strength of asking about anger when assessing depression in the country.

Our participants’ confusion about some EPDS and PHQ-9 questions’ wording underscores the importance of careful validation that includes a close examination of both linguistic and cultural relevance when using tools in settings outside of contexts in which they were developed (Green et al., 2018; Jayawickreme et al., 2017; Sweetland et al., 2014). Qualitative data can reveal that the DSM features in Western screening tools may not adequately detect or fully characterize depression experiences locally, even if the tools have been validated for quantitative performance characteristics (Haroz et al., 2017; Mayston et al., 2020; Psaki and Hindin, 2016). When the EPDS and PHQ-9 were administered for a score at the beginning of our qualitative interviews, women rarely asked for wording clarification, yet later during the cognitive interview style section, they acknowledged confusion when asked to explain what each question meant. The root of participants’ difficulty may be imperfect semantic and/or conceptual equivalence between the Chichewa and English versions. For example, ‘sadness’ in Chichewa, “kukhumudwa,” can also mean depression, and may have differing connotations in lay and medical contexts. We expect that similar issues are present in other languages with subtle or substantial semantic differences.

We propose specific recommendations based on our data to improve cultural relevance and depression measurement (Box 1). The idiom- based EPDS questions 1 and 3–6 were difficult for our participants, particularly the ‘for no good reason’ qualifiers in the anxiety questions (EPDS3–5), similar to studies among Ethiopian and Canadian women (Godderis et al., 2009; Hanlon et al., 2008). Our participants named ‘thinking too much’ but not explicitly anxiety or extreme worry as a clear sign of being depressed, though they were not

asked to distinguish symptoms during versus outside the perinatal time (Lee et al., 2007). Given common confusion with all three anxiety questions, investigating whether anxiety is central to perinatal depression in Malawi and elsewhere would be worthwhile for researchers or practitioners using the EPDS. Other ways to improve cultural validity include rephrasing the idioms “things have been getting on top of me” (EPDS6) and “see the funny side of things” (EPDS1). Although the Malawian EPDS validation included multiple bilingual professionals revising wording for conceptual equivalence (Stewart et al., 2013), our participants’ responses suggest that some concepts may not be clearly captured in Chichewa, a finding noted in other global contexts for the local language(s) (Haroz et al., 2017; Psaki and Hindin, 2016).

Three PHQ-9 questions in particular may warrant revision. Clarifying the wording of ‘little interest or pleasure in doing things’ (PHQ1) could improve interpretability. Specifying that food is available for ‘poor appetite or overeating’ (PHQ5) may be important given the prevalence of food insecurity in Malawi. Rephrasing ‘feeling bad about yourself that you are a failure’ (PHQ6) to “feeling ashamed” helped participants. Consistent with participants from Kenya and England (Malpass et al., 2016; Monahan et al., 2008), our participants focused on one of the extremes (e.g., poor appetite versus overeating) but not both, when explaining the meanings of questions on changes in sleep, appetite, or psychomotor speed (PHQ3, 5, and 8).

To determine who is depressed, our participants emphasized the importance of knowing the person and evaluating facial expressions and demeanor rather than only the verbal responses to PHQ-9 or EPDS questions. Neither tool currently has a way to formally incorporate the interviewer’s impression of a person’s mood or mannerisms. A perinatal depression assessment in Kenya included the counselor’s clinical judgment (Green et al., 2018), but that is uncommon in screening or diagnostic protocols. Developing a time-efficient screening format that encompasses the person’s manner of answering questions may augment the performance of the EPDS and PHQ-9 in certain settings. That our participants recognized the challenge in identifying someone with depression supports the need for in-depth training in psychosocial care provision beyond simple orientation on how to administer screening tools such as the EPDS and PHQ-9. Dedicated training in psychosocial care and specifically in depression is necessary to properly differentiate between depressive features of a normal reaction to stressful life events, and clinically diagnosable conditions such as adjustment disorder, major depression, or post-traumatic stress disorder (Mayston et al., 2020).

Participants spontaneously connected HIV and depression throughout the interviews, including in most EPDS or PHQ-9 questions. A recurring theme was worry about HIV-associated stigma and ramifications thereof, such as hopelessness, feeling inferior, and self-exclusion from groups. Though HIV did not necessarily alter interpretation of the questions, HIV can contribute to why a person may endorse a given symptom on the EPDS or PHQ-9. For example, participants clearly understood the PHQ-9 questions on sleep and energy (PHQ3–4), but multiple women described that ART can affect their sleep or energy levels. Depression assessments should be interpreted with awareness that there may be possible overlap between symptoms of depression and HIV. Of note, a review of depression in sub-Saharan Africa found that “people already engaged with the health system for another illness

such as HIV were more likely to describe their depression in biomedical terms” (Mayston et al., 2020), which suggests that careful study, contextualization, and assessment of persons being screened for depression are needed to accurately interpret and provide health services.

Limitations

Our qualitative participants were a convenience sample and may not be representative of all perinatal women living with HIV, yet the goal was to contextualize data locally rather than generally (Robinson, 2014). Women suffering with depression may have been more or less likely to agree to the qualitative interview. During the interview, the EPDS was discussed before the PHQ-9, and some participants may have been fatigued when asked about the PHQ-9, which may have led to shorter or less complete responses. It is unknown with the available information which participants had clinically diagnosable depression due to lack of confirmatory depression assessments, however, part of the current study’s goal was to characterize understandings and experiences of depression from the local perspective, to include symptoms that are not necessarily featured in DSM-5 criteria, rather than relying on Western criteria that might have introduced selection bias to our study (Haroz et al., 2017; Kirmayer et al., 2017; Mayston et al., 2020).

Conclusions

Participants’ conceptualization of depression generally featured DSM diagnostic depression symptoms, though the EPDS and PHQ-9 did not capture all important depression symptoms that women named, such as anger and ‘thinking too much.’ Women readily described a complex interplay between HIV and depression. While participants reasonably interpreted most of the EPDS and PHQ-9 questions in their own words, they overall had more confusion with the EPDS than the PHQ-9. Few women believed the tools were sufficient for detecting depression, and instead emphasized the importance of observing a person’s facial expressions, mood, and behavior in the community. Researchers and practitioners who use the EPDS and PHQ-9 should be aware of the tools’ limitations in their context and population, whether working in Malawi, with migrants from Malawi, or more broadly with persons from diverse cultures whose conceptualizations and experiences of depression may not be fully assessed with Western-based screening tools even if validated quantitatively. New or adapted instruments that capture local linguistic and behavioral expressions of depression may need to be developed to improve accuracy of depression screening and diagnosis.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

ART	antiretroviral therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
EPDS	Edinburgh Postnatal Depression Scale
HIV	human immunodeficiency syndrome
PHQ-9	Patient Health Questionnaire 9
S4	Safety, Suppression, Second-line, Survival study

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Box 1

Recommendations

- Evaluate rephrasing of questions that posed difficulty (EPDS 1, 3–6; PHQ 1, 6; clarify for PHQ5 that food available).
- Assess performance of including locally relevant symptoms and wording of depression (e.g., anger, ‘thinking too much’).
- Examine ways to include client’s facial expressions and evaluator’s impressions rather than only client’s verbal response to EPDS or PHQ-9 questions in depression assessment.
- Evaluate the relevance of anxiety as part of perinatal depression in Malawi.
- Comorbid conditions: may not need a separate validation in populations with comorbid conditions such as HIV, but clinicians and researchers should interpret depression assessment and treatment in the context of possible overlapping symptoms between depression and the comorbid condition.

Table 1

Participant characteristics (n=30)

At time of enrollment in parent cohort study	Median (IQR)
Age (years)	24 (21–31)
Total N (%)	
Marital status	
Currently married	27 (90)
Not currently married	3 (10)
Education attained	
None/some primary	14 (47)
Finished at least primary	16 (53)
Employment status	
Unemployed	20 (67)
Employed	10 (33)
WHO HIV Clinical Stage	
Stage 1	29 (97)
Stage 2–4	1 (3)
At time of qualitative interview	
Current probable depression (EPDS score = 6)	
No	24 (80)
Yes	6 (20)
Current probable depression (PHQ-9 score = 5)	
No	23 (77)
Yes	7 (23)

Table 2

Themes about depression and illustrative quotes

Theme	Common Responses	Representative Quote(s)
Understanding of depression	<ul style="list-style-type: none"> • Knowledge/recognition of the term 'depressed' was common, but not of 'depression as an illness/disease' • Symptoms typically consistent with the EPDS & PHQ-9 • Spontaneous discussion of link between HIV & depression 	<p>Have you ever heard of depression? "No, I have never heard of that." But have you ever seen someone depressed? "Yes." What are the signs? "The person is very quiet, they prefer to stay alone and they are easily agitated."</p>
Beliefs about depression	<ul style="list-style-type: none"> • Depression has negative effects on health (e.g., weight loss, high blood pressure) • Connection between depression and overall health • Depression can impact how ART works in the body • Few participants mentioned how to differentiate depression from day-to-day variation in mood, though feeling sad one day was not considered as being depressed 	<p>"Psychological problems are a very serious thing, perhaps more than the actual illness. You can stay idle, but if you are thinking about something, it becomes hard for you to have peace of mind. So, such things affect the health of a person."</p>
Symptoms of depression	<ul style="list-style-type: none"> • Looking unhappy, sad, or tearful; being angry or irritable • Being more quiet than usual or self-isolation • Decreased appetite, weight loss, difficulty sleeping • Over-thinking things that have happened such that it interferes with completing tasks 	<p>"They look unhappy, you might be chatting with them and you can tell that the way she is today is different from the other days. You can be talking to them, but you can still see that she is not happy, so from that you know that my friend is depressed."</p>
Self-reported symptoms of depression experienced	<ul style="list-style-type: none"> • Hopelessness, tearfulness • Inability to complete tasks • General absence of "peace of mind" • Loss of appetite, sleep difficulty • Irritability • Suicidal ideation, infanticidal ideation 	<p>"I had concerns especially when I was found HIV positive because I did not expect it. So, I was thinking very much and my blood pressure started to rise... I reached the extent of thinking that it was better if I had died because there was nothing good that I was seeing. At that time, I would often get sick and I frequently visited the hospital."</p>
Ability of EPDS and PHQ-9 to identify depression	<ul style="list-style-type: none"> • Respondent's manner when answering more important than the actual responses to EPDS or PHQ-9 questions • Cannot tell if a person is depressed if you do not know them personally 	<p>"It depends on the way s/he answers and the facial expressions which can tell you that s/he is depressed." "I am able to tell about people [being depressed], saying, 'This one is fine today and this one is not' because I have lived with them for a long time and I know them."</p>
HIV and depression connections	<ul style="list-style-type: none"> • A person with HIV is more likely to be depressed; HIV-related stigma contributes to depression • Not knowing one's HIV status is a risk factor for depression • Depression may negatively impact ability to take ART properly • One may experience depression due to over-thinking how they contracted HIV 	<p>"The one who is most likely to be depressed is the one who is HIV positive ... if she has not understood how she was infected but if she can understand she cannot be depressed." "The one without HIV is more likely to be depressed... because she does not know her status. She would envy her friend saying, 'my friend is better, she has the virus and is taking ART and as for me, I do not go [for treatment] but my husband is promiscuous."</p>

Abbreviations: ART – antiretroviral therapy; EPDS – Edinburgh Postnatal Depression Scale; HIV – human immunodeficiency virus; PHQ-9 – Patient Health Questionnaire-9

Table 3a Cognitive interview response summary for Edinburgh Postnatal Depression Scale (EPDS) questions

Common interpretations	Points of confusion	Representative Quote(s)
<p>Q1: I have been able to laugh and see the funny side of things</p> <ul style="list-style-type: none"> - Not hang concerns, happiness - Having "peace of mind" - Being able to laugh, happiness 	<ul style="list-style-type: none"> - "The funny side of things"; - Question interpreted as there is a time for sadness and for happiness 	<p>"You let go of your worries if you had any and you are able to laugh along with what is happening."</p>
<p>Q2: I have looked forward with enjoyment to things</p> <ul style="list-style-type: none"> - Met expectations - Having hope, living a long life 	<ul style="list-style-type: none"> - The future is unknowable 	<p>"It means your hopes for tomorrow. Like what do you expect tomorrow will be like."</p>
<p>Q3: I have blamed myself unnecessarily when things went wrong</p> <ul style="list-style-type: none"> - Feeling unimportant or inferior - Failure to complete task - Things do not go as planned; HIV 	<ul style="list-style-type: none"> - "Unnecessarily" - "When things go wrong" 	<p>"You are in the business of selling fritters and the whole day you don't sell any... so you start blaming yourself."</p>
<p>Q4: I have been anxious or worried for no good reason</p> <ul style="list-style-type: none"> - Worry about unnecessary items - Hate or look down on oneself - Self-isolate; HIV 	<ul style="list-style-type: none"> - "For no good reason" - Listed actual reasons to worry 	<p>"It might be a small issue which can be easily resolved, but you find that you take it to heart and you become worried."</p>
<p>Q5: I have felt scared or panicky for no very good reason</p> <ul style="list-style-type: none"> - No peace of mind; fear - Anxiousness, isolation; HIV - Sadness, depression 	<ul style="list-style-type: none"> - "For no good reason" - Listed actual reasons to fear - Believed same question as EPDS4 	<p>"I was thinking too much...I was afraid that everything I would do, I would end up doing it wrong."</p>
<p>Q6: Things have been getting on top of me</p> <ul style="list-style-type: none"> - Failing to complete tasks - Having low energy - Financially failing to meet needs 	<ul style="list-style-type: none"> - Commonly rephrased to "had many things to do but couldn't manage" 	<p>"I would like to buy clothes for my baby, but plans did not work out and you think about it a lot."</p>
<p>Q7: I have been so unhappy that I have had difficulty sleeping</p> <ul style="list-style-type: none"> - Difficulty sleeping due to over-thinking - Feel depressed, anxious, or sad - Daytime events impact sleep 	<ul style="list-style-type: none"> - Difficulty describing if had not experienced recently 	<p>"If you are depressed, you feel down and you just sit quietly, sleep does not even come to your eyes."</p>
<p>Q8: I have felt sad or miserable</p> <ul style="list-style-type: none"> - Lack of hope, unhappiness - Thinking too much, anxiousness - Inability to concentrate 	<ul style="list-style-type: none"> - Difficulty describing if had not experienced recently 	<p>"We all have thoughts, but there are instances where these thoughts are in excess resulting in misery."</p>
<p>Q9: I have been so unhappy such that I have been crying</p> <ul style="list-style-type: none"> - Looking down on yourself - Being miserable, no peace of mind; bereavement - Being overwhelmed 	<ul style="list-style-type: none"> - Tears due to sadness versus happiness 	<p>"Things can happen to the point that you cry when you see that they are beyond what you can handle."</p>
<p>Q10: The thought of harming myself has occurred to me</p>		

Common interpretations	Points of confusion	Representative Quote(s)
<ul style="list-style-type: none"> - Self-harm, suicide methods - Negative opinions of suicide 	<ul style="list-style-type: none"> - "They want to know my line of thought in life?" 	<ul style="list-style-type: none"> "Being depressed you start to think it is better to take medicine so you can just die."

Abbreviations: ART – antiretroviral therapy; HIV – human immunodeficiency virus

Table 3b
Cognitive interview response summary for Patient Health Questionnaire-9 (PHQ-9) questions

Common Interpretations	Points of confusion	Representative Quotes
<p>Q1: Little interest or pleasure in doing things</p> <ul style="list-style-type: none"> - Incomplete tasks - Working half-heartedly, reluctantly - Disinterest, self-isolation 	<ul style="list-style-type: none"> - Complex wording: "that one is hard" - Misinterpreted as hollow invite to do something 	<p>"Other people can do something good but it just bores you. You fail to rejoice with them. You prefer to isolate yourself while everyone else is happy." "You may wake up not feeling very well and even moping becomes a problem."</p>
<p>Q2: Feeling down, depressed, or hopeless</p> <ul style="list-style-type: none"> - Depression due to hopelessness - Unable to manage, disappointed 	<ul style="list-style-type: none"> - 'Hopeless' as someone not fulfilling a promise 	<p>"It means you do not have any hope for the future or plan for the next day."</p>
<p>Q3: Trouble falling or staying asleep, or sleeping too much</p> <ul style="list-style-type: none"> - Worry causing sleeplessness - Thinking too much, no peace of mind - ART drug side effects 	<ul style="list-style-type: none"> - Difficulty describing if had not experienced sleep issues recently 	<p>"Trouble falling asleep is because you continue thinking, and sleeping too much, you just sleep because you do not have any troubles."</p>
<p>Q4: Feeling tired or having little energy</p> <ul style="list-style-type: none"> - Worry causing fatigue, weakness - Physical illness or exertion, ART drug side effects 	<ul style="list-style-type: none"> - When one cannot consume food (e.g., illness) 	<p>"If they have heard something that has surprised them, it is possible to be weak and have little energy."</p>
<p>Q5: Poor appetite or overeating</p> <ul style="list-style-type: none"> - No appetite due to food scarcity - Eating too little due to physical illness (e.g., malaria), or depression or anxiety 	<ul style="list-style-type: none"> - Needed to clarify that food available but no appetite - Repetition often needed, but not rephrasing 	<p>"You may want to eat something when you don't have the money to buy it, or the food may be there, but you don't want to eat it because of anxiety."</p>
<p>Q6: Feeling bad about yourself that you are a failure or let yourself/family down</p> <ul style="list-style-type: none"> - Feeling incapable or useless - Looking down on oneself - Stigma of HIV infection 	<ul style="list-style-type: none"> - Difficulty describing if had not experienced recently - Complex wording 	<p>"[It means] self-doubt, pitying yourself and feeling like you have failed." "They talk a lot of things [about your HIV status] which make you think 'am I a living corpse?'. So, that makes you lose your peace of mind."</p>
<p>Q7: Trouble concentrating such as participating in a meeting or watching T.V.*</p> <ul style="list-style-type: none"> - Logistical barriers to participation - Disinterest in participation - Thinking too much 	<ul style="list-style-type: none"> - Missing out on event versus trouble concentrating at a given event 	<p>"If they are thinking of something, even if they want to do another thing, they might be unable to because of the thoughts they have."</p>
<p>Q8: Moving or speaking so slowly that other people could have noticed? Or the opposite being so fidgety or restless that you have been moving around a lot more than usual?</p> <ul style="list-style-type: none"> - Slowed talking or walking due to thinking too much, stammer, or physical illness 	<ul style="list-style-type: none"> - Concept of being fidgety and restless 	<p>"You are walking and talking to yourself to the point that even your steps go slow because you are discussing things in your mind."</p>
<p>Q9: Thoughts that you would be better off dead or hurting yourself in some way</p> <ul style="list-style-type: none"> - Thoughts of suicide, self-harm, or self-hate - Depression, feeling like a failure 	<ul style="list-style-type: none"> - Repetitions of question often needed, but not necessarily rephrasing 	<p>"Maybe they are so depressed and they have reached a point where they... may just decide to kill themselves."</p>

* example of participating in a meeting adapted for Chichewa version of PHQ-9

Abbreviations: ART – antiretroviral therapy; HIV – human immunodeficiency virus