Understanding depression and the PHQ-9 items among people living with HIV: A multiple methods qualitative study in Yaoundé, Cameroon

Natalia Zotova[a,*], Dana Watnick[b], Rogers Awoh Ajeh[c], Elodie Flore Tchiengang Moungang[c], Julie Laure Nguemo Noumedem[c], Guy Calvin Nko'o Mbongo'o[d,e], Kathryn Anastos[a], Marcel Yotebieng[a] CA-IeDEA Consortium

[a]Division of General Internal Medicine, Department of Medicine, Albert Einstein College of Medicine, Bronx, NY, USA

[b]Department of Pediatrics, Albert Einstein College of Medicine, Bronx, NY, USA

[c]Clinical Research Education and Consultancy, Yaoundé, Cameroon

[d]Department of Psychiatry, Jamot Hospital, Yaoundé, Cameroon

[e]Faculty of Medicine and Pharmaceutical Sciences of Dschang, Dschang, Cameroon

Abstract

People living with HIV (PLWH) are disproportionately affected by depression, which often remains underdiagnosed and untreated, negatively impacting quality of life and treatment outcomes. Low resource settings often lack clinical professionals to identify depression, therefore screening tools such as the PHQ-9 allow for broader depression screening. This qualitative study among PLWH in Yaoundé Cameroon aimed to a) explore local understandings of depression and mental distress and b) assess comprehension and interpretation of the PHQ-9 items and response categories.

This study was nested in a larger study that assessed performance of the PHQ-9 among PLWH in Central, East, and West Africa. In Yaoundé, Cameroon, 30 in-depth interviews (IDIs) and 24

*Corresponding author. 3300 Kossuth Ave, Bronx, NY, 10467, USA. natalia.zotova@einsteinmed.edu (N. Zotova).

cognitive interviews (CIs) were conducted with PLWH to explore how depression is experienced and to examine understanding and interpretation of the PHQ-9 items. Thematic analysis was used to identify emergent themes across IDIs focusing on shared understandings of depression. An interpretivist content analysis of CIs incorporated understandings of PHQ-9 items into cognitive processes of interpretation, retrieval, judgment, and response formulation.

Out of 54 unique study participants, 15% (n = 8) had depressive symptoms (PHQ-9 score >9). The PHQ-9 items related to somatic manifestations of depression were understood as intended by most participants, while other items were not consistently understood and interpreted. "Thinking too much" and similar cognitive manifestations were central for local understandings of depression. Cognitive and somatic symptoms commonly intertwined and were often linked to experiences living with HIV. Local understanding of depression may not align with Western defined depression criteria, and symptoms related to HIV may conflate symptoms of depression. Incorrect interpretations of almost half of the PHQ-9 items suggests this tool may have limited validity in PLWH, and warrants the need for further testing and adaptation. Further research should be done to develop culturally relevant screening tools among PLWH.

1. Introduction

Depression is common among people living with HIV (PLWH), affecting over one-third of adult and one-quarter of adolescent PLWH (DiPrete et al., 2019; Uthman et al., 2014; Ayano et al., 2021). Depression negatively impacts their health outcomes, including quality of life, adherence to antiretroviral therapy (ART), viral suppression, and morbidity and mortality (DiPrete et al., 2019; Gonzalez et al., 2011; Todd et al., 2017; Mugavero et al., 2007). Integrating screening and treatment for depression into HIV care has been shown to reduce depression, and improve ART adherence and viral suppression (DiPrete et al., 2019; Safren et al., 2016; Wagner et al., 2016; Schumacher et al., 2013; Pence et al., 2015; Himelhoch and Medoff, 2005; Springer et al., 2012). However, despite the high burden of depression, it remains unrecognized and untreated in many PLWH.

Diagnosis of depression and major depressive disorder (MDD) requires an assessment of symptom severity and functional impairment. Short, structured instruments are commonly used in depression screening to identify persons with scores above a cutoff threshold for further evaluation (Levis et al., 2020; Thombs and Ziegelstein, 2014). The World Health Organization (WHO) recommends using screening tools for an integration of mental health and HIV services and interventions (Integration of mental health and HIV interventions, 2022). Screening tools are not designed to establish a definitive diagnosis of major depression because they can yield a significant number of false positive or false negative results. However, depression screeners have proven useful as they allow healthcare providers and community health workers to identify potential symptoms of mental health conditions and to monitor them over time (Integration of mental health and HIV interventions, 2022). Low-resource settings with high HIV burden may have scarce resources for full clinical assessment and management of depression and, thus, can especially benefit from tools to identify those most in need for referral to specialized interventions or treatment. The Patient Health Questionnaire (PHQ-9) is widely used to screen for depression (Levis et al., 2020; Kroenke et al., 2001). The tool is based on the DSM-IV diagnostic criteria for

MDD and its total score ranges from 0 to 27. A recent meta-analysis has compared PHQ-9 scores with MDD diagnoses from validated diagnostic interviews and found that combined sensitivity and specificity of the PHQ-9 was maximized at a cut-off score of 10 and above (sensitivity 88%, specificity 85%) (Levis et al., 2019). However, these studies have not specifically evaluated the PHQ-9 performance among PLWH and were not primarily drawn from low-resource settings.

Sub-Saharan Africa (SSA) accounts for over 60% of the global HIV burden (Kharsany and Karim, 2016). Systematic reviews have estimated the overall prevalence of depressive disorders and probable major depressive disorders among PLWH in Africa to be 36.5% and 14.9%, respectively (Bigna et al., 2019). High rates of HIV and depression comorbidity make screening for depression essential for better outcomes of HIV care. The PHQ-9 is commonly used for this purpose. However, despite its wide implementation, the tool has been minimally evaluated for comprehension and performance among PLWH. Only several studies from SSA have assessed the PHQ-9 performance among PLWH against a clinical diagnosis of depression providing mixed evidence (Tsai, 2014). In Cameroon, the PHQ-9 was found to have sensitivity and specificity of 27% and 94% (Gold Standard: Composite International Diagnostic Interview) in one study (Pence et al., 2012), and 50% and 95% in another study (Yotebieng et al., 2024). Sensitivity and specificity of the PHQ-9 among PLWH were found to be higher in studies from Southern and Eastern Africa: 78.7% and 83.4% in South Africa (Gold Standard: Mini International Neuropsychiatric Instrument [MINI]) (Cholera et al., 2014), 91% and 77% (Gold Standard: MINI) in Kenya (Monahan et al., 2009), and 91.6% and 81.2% (Gold Standard: MINI), respectively, in Uganda (Akena et al., 2013).

To date, there has been little explanation of the observed variability in sensitivity and specificity among PLWH in SSA (Tsai, 2014), questioning the validity of a widely implemented tool in this population and context. Some have questioned if PHQ-9 items are ill comprehended or interpreted differently based on contextual factors (Velloza et al., 2020; Malpass et al., 2016). Others suggested that high variability in sensitivity and specificity of the PHQ-9 among PLWH in Africa is linked to questionnaire's mode of administration. The PHQ-9 was initially developed as a self-administered tool. However, due to the low literacy of the studied populations in low-resource settings and their little experience with structured questionnaires, evaluations of the PHQ-9 performance against a psychiatrist's diagnosis usually rely on interviewer administration of the tool. Although previous studies have not found differences in the PHQ-9 performance between self-administration and interviewer administration in the general population (Pinto-Meza et al., 2005), interviewer administration was named a study limitation in Cameroon that could impact sensitivity of the screener among PLWH (Pence et al., 2012).

Culture was shown to play an important role in the ways individuals understand and express mental health problems worldwide (Kohrt et al., 2014; Haroz et al., 2017). There is growing research in global mental health on shared linguistic and cultural connotations - idioms of distress – that provide insights into localized understandings of psychological suffering and the ways depression is experienced and spoken about (Kohrt et al., 2014). Allowing to capture possible symptomatology of depression, idioms of distress can prove useful in

clinical settings (Kohrt et al., 2014; Backe et al., 2021) Idioms of distress used across many cultural contexts globally may differ from the understandings of depression in high-income Western settings, where standardized screeners were developed and tested. These differences along with socioeconomic inequalities make challenging the use of standardized tools in low-resource settings as they were developed outside the contexts in which they are used (Mendenhall et al., 2016). In SSA, "thinking too much" was found to be the primary idiom for psychiatric distress among different sub-populations including PLWH (Backe et al., 2021). "Thinking too much", an idiom reflective of emotional and cognitive disquiet, spanned a broad range of personal, familial, and other concerns, causing someone to be overwhelmed with excess thought (Haroz et al., 2017). In urban Kenya, somatization and "thinking too much" were found central to local expressions of mental distress (Mendenhall et al., 2019). To note, "thinking too much" is not mentioned or measured in the PHQ-9.

There is a need to better understand how well the PHQ-9 captures symptoms of depression and idioms of distress relevant for PLWH in SSA, and whether the tool captures depression as intended. This is a critical step in ensuring PHQ-9 validity in this population and context. This study among PLWH in Yaoundé Cameroon aimed to a) explore local understandings of depression and mental distress and b) assess cognitive response processes during PHQ-9 administration.

2. Methods

This sequential multiple methods study was nested in a parent study that sought to assess performance of the PHQ-9 among PLWH in Cameroon, Kenya, the Republic of Congo, Senegal, and Côte d'Ivoire (Yotebieng et al., 2024). The parent study used a cross-sectional design and was conducted across five countries participating in the International epidemiology Databases to Evaluate AIDS (IeDEA) consortium within the East-, Central-, and West Africa IeDEA. Participating sites were hospitals located in urban areas, served large active cohorts of PLWH, and were selected if onsite psychiatric services were available. Participants were administered the PHQ-9 and a questionnaire that collected socio-demographic information. Within 3 days of completing the questionnaires, participants were referred to a psychiatrist with experience working with PLWH for an independent evaluation for a major depressive disorder. Data from 779 participants who completed both the PHQ-9 and a psychiatric evaluation were collected between January 2018 and July 2022 (Yotebieng et al., 2024).

This paper presents findings from a multiple methods qualitative study, conducted in Yaoundé, Cameroon, as part of the larger parent study. Qualitative data were collected from 54 unique study participants. 30 in-depth interviews (IDIs) were conducted first, followed by a single round of 24 cognitive interviews (CIs). Participants for both sets of interviews were recruited from the pool of parent study participants and were enrolled between June 2019 and May 2020 in a hospital that serves over 3000 people living with HIV.

2.1. In-depth interviews

Sequential invitations were used to enroll 30 IDI participants and to balance the sample by age and sex. Thematic data saturation is generally achieved in small samples of 20–

30 qualitative interviews (Guest et al., 2006, 2020). In our study, we stopped conducting interviews at N = 30 because that was the point at which thematic saturation was reached. The interview guide was designed in English and translated into French. IDIs explored participants' knowledge of depression and/or the "disease of worries/thinking too much" (Appendix A), its symptoms and perceived causes, and locally relevant expressions of depression, and the understanding of the PHQ-9 items. While developing the IDI guide, we hypothesized that a significant part of participants in this setting may have limited knowledge of the word "depression" and associated terminology. The choice to describe depression as "disease of worry/disease of thinking too much" in the guide was made to best capture depressive symptomatology if the word "depression" was unknown to participants. This conceptualization was guided by foundational works in global mental health and transcultural psychiatry, which identified "thinking too much" as a common idiom of distress that overlap with common psychiatric symptomatology including depression, anxiety, and PTSD (Kaiser et al., 2015) and perceived to be caused by multiple problems and worry in Central African context (Ventevogel et al., 2013). "Thinking too much" is also included in the DSM-V as one of the cultural concepts of distress. IDI participants were invited to describe the symptoms of depression or "disease of worries" that each PHQ-9 item related to, provide examples of how people experience these symptoms and how common they are, and to tell if those symptoms described by the PHQ-9 items were a meaningful part of depression or "thinking too much"/"disease of worry".

IDIs were conducted in French in private rooms within the hospital. The local study staff who conducted IDIs had previous experience collecting qualitative data and received a refresher training prior to the start of this study. Response rates were high due to prior participation in the parent study and all individuals recruited participated in the interviews. All interviews lasted 30–45 min, were audio recorded, and transcribed by study staff. We conducted a thematic analysis (Kiger and Varpio, 2020) that involved reading through the transcripts, identifying emergent themes and comparing them across interviews, developing a codebook, and coding transcripts in the MAXQDA software package. Shared understandings of depression and mental distress were the primary focus. Reported symptoms of depression were grouped into somatic, affective, cognitive, and behavioral manifestations. We then compared local expressions of depression with participants' understanding of the PHQ-9 items.

2.2. Cognitive interviews

Subsequent to IDIs, we recruited an additional sub-sample to participate in cognitive interviews (CIs), purposively sampling participants to ensure a range of PHQ-9 scores among participants. One round of CIs was conducted, assessing the following cognitive domains as defined by (Tourangeau et al., 1984): 1) comprehension and interpretation of PHQ-9 items; 2) retrieval of information; 3) decision-making about what and how to report; and 4) mapping experiences to available response categories (Tourangeau et al., 1984; Willis, 2005). Additional rounds of CIs were precluded by the onset of the COVID-19 pandemic in 2020. A semi-structured CI protocol was designed by an expert in cognitive interviewing (DW) in English and translated to French by Cameroonian study team staff, including scripted and optional emergent probes. The protocol involved a full administration

of the PHQ-9 in French (The PHQ-9), which was subsequently re-administered item by item, with probing and think-aloud techniques (Appendix B). Participants were also asked to describe their experience taking the PHQ-9 and the timeframe that they were referencing when responding to the PHQ-9 items. CIs were conducted in private rooms within the hospital by three local study staff who had previous experience with qualitative research and had received training in CI data collection and management from CI experts before the study. CIs lasted approximately 60 min, were audio recorded, transcribed and translated to English by local study staff. Interviewers also took extensive notes during and after the interview, referring to the recordings as necessary. Participants who expressed depressive symptoms during the interview were escorted to a psychiatrist on-site for further evaluation.

We conducted an interpretivist content analysis that incorporated contextual and social understandings of PHQ-9 items into cognitive processes: 1) Interpretation/understanding; 2) Retrieval/recall; 3) Decision-making/judgment; and 4) Response formulation. We used a hybrid text summary-coding approach (Willis, 2015). First, each interviewer/analyst developed a case-based debriefing report immediately following the interview, identifying contextual factors, participant difficulty responding, and the 4 cognitive processes above as they related to the intent of PHQ-9 items. Bilingual French-English speaking staff collaborated with a senior English-speaking Cognitive Interviewing expert (DW) to guide the analysis. We then aggregated data from the 24 cases and condensed the text. Using cross-case matrices we coded the full data set for cognitive domains (Appendix C). Analytic memos were used to identify emergent themes and numeric frequencies were tabulated for relevant themes.

Participants who completed IDIs or CIs were compensated for their time and transport to the clinic. The study was approved by the Institutional Review Board of the Ohio State University, Albert Einstein College of Medicine, and Cameroon's Ethics Committee. All participants provided signed informed consent.

3. Results

I. In-depth Interviews

3.1. Characteristics of IDI participants—IDIs participants were from 20 to 58 years old (mean age: 39.1) and over two-thirds of the sample were aged 35 and over (Table 1). Forty percent of the sample (n = 12) were female and one-third of participants were married. Almost two-thirds of the sample (n = 19) completed secondary or tertiary education. Most IDIs participants (n = 21) had a PHQ-9 score of 0–4 indicating lack of depressive symptoms. One-sixth of the sample (n = 5) has a PHQ-9 score of 5–9 indicating the presence of some depressive symptoms. Thirteen percent of IDIs participants (n = 4) had a PHQ-9 score of 10 and over, which indicated possible depression.

3.2. Local expressions of depression among PLWH—IDIs started with a question whether participants know the term "Depression" or "Disease of worries/disease of thinking too much" followed by an invitation to explain this condition's meaning, symptoms, and possible causes. Over a half of participants (n = 17) recognized the term depression. Thirteen people had not heard about depression, but recognized and provided detail on

the "disease of worries". Data from all 30 IDI participants were included in this section to describe commonly discussed depressive symptomatology and possible causes of this condition. The IDI guide was using terminology "depression" and culturally relevant expressions such as "disease of worry/thinking too much" interchangeably to solicit responses from all participants. Perceived causes included problems such as financial hardships, concerns about their family, relationships with significant others, and illness. The relationship between HIV and depression was a significant theme as participants worried about their physical condition, the future, and an ability to have family. These concerns could cause excess thoughts, closely related to the local understanding of depression. One participant explained:

> Someone thinks too much only when maybe you have an illness that bothers you. Poverty can make you think, you have nothing to eat can it make you think.

> Woman, 33 years old. PHQ-9 score = 2.

> Another participant further elaborated on how difficulties managing her disease and financial hardships intertwined:

> The disease of worry [happens] when I think a lot. First, when I have no money, I think, what should I do to eat. How can I possibly buy my medicines? And even to come here [to the hospital], how do I pay for my transport and everything and everything?

> Woman, 22 years old. PHQ-9 score = 14.

The initial diagnosis of HIV was stressful: it triggered distress and often had a lasting effect on participants' mental health who worried about their future. Participants were also concerned whether family and others accept their disease. Family ties and social relationships were important, so when someone is "rejected by their entourage", that may cause depression.

An open-ended question prompting participants to elaborate on the meaning and expressions of depression and/or "disease of worry/thinking too much" provided rich data. We organized repeating meanings into four domains: somatic, affective, cognitive, and behavioral symptoms. Cognitive symptoms were mentioned most often and included "thinking too much," "excess thought," "lost in his thoughts," "loss of memory," "forgetting (himself)," "not focused," and "not clearheaded". This participant's description included cognitive, somatic, and behavioral symptoms:

> The disease of the worries is when people have excess thoughts; people who are depressed for some reason. It can happen when you lose a close person, or your job, you will have worries. It can also lead to strong mental illness. Sometimes there is a loss of memory: you can talk to someone and think they are listening, but they are not focused on the conversation. One can forget an appointment or miss sleep. You can also notice [depression] if the dress has changed, if someone neglects one's hair or nails.

> Man, 50 years old. PHQ-9 score = 7.

Cognitive and somatic symptoms commonly intertwined. Participants listed poor appetite and weight loss, lack of sleep, and feeling unwell or uncomfortable. One woman (44 years old, PHQ-9 score = 5) explained the "disease of worry" as "thinning and [someone] lost in his thoughts". Participants also discussed headaches, stomach aches, tension, and "nerves". Fatigue was mentioned least often.

Affective manifestations commonly included irritability followed by mood swings, "something wrong", and sadness. Finally, a group of behavioral meanings linked to withdrawal was important for the local understandings of depression and mental distress. Participants talked about wanting to "sit alone in your corner" (26-year-old woman; PHQ-9 score = 19) avoiding people and conversations.

3.3. Understanding of the PHQ-9 items—The PHQ-9 items 3 ("Trouble falling or staying asleep, or sleeping too much"), 4 ("Feeling tired or having little energy"), and 5 ("Poor appetite or overeating"), related to somatic manifestations of depression, were most often well understood by IDI participants (Table 2). Participants agreed that symptoms described by these PHQ-9 items may describe depression or "disease of worries". Item 3 (insomnia or hypersomnia) was interpreted correctly, while most participants usually reported insomnia. Item 4 (fatigue, little energy) was commonly associated with three different factors including disease, particularly HIV, poor physical health, or heavy workload. Several participants noted that fatigue and insomnia may be associated with excess thought: "Someone thinks a lot, his brain works and he doesn't sleep" (22-year-old woman; PHQ-9 score = 14). Lack of appetite (Item 5) was well understood and often viewed as an indicator of physical illness.

Items 1 ("little interest or pleasure in doing things"), 2 ("Feeling down, depressed, or hopeless"), and 7 ("Trouble concentrating on things, such as reading the newspaper or watching television") were sufficiently understood, but some activities were not relevant to participants' lived experiences. Part of participants interpreted Item 1 as intended noting that "when you are unhappy you cannot do anything" (46-year-old man; PHQ-9 score = 2). However, participants more often associated anhedonia with someone's poor physical health or being tired due to daily routines rather than depression. A shared theme in interpretations of Item 1 was "lack of will" as participants spoke about "your choices in life" meaning that someone needs to properly focus on their family, work or other duties. Item 7 was well understood, but problems with reading and watching TV were not among their primary concerns and did not align well with commonly mentioned themes relevant to depressive symptomatology such as "thinking too much" or "lost in one's thoughts". Other commonly used terms that can be associated with cognitive manifestations included "forget oneself", "loss of memory", 'holes in memory" rather that troubles concentration on TV or reading.

Items 2 ("Feeling sad, down, or hopeless"), 6 ("Feeling bad about yourself"), and 9 ("Thoughts you would be better off dead") were understood and correctly interpreted by most participants, but were often associated with experiences of HIV. Reflecting on these items' meaning, PLWH discussed problems with accepting their diagnosis, worries about their future, and an ability to maintain relationships and have children. Item 6 evoked meanings such as failure, worthless, lost taste in life, cannot meet expectations. These

connotations commonly related to internalized HIV stigma as participants remembered how they learned about their diagnosis, feeling bad about themselves for getting the disease, and fear of rejection due to their status. Item 9 ("Thoughts you would be better off dead") was interpreted correctly and resonated with participants, but many were avoiding the word "death," speaking instead about "doing something stupid" and/or "weakness of character".

Finally, Item 8 ("Moving or speaking so slowly that other people could have noticed") was not understood and was misinterpreted by most respondents along with interviewers who had shared cultural background with participants. Several IDI participants suggested that Item 8 related to severe mental illness such as "speaking alone" (i.e. when someone speaks aloud to themselves).

II.   Cognitive Interviews

3.4.   Characteristics of CI participants—Two-thirds of CI participants were aged 35 and over (Table 1). Just over a half of the sample (n = 13) were female and two-thirds were married. Most (n = 13) completed secondary or tertiary education. Over a half of participants (n = 14) had a PHQ-9 score of 0–4 indicating lack of depressive symptoms. One-quarter of the sample (n = 6) had a score of 5–9 indicating some depressive symptoms. Seventeen percent (n = 4) had a PHQ-9 score of 10 and over, which indicated possible depression. Mean PHQ-9 Score was 5.67.

3.5.   Comprehension and interpretation—We explored participants' comprehension of all instructions, items and response categories to determine if their interpretation aligned with intended meanings. Denominators were used to indicate the relative prevalence of observed issues within the sample. Denominators are less than 24 if responses were unclear to the analysis team and/or analyst consensus was not achieved. Item 1 was correctly interpreted by less than a half of respondents (7/20), who described anhedonia and provided examples such as having little interest in things they once took pleasure in but no longer did such as romantic relationships, raising children and buying gifts. The majority of respondents (12/20) did not describe anhedonia and instead described lack of interest as being related to tasks that felt more like obligations than choices. One woman stated that she "didn't want to do anything" because she had been working hard sewing masks for many weeks. Another participant noted that "It depends on how you do things, there are times you want to do things and times you don't want to do things" (44-year-old man; PHQ-9 score = 3): only obligations that brought *pleasure* in some form (e.g. renewing a license to be able to make a living) would be rated as 'not at all' on the PHQ-9 scale. Further, 4 of these 12 respondents included a specific judgment about being "lazy" when someone was not engaging in the activity, e.g. "Mrs. [X] doesn't want to do the fields". (66-year-old woman; PHQ-9 score = 9) There was one notable case of the 20 respondents who interpreted Item 1 as a lack of sexual pleasure specifically, and related it HIV status being a barrier to engaging in sexual activity.

Most participants (22/24) correctly interpreted Item 2 and used synonyms such as lost, weak, discouraged, despair, losing the will to live. Most participants (20/24) interpreted Item 3 correctly and did not struggle with the double-barreled question. Some of those

reporting trouble falling asleep attributed this to "having too many problems in their head." (26-year-old woman; PHQ-9 score = 24) Most understood the concept of tiredness in Item 4 (21/24), but respondents attributed fatigue to three different factors including HIV or HIV medication (10/20), heavy workload (3/20), and poor physical health (8/20), but not depression-related fatigue. One woman often felt tired, because "I get up every day to go out and buy the merchandise and come back to sell" (58-year-old woman; PHQ-9 score = 3). Generally, "poor appetite" (Item 5) was interpreted as not being hungry or not wanting to eat due to physical illness. The concept of "overeating" in Item 5 was almost universally not understood (22/24): participants interpreted overeating in different ways "being greedy", "eating more than you need when you are not hungry"; "forcing yourself to eat".

Item 6 ("Feeling bad about yourself") was the most robustly articulated among all items in the PHQ-9, referencing both internal and family-related worthlessness and guilt. Participants included terms like: failure, worthless, pitiful, lost taste in life, feel like a loser, can't meet expectations. One man noted: "I used to help my brothers but now I can't because I don't have anything they don't look for me anymore" (26-year-old woman; PHQ-9 score = 24). Four of 24 explicitly named their HIV status as being related to their feelings of worthlessness or guilt.

Item 7 was interpreted correctly by less than a half of participants (7/22) as diminished ability to concentrate, think or make decisions using terms like "holes in my memory" or "lost in thoughts". Most interpreted this incorrectly (13/22) as instead capturing an overarching focus on attaining life goals, or prioritizing tasks or goals. Item 8 was interpreted correctly by few (4/20); participants gave examples of both types of psychomotor problems including moving slowly and being restless (French version did not use word "fidgety"). This item was misinterpreted by most (16/20). With some capturing moving slowly correctly, but misinterpreting the term "restless" as being "completely diminished", "over thoughtful", "afraid", "disturbed". The double barrel nature of the question made it difficult for people to choose which type of psychomotor disturbance they were being asked about. Item 9 was interpreted correctly by almost everyone (22/23).

3.6. Retrieval in CI—For each of the PHQ-9 items, there is a question stem that acts as a reference period to which respondents are asked about frequency of depressive symptoms. It reads (in the French version) "Au cours des deux derniere's semaines, y-a-t-il eu un moment ou …" or in the English version as "Over the past two weeks, how often were you bothered by any of the following problems …". Only 2 out of 24 respondents identified the prior 2 weeks as the reference period for reporting depressive symptoms. Instead, participants responded to items by using one of two approaches to define a time anchor. The first approach was to anchor responses to a traumatic event in the past, often being the time around their HIV diagnosis. Alternately, a second approach was used in which they conjured typical daily struggles related to poverty, difficult relationships or their HIV status. For both of these approaches, there was no clear or consistent time interval defined or referenced across participants. In the absence of a clearly demarcated time interval, this likely made it difficult for participants to choose from response categories that assumed a two-week period. Others have suggested that a calendar be used to mark off a 14-day window to demarcate the time interval of reference (Velloza et al., 2020). In our research however, a calendar strategy

would continue to pose challenges for participants because the items themselves appear to trigger memories of experiences that occurred at an earlier time period of unknown duration. This likely led to an overestimation of symptoms, since the referenced period of symptom presence extended beyond the prior two weeks and selected specifically for symptomatic episodes.

3.7. Decision process—A third component in the cognitive response process relies on decision making and judgment over what respondents deem acceptable or appropriate to report (Willis, 2005). CI interviewer field notes proposed that some respondents may have deflated the frequency that they reported depressive symptoms due to perceived negative social norms associated with them; specifically, "laziness" or lack of ambition. When administered the PHQ-9, three respondents reported having little energy (Item 4) "none of the time" but when probed, all three described that they did in fact experience fatigue. This incongruence in reporting may reflect a deeper social desirability to not be perceived as being lazy, therefore underreporting a depressive symptom of interest in the PHQ-9.

Additionally, CI respondents sometimes conflated depressive symptoms with factors typically associated with HIV: viral symptoms, ARV side effects and experiences related to HIV stigma. This was especially true in items 3 (i.e. perseverating about problems related to their relationship) and 4 (i.e.feeling tired after taking HIV drugs at night).

3.8. Response categories—Overall, the four available response categories (1. "not at all", 2. "several days", 3. "more than half the days", 4. "nearly every day") created considerable challenges for participants to accurately map depression symptoms in items 1–9 onto their lived experiences. In part, this may have been a function of participants referring to a time interval beyond the 2-week time period (see *Decision Process*, above). Additionally, respondents had difficulty understanding and, subsequently, incorrectly sequenced the four ordinal response categories. The first and the fourth categories (not at all and nearly every day) were mostly interpreted correctly. However, the two middle categories posed a great deal of confusion, where some respondents sequentially inverted them, citing "several says" (category 2) meant "a repetitive act that occurs regularly" or "several hours in the day", and "more than half the days" (category 3) meant a range of durations that were calculated as less frequent than category 2 (e.g. "sometimes", "doing something with interruption", "5 days in a month"). Six people explicitly stated they did not know the meaning of categories 1 or 2. Interviewers posited this could have been related to low literacy, as 5 of those 6 had never attended or advanced beyond primary school.

III. Comparative Findings: Higher vs. Lower PHQ-9 Scores

To identify potential differences in participant narratives or response patterns, we conducted post hoc comparative analyses of IDI and CI participants, separately, by PHQ-9 scores: participants scoring 0–9 (fewer reported symptoms) vs. 10–27 (greater reported symptoms).

In the IDIs, 4 participants, 2 women and 2 men, had the PHQ-9 score >9 indicative of possible depression. Asked about their understanding of depression or "disease of thinking too much", they spoke from their current experiences and evoked a comprehensive picture of depressive symptoms. Somatic and cognitive manifestations were central to their

explanatory models of depression. On the somatic side, these four participants spoke about fatigue, insomnia or sleepiness, complete lack of appetite (two participants mentioned that they could go for up to one month without eating anything), thinning, and headaches, often severe. Cognitive symptoms included excess thought, forgetfulness, and problems with concentration or reasoning. The combination of somatic and cognitive symptoms listed by these individuals with PHQ-9 scores >9 did not differ from the models developed by other participants. However, these four participants included two other symptoms in their descriptions. Two participants, one man and one woman, discussed suicidality, often around the time of their initial HIV diagnosis. Irritability, anger, and aggression were brought up by 3 out of 4 people – two men and one woman. They spoke about being angry with everyone and even "crisis of anger". One participant explained that his children were sometimes afraid to come near or pass by, when he was in this condition (42-year-old man, PHQ-9 score = 11). To note, the PHQ-9 questionnaire lacks items related to irritability, which may be an important symptom of mental distress in this setting.

In the CIs, 4 participants, 1 man and 3 women, had the PHQ-9 score >9 indicative of possible depression. These respondents shared vivid descriptions of loss, embarrassment, abandonment and trauma closely related to their HIV diagnosis and the impact it had on familial and employer relationships. One woman with the highest PHQ-9 score in the sample described deep ongoing despair, having lost all of her family, suffering physical and sexual abuse from her husband of 5 years "before I used to like to do the laundry but now all this desire has disappeared I wake up in the morning I look at the floor and the plates, I don't want to do anything. While I used to work as a housekeeper in people's homes, now I don't want to do anything". (26-year-old woman, PHQ-9 score = 24) While these reports were particularly vivid, they did not differ dramatically from recounts of traumatic situations experienced from the remaining 20 participants scoring <9 on the PHQ-9. We reviewed misapplication of response categories and found that 2 of the 4 participants had misinterpreted the two middle categories, but in opposite directions: overinflating "several days" to mean 10 of 14 days, and deflating "nearly every day" to mean 5 of 14 days. However, this misinterpretation was not proportionately different from those with lower PHQ-9 scores. Overall, there were few to no obvious differences for those scoring high vs. low.

4. Discussion

This study aimed to explore the ways PLWH in Cameroon understand symptoms of depression and identify how effectively the PHQ-9 screening tool captures symptom manifestation. Conceptually, our study drew from the field of global mental health that has called for attention to idioms of distress that can help with identification of the presentation of depression, particularly in non-Western settings. Transcultural psychiatry and cultural anthropologists go further to explain how depression presents differently across contexts. The conceptual "biopsychiatric model" of depression (more common in Western contexts) frames depression as a disease process embedded in individual genetics or anatomy as compared to the "situational model" (more common in non-Western or collectivist contexts), which describes depression as responsive to external or interpersonal situations (Patel, 1995; Mayston et al., 2020; Karasz, 2005).

Our findings are consistent with the evidence from diverse settings that show that non-Western understandings and presentations of depression may not align with structured assessment tools developed in Western settings for the general population (Kohrt et al., 2014; Mendenhall et al., 2016). Studies showed that presentations of depression symptoms also differ among racial and ethnic groups in the USA (Kirmayer, 2001) and between cultural groups globally (Goodmann et al., 2021). Over the past decade, a growing number of studies have shown low sensitivity of the PHQ-9 among PLWH in both Western settings (Mufson et al., 2022) and SSA (Tsai, 2014; Pence et al., 2012; Yotebieng et al., 2024). A recent assessment of the PHQ-9 performance among PLWH in five SSA countries found that sensitivity for the PHQ-9 cut-off score 10 was 50% or lower in Cameroon, Congo and Senegal; 67% in Kenya and 71% in Cote d'Ivoire, respectively (Yotebieng et al., 2024). Drawing from our qualitative study findings among PLWH in Cameroon, we suggest that low sensitivity of the PHQ-9, particularly in Central and Western Africa, may be partially explained by the poor overlap between local culturally-relevant conceptualizations of depression and notions that the PHQ-9 items intend to grasp. The wording of Item 7, or rather, lack of culturally-relevant activities described by this item, are particularly worrisome. Although "thinking too much" was shown central to local understandings of mental distress across diverse SSA settings (Backe et al., 2021), only one Item 7 of the PHQ-9 targets cognitive symptomatology and does that imperfectly.

Other explanations of the PHQ-9 low sensitivity among PLWH can relate to cognitive processes people use to interpret items. Cognitive testing of the PHQ-9 among pregnant and postpartum women with and without HIV in Kenya has identified problems related to PHQ-9 comprehension, decision processes, and response processes (Velloza et al., 2020). However, there is still limited evidence from other SSA settings on how PLWH express depression and interpret the PHQ-9 items. This study fills this gap in knowledge and adds on the growing concerns over the wide use of the PHQ-9 as a depression screener among PLWH.

The PHQ-9 uses the DSM-IV diagnostic criteria for MDD and was designed to assess depressive symptoms and their severity among the general population. To screen positive for MDD, in the past two weeks, an individual should experience five or more symptoms such as depressed mood, lack of interest, problems with sleep or appetite, etc., and at least one of the symptoms should be either depressed mood or anhedonia. In the PHQ-9 questionnaire, the latter are assessed through Items 1 and 2. However, our study showed that somatic and cognitive manifestations of depression were most often included in the local understandings of depression. Generally, those entailed excess worry or thought related to hardship and problems in life, HIV being among essential concerns on this list, and a range of somatic manifestations. Those did not necessarily include low mood or lack of interest as prime indicators of mental distress according to the DSM-IV and, accordingly, the PHQ-9.

Systematic reviews showed that depressed mood, problems with sleep and appetite, fatigue, and social isolation were the most frequently described depression indicators among the general population in SSA (Haroz et al., 2017). A study from urban Kenya also emphasized cognitive and somatic expressions of psychological suffering and mental distress such as "thinking too much", problems with the appetite and sleep and the like (Mendenhall et al.,

2019). This aligns with our findings that showed that cognitive and somatic manifestations were the most commonly expressed features of depression among PLWH in Cameroon. Both IDI and CI participants spoke about experiencing cognitive problems but referred to them as problems of "thinking too much", "lost in his thought", "hole in memory" rather than difficulties to concentrate while reading or watching TV as Item 7 of the PHQ-9 suggests. We have also found that the notion of lack of interest or pleasure (Item 1 of the PHQ-9), typically understood as a hallmark of depression in Western settings, often inferred "lack of willpower" or laziness among PLWHs in Cameroon. These culturally stigmatizing notions of laziness may reflect social desirability bias, therefore resulting in participants underreporting their symptom frequency. Along with cognitive and somatic manifestations of depression noted among the general population in Kenya, we found that behavioral and affective symptoms such as withdrawal/social isolation and irritability were also important for the ways PLWH described depressive symptoms. Consistent with other evidence from SSA (Haroz et al., 2017), we found that psychomotor slowing or agitation were not part of participants' understandings of depression, and Item 8 of the PHQ-9 was almost universally misinterpreted.

Using culturally relevant screening tools may yield promising results while working with PLWH. Yet, we also identified unique challenges of PLWH, which can challenge differentiation and recognition of depressive disorders in this population. PLWH commonly interpret depressed mood, fatigue, lack of energy, and poor appetite as effects of HIV or HIV medications rather than depression. Feelings linked to experiences of HIV also include worry about relationships with others. Feeling bad about themselves due to initial diagnosis, and living with HIV translates into internalized stigma associated with feelings of shame, guilt and worthlessness. Internalized and anticipated stigma of HIV (Pantelic et al., 2019) affects social relationships and cause the fear of rejection by families and significant others and concerns about their ability to start a family, have children, and live long lives. Experiences of living with HIV, particularly feeling shame, sadness and somatic symptoms of disease, may conflate or overshadow depressive symptomatology. Although PLWH sufficiently understood over half of PHQ-9 items, we found that they had problems mapping their experiences onto response categories. This can cause some PLWH to underreport or overreport depressive symptoms while responding to the PHQ-9 questions, which skews PHQ-9 scores by artificially inflating or deflating them.

We have also identified areas of the PHQ-9 that are prone to response errors and social desirability bias. An analysis of the retrieval process showed that the PHQ-9 items often triggered traumatic memories of the initial HIV diagnosis. Responding to the PHQ-9 questions, participants linked their experiences to that moment in the past rather than the previous two-week interval. Cognitive psychologists have traditionally labelled this retrieval process as a function of an individual's cognitive capacity. However, the emerging field of Cognitive Sociology (Chepp et al., 2014) offers an important perspective on this retrieval behavior, that contextualizes an individual's question-response process as being governed by memories developed within larger social contexts and shaped by social events (Chepp et al., 2014; Olick et al., 2011). This may have been evidenced by the CI participant with the highest PHQ-9 score of 24, who had a vivid recount of ongoing trauma. This aligns with conceptual models of depression reported by researchers of non-Western cultures, wherein

causes of depression are viewed as "situational" (Karasz, 2005; Kirmayer, 2001). In the case of PLWH in Cameroon, their memories were strongly shaped by the multiple stigmas associated with their HIV status, exemplified in the diagnosis event. The implications for this retrieval approach for PLWH, anchoring the socially and personally critical memory of HIV diagnosis vs. the previous 2 weeks, may escalate reports of symptoms captured in the current PHQ-9.

Most CI participants also had problems with response categories such as "half of the time" and were unsure how to map their daily challenges into them. The order of survey items in the original CI protocol starting from the question: "When did you learn about your HIV status for the first time?" prior to the PHQ-9 administration may have also played a role in the way participants responded to the PHQ-9 items, priming them to consider their HIV diagnosis event instead of the previous two weeks. Together, this may explain generally low performance of the PHQ-9 and mixed evidence on the tool's sensitivity and specificity from studies among PLWH in SSA.

The following recommendations are derived from findings of this study. Further adaptation and testing of the PHQ-9 in French and Cameroon's local languages (Ewondo, Pidgin English and others) are recommended. This may help to improve the tool's cultural validity, reduce response errors, and potentially improve PHQ-9 sensitivity and specificity among PLWH in this setting. Although the PHQ-9 items related to somatic symptoms of depression were well understood and interpreted as intended by PLWH, adding additional instructions to these items is recommended to disentangle HIV experiences (ill health, fatigue and other psychical symptoms) from possible depressive symptoms. Further adaptation and testing of wording are needed to introduce culturally-relevant activities to the PHQ-9 items (particularly Item 7, intended to capture cognitive manifestations of depression), and to reduce confusion with double-barreled questions. Finally, similar to recommendations provided from cognitive testing of the PHQ-9 in Kenya (Velloza et al., 2020), adding a visual aid for selecting response options in form of a rating scale or thermometer scale is highly recommended. Several limitations of the study should be acknowledged. IDIs and CIs were conducted in French and may not include culturally-relevant expressions of depression in other languages spoken in Cameroon. Also, CI studies typically include multiple rounds of testing when potential problems are identified during a first cognitive interview, problematic items are adjusted, and then additional rounds of CIs are conducted until the problems no longer occur. In our study, the COVID pandemic made it not feasible to conduct further rounds and test hypothesized problems, therefore limiting our ability to identify and test suggested changes to the PHQ-9 with certainty. The study was conducted in a single setting among PLWH receiving care at a large urban hospital. PLWH who were linked to care and PLWH who living in peri-urban and rural areas in Cameroon were not recruited in the study. Their perspectives and experiences could differ from participants enrolled in the study. Those limitations notwithstanding, our study has significant strengths: its multiple method design provided rich data for an understanding how PLWH experience and speak about depression. To the best of our knowledge, our study has become the first to examine local understandings of depression and interpretation of the PHQ-9 items among PLWH in Central Africa.

5. Conclusions

Excess thought, problems with sleep and appetite, fatigue, and irritability were the most frequently used depression features by PLWH in Cameroon. While this is consistent with evidence from the general SSA population, HIV experiences were essential for PLWH's understandings of depression. We noted important areas of concern over the PHQ-9 performance as a valid depression screener among PLWH. First, local expressions of depression did not align well with the hallmarks of depression in Western settings that the PHQ-9 was designed to capture. PLWH also described unique challenges associated with HIV, which may cause additional problems fitting their experiences into the PHQ-9 items. Second, several PHQ-9 areas are prone to response errors. Incorrect interpretations of almost half of the PHQ-9 items suggests this tool may have limited validity in this population, and warrants the need for its further testing and adaptation. Depression has important implications for PLWH health and, in the light of concerns over the PHQ-9 performance, there is an urgent need for a valid culturally relevant tool for identification and treatment of depression in this population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

References

Akena D, Joska J, Obuku EA, Stein DJ, 2013. Sensitivity and specificity of clinician administered screening instruments in detecting depression among HIV-positive individuals in Uganda. AIDS Care 25 (10), 1245–1252. 10.1080/09540121.2013.764385. [PubMed: 23398282]

Ayano G, Demelash S, Abraha M, Tsegay L, 2021. The prevalence of depression among adolescent with HIV/AIDS: a systematic review and meta-analysis. AIDS Res. Ther 18 (1), 23. 10.1186/s12981-021-00351-1. [PubMed: 33906698]

Backe EL, Bosire EN, Kim AW, Mendenhall E, 2021. "Thinking too much": a systematic review of the idiom of distress in sub-saharan Africa. Cult. Med. Psychiatry 45 (4), 655–682. 10.1007/s11013-020-09697-z. [PubMed: 33387159]

Bigna JJ, Tounouga DN, Kenne AM, Djikeussi TK, Foka AJ, Um LN, Asangbeh SL, Sibetcheu AT, Kaze AD, Ndangang MS, Nansseu JR, 2019. Epidemiology of depressive disorders in people living with HIV in Africa: a systematic review and meta-analysis: burden of depression in HIV in Africa. Gen. Hosp. Psychiatr 57, 13–22. 10.1016/j.genhosppsych.2018.10.005.

Chepp V, Gray C, 2014. Foundations and new directions. In: Miller K, Willson S, Chepp V, Padilla JL (Eds.), Cognitive Interviewing Methodology, pp. 7–14. 10.1002/9781118838860.ch2. Hoboken, Whiley.

Cholera R, Gaynes BN, Pence BW, Bassett J, Qangule N, Macphail C, Bernhardt S, Pettifor A, Miller WC, 2014. Validity of the Patient Health Questionnaire-9 to screen for depression in a high-HIV burden primary healthcare clinic in Johannesburg, South Africa. J. Affect. Disord 167, 160–166. 10.1016/j.jad.2014.06.003. [PubMed: 24972364]

DiPrete BL, Pence BW, Bengtson AM, Moore RD, Grelotti DJ, O'Cleirigh C, Modi R, Gaynes BN, 2019. The depression treatment cascade: disparities by alcohol use, drug use, and panic symptoms among patients in routine HIV care in the United States. AIDS Behav. 23 (3), 592–601. 10.1007/s10461-018-2282-3. [PubMed: 30288684]

Gonzalez JS, Batchelder AW, Psaros C, Safren SA, 2011. Depression and HIV/AIDS treatment nonadherence: a review and meta-analysis. J. Acquir. Immune Defic. Syndr 58 (2), 181–187. 10.1097/QAI.0b013e31822d490a. [PubMed: 21857529]

Goodmann DR, Daouk S, Sullivan M, et al. , 2021. Factor analysis of depression symptoms across five broad cultural groups. J. Affect. Disord 282, 227–235. 10.1016/j.jad.2020.12.159. [PubMed: 33418371]

Guest G, Bunce A, Johnson L, 2006. How many interviews are enough? An experiment with data saturation and variability. Field Methods 18 (1), 59–82. 10.1177/1525822X05279903.

Guest G, Namey E, Chen M, 2020. A simple method to assess and report thematic saturation in qualitative research. PLoS One 15 (5), e0232076. 10.1371/journal.pone.0232076. [PubMed: 32369511]

Haroz EE, Ritchey M, Bass JK, Kohrt BA, Augustinavicius J, Michalopoulos L, Burkey MD, Bolton P, 2017. How is depression experienced around the world? A systematic review of qualitative literature. Soc. Sci. Med 183, 151–162. 10.1016/j.socscimed.2016.12.030. [PubMed: 28069271]

Himelhoch S, Medoff DR, 2005. Efficacy of antidepressant medication among HIV-positive individuals with depression: a systematic review and meta-analysis. AIDS Patient Care STDS 19 (12), 813–822. 10.1089/apc.2005.19.813. [PubMed: 16375613]

IeDEA: International epidemiology Databases to Evaluate AIDS, https://www.iedea.org/.

Integration of mental health and HIV interventions, 2022. Key Considerations. Joint United Nations Programme on HIV/AIDS and the World Health Organization, Geneva.

Kaiser BN, Haroz EE, Kohrt BA, Bolton PA, Bass JK, Hinton DE, 2015. "Thinking too much": a systematic review of a common idiom of distress. Soc. Sci. Med 147, 170–183. 10.1016/j.socscimed.2015.10.044. [PubMed: 26584235]

Karasz A, 2005. Cultural differences in conceptual models of depression. Soc. Sci. Med 60 (7), 1625–1635. 10.1016/j.socscimed.2004.08.011. [PubMed: 15652693]

Kharsany AB, Karim QA, 2016. HIV infection and AIDS in sub-saharan Africa: current status, challenges and opportunities. Open AIDS J. 10, 34–48. 10.2174/1874613601610010034. [PubMed: 27347270]

Kiger ME, Varpio L, 2020. Thematic analysis of qualitative data: AMEE Guide No. 131. Med. Teach 42 (8), 846–854. 10.1080/0142159X.2020.1755030. [PubMed: 32356468]

Kirmayer LJ, 2001. Cultural variations in the clinical presentation of depression and anxiety: implications for diagnosis and treatment. J. Clin. Psychiatry 62 (Suppl. 13), 22–28. ; discussion 29-30.

Kohrt BA, Rasmussen A, Kaiser BN, Haroz EE, Maharjan SM, Mutamba BB, de Jong JT, Hinton DE, 2014. Cultural concepts of distress and psychiatric disorders: literature review and research recommendations for global mental health epidemiology. Int. J. Epidemiol 43 (2), 365–406. 10.1093/ije/dyt227. [PubMed: 24366490]

Kroenke K, Spitzer RL, Williams JB, 2001. The PHQ-9: validity of a brief depression severity measure. J. Gen. Intern. Med 16 (9), 606–613. 10.1046/j.1525-1497.2001.016009606.x. [PubMed: 11556941]

Levis B, Benedetti A, Thombs BD, 2019. DEPRESsion Screening Data (DEPRESSD) Collaboration. Accuracy of Patient Health Questionnaire-9 (PHQ-9) for screening to detect major depression: individual participant data meta-analysis. BMJ 365, l1476. 10.1136/bmj.l1476. [PubMed: 30967483]

Levis B, Sun Y, He C, et al. , 2020. Accuracy of the PHQ-2 alone and in combination with the PHQ-9 for screening to detect major depression: systematic review and meta-analysis. JAMA 323 (22), 2290–2300. 10.1001/jama.2020.6504. [PubMed: 32515813]

Malpass A, Dowrick C, Gilbody S, Robinson J, Wiles N, Duffy L, Lewis G, 2016. Usefulness of PHQ-9 in primary care to determine meaningful symptoms of low mood: a qualitative study. Br. J. Gen. Pract 66 (643), e78–e84. 10.3399/bjgp16X683473. [PubMed: 26823268] .

Mayston R, Frissa S, Tekola B, Hanlon C, Prince M, Fekadu A, 2020. Explanatory models of depression in sub-Saharan Africa: synthesis of qualitative evidence. Soc. Sci. Med 246, 112760. 10.1016/j.socscimed.2019.112760. [PubMed: 32006814]

Mendenhall E, Yarris K, Kohrt BA, 2016. Utilization of standardized mental health assessments in anthropological research: possibilities and pitfalls. Cult. Med. Psychiatry 40 (4), 726–745. 10.1007/s11013-016-9502-y. [PubMed: 27553610]

Mendenhall E, Rinehart R, Musyimi C, Bosire E, Ndetei D, Mutiso V, 2019. An ethnopsychology of idioms of distress in urban Kenya. Transcult. Psychiatr 56 (4), 620–642. 10.1177/1363461518824431.

Monahan PO, Shacham E, Reece M, Kroenke K, Ong'or WO, Omollo O, Yebei VN, Ojwang C, 2009. Validity/reliability of PHQ-9 and PHQ-2 depression scales among adults living with HIV/AIDS in western Kenya. J. Gen. Intern. Med 24 (2), 189–197. 10.1007/s11606-008-0846-z. [PubMed: 19031037]

Mufson L, Morrison C, Shea E, Kluisza L, Robbins R, Chen Y, Mellins CA, 2022. Screening for depression with the PHQ-9 in young adults affected by HIV. J. Affect. Disord 297, 276–282. 10.1016/j.jad.2021.10.037. [PubMed: 34695500]

Mugavero MJ, Pence BW, Whetten K, Leserman J, Swartz M, Stangl D, Thielman NM, 2007. Predictors of AIDS-related morbidity and mortality in a southern U.S. cohort. AIDS Patient Care STDS 21 (9), 681–690. 10.1089/apc.2006.0167. [PubMed: 17919095]

Olick K, Vinitzky-Seroussi, Levy D, 2011. In: The Collective Memory Reader. Oxford University Press, Oxford.

Pantelic M, Sprague L, Stangl AL, 2019. It's not "all in your head": critical knowledge gaps on internalized HIV stigma and a call for integrating social and structural conceptualizations. BMC Infect. Dis 210. 10.1186/s12879-019-3704-1.

Patel V, 1995. Explanatory models of mental illness in sub-Saharan Africa. Soc. Sci. Med 40 (9), 1291–1298. 10.1016/0277-9536(94)00231-h. [PubMed: 7610434]

Pence BW, Gaynes BN, Atashili J, O'Donnell JK, Tayong G, Kats D, Whetten R, Whetten K, Njamnshi AK, Ndumbe PM, 2012. Validity of an interviewer-administered patient health questionnaire-9 to screen for depression in HIV-infected patients in Cameroon. J. Affect. Disord 143 (1–3), 208–213. 10.1016/j.jad.2012.05.056. [PubMed: 22840467]

Pence BW, Gaynes BN, Adams JL, Thielman NM, Heine AD, Mugavero MJ, McGuinness T, Raper JL, Willig JH, Shirey KG, Ogle M, Turner EL, Quinlivan EB, 2015. The effect of antidepressant treatment on HIV and depression outcomes: results from a randomized trial. AIDS 29 (15), 1975–1986. 10.1097/QAD.0000000000000797. [PubMed: 26134881]

Pinto-Meza A, Serrano-Blanco A, Peñarrubia MT, Blanco E, Haro JM, 2005. Assessing depression in primary care with the PHQ-9: can it be carried out over the telephone? J. Gen. Intern. Med 20 (8), 738–742. 10.1111/j.1525-1497.2005.0144.x. [PubMed: 16050884]

Safren SA, Bedoya CA, O'Cleirigh C, Biello KB, Pinkston MM, Stein MD, Traeger L, Kojic E, Robbins GK, Lerner JA, Herman DS, Mimiaga MJ, Mayer KH, 2016. Cognitive behavioural therapy for adherence and depression in patients with HIV: a three-arm randomised controlled trial. Lancet HIV 3 (11), e529–e538. 10.1016/S2352-3018(16)30053-4. [PubMed: 27658881]

Schumacher JE, McCullumsmith C, Mugavero MJ, Ingle-Pang PE, Raper JL, Willig JH, You Z, Batey DS, Crane H, Lawrence ST, Wright C, Treisman G, Saag MS, 2013. Routine depression screening in an HIV clinic cohort identifies patients with complex psychiatric co-morbidities who show significant response to treatment. AIDS Behav. 17 (8), 2781–2791. 10.1007/s10461-012-0342-7. [PubMed: 23086427]

Springer SA, Dushaj A, Azar MM, 2012. The impact of DSM-IV mental disorders on adherence to combination antiretroviral therapy among adult persons living with HIV/AIDS: a systematic review. AIDS Behav. 16 (8), 2119–2143. 10.1007/S10461-012-0212-3. [PubMed: 22644066]

The PHQ-9 https://www.phqscreeners.com/images/sites/g/files/g10060481/f/201412/PHQ9French%20for%20Canada.pdf.

Thombs BD, Ziegelstein RC, 2014. Does depression screening improve depression outcomes in primary care? BMJ 348, g1253. 10.1136/bmj.g1253. [PubMed: 24496211]

Todd JV, Cole SR, Pence BW, Lesko CR, Bacchetti P, Cohen MH, Feaster DJ, Gange S, Griswold ME, Mack W, Rubtsova A, Wang C, Weedon J, Anastos K, Adimora AA, 2017. Effects of antiretroviral therapy and depressive symptoms on all-cause mortality among HIV-infected women. Am. J. Epidemiol 185 (10), 869–878. 10.1093/aje/kww192. [PubMed: 28430844]

Tourangeau R, 1984. Cognitive sciences and survey methods: a cognitive perspective. In: Jabine T, Straf M, Tanur J, Tourangeau R (Eds.), Cognitive Aspects of Survey Methodology: Building a Bridge between Disciplines. National Academy Press, Washington, DC.

Tsai AC, 2014. Reliability and validity of depression assessment among persons with HIV in sub-Saharan Africa: systematic review and meta-analysis. J. Acquir. Immune Defic. Syndr 66 (5), 503–511. 10.1097/QAI.0000000000000210. [PubMed: 24853307]

Uthman OA, Magidson JF, Safren SA, Nachega JB, 2014. Depression and adherence to antiretroviral therapy in low-, middle- and high-income countries: a systematic review and meta-analysis. Curr. HIV AIDS Rep 11 (3), 291–307. 10.1007/s11904-014-0220-1. [PubMed: 25038748]

Velloza J, Njoroge J, Ngure K, Thuo N, Kiptinness C, Momanyi R, Ayub S, Gakuo S, Mugo N, Simoni J, Heffron R, 2020. Cognitive testing of the PHQ-9 for depression screening among pregnant and postpartum women in Kenya. BMC Psychiatr. 20 (1), 31. 10.1186/s12888-020-2435-6.

Ventevogel P, Jordans M, Reis R, de Jong J, 2013. Madness or sadness? Local concepts of mental illness in four conflict-affected African communities. Conflict Health 7 (1), 3. 10.1186/1752-1505-7-3. Published 2013 Feb 18. [PubMed: 23418727]

Wagner G, Ghosh-Dastidar B, Ngo V, Robinson E, Musisi S, Glick P, Dickens A, 2016. A cluster randomized controlled trial of two task-shifting depression care models on depression alleviation and antidepressant response among HIV clients in Uganda. Res. Adv. Psychiatr 3 (1), 12–21.

Willis GB, 2005. Cognitive Interviewing: A Tool for Improving Questionnaire Design. Sage publications, Thousand Oaks.

Willis GB, 2015. Analysis of the Cognitive Interview in Questionnaire Design. Oxford University Press, Oxford.

Yotebieng M, Zotova N, Bernard C, Goodrich S, Awoh AR, Watnick D, Nsonde DM, Tchiengang EF, Noumedem JL, Mbongo'o GC, Minga A, Seydi M, Gandou P, Kwobah EK, Atwoli L, Jaquet A, Wools-Kaloustian K, Anastos K, the IeDEA Consortium, 2024. Accuracy of nine-item Patient Health Questionnaire against psychiatric diagnosis for depression among people with HIV. AIDS 38 (12), 1765–1773. 10.1097/QAD.0000000000003963. [PubMed: 38905494]

Table 1

Demographics of the qualitative and cognitive interview participants.

	In-depth interviews (n = 30)		Cognitive interviews (n = 24)	
	N	%	N	%
Age				
24	3	10	0	0
25-34	6	20	7	29.2
35+	21	70	17	70.8
Missing	0	0	0	0
Gender				
Male	18	60	11	45.8
Female	12	40	13	54.2
Missing	0	0	0	0
Marital status				
Married	10	33.3	16	66.7
Single/divorced/separated/widowed	20	66.7	8	33.3
Missing	0	0	0	0
Education				
Primary	10	33.3	9	37.5
Secondary	12	40	10	41.7
Tertiary	7	23.3	3	12.5
Missing	1	3.4	2	8.3
PHQ-9 Score				
0-4	21	70	14	58.3
5-9	5	16.6	6	25
10-14	2	6.7	3	12.5
15-19	2	6.7	0	0
20-27	0	0	1	4.2
Total	**30**	**100**	**24**	**100**

Table 2

Understanding and interpretation of the PHQ-9 items by IDI and CI participants.

PHQ-9 items	IDIs	CIs*
1. Little interest or pleasure in doing things	Well understood, but did not align well with local models of depression. Anhedonia was often related to poor physical health or being tired due from daily routine. "Lack of interest in doing things" was commonly interpreted as lack of will or morale; may be subject to social desirability bias	Over half participants misinterpreted this. Correct Interpretations provided a range of examples such as having little interest in things they once took pleasure in but no longer did. Incorrect Interpretations described lack of interest as being related to tasks that felt more like obligations than choices. Several interpretations included a specific judgment linking "lack of interest" to being "lazy".
2. Feeling sad, down, depressed or hopeless	Well understood; often associated with experiences of HIV	Most interpreted correctly, evidenced by synonyms used: "lost", "weak", "discouraged", "despair", "losing the will to live"
3. Trouble falling or staying asleep, or sleeping too much	Well understood	Most interpreted the question correctly as asking about insomnia or hypersomnia
4. Feeling tired or having little energy	Well understood, but fatigue is most often associated with illness/poor physical health, heavy workload, or excess worry	Most understood the concepts of. However, fatigue was attributed to HIV, HIV treatment effects, heavy workload, or poor physical health, not mental health.
5. Poor appetite or overeating	Well understood	Poor appetite was interpreted as not being hungry or not wanting to eat, and was seen as an indicator of physical illness. Overeating was almost universally misunderstood (22/24) in a context of food scarcity: interpreted as "eat[ing] enough" or "forcing [oneself] to eat"
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	Well understood; often associated with experiences of HIV and internalized stigma	This item was the most robustly articulated of all items in the PHQ-9, referencing both internal and family-related worthlessness and guilt. Four participants explicitly named their HIV status as rationale for these feelings.
7. Trouble concentrating on things, such as reading the newspaper or watching television	Understood, however, trouble concentrating on TV or reading were not among the primary concerns of participants and did not align well with local manifestations of depression. Instead, respondents described "thinking too much", "lost in one's thoughts", etc.)	One-third interpreted correctly as having a diminished ability to concentrate, to think or to make decisions using terms like "holes in my memory" or "lost in thoughts". Two-thirds however interpreted this incorrectly, instead capturing a broader inability to prioritize tasks or attain life goals: "[no] focus on education and on the future of children"
8. 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	Not understood and did not align with local models of depression	Mostly misinterpreted, where participants gave examples of both types of psychomotor problems including moving slowly and being restless: some captured 'moving slowly' correctly, but then misinterpreted the term 'restless' as being 'completely diminished', 'over thoughtful', afraid' or 'disturbed'. The double barrel nature of the question also made it difficult for people to choose which type of psychomotor disturbance they were being asked about
9. Thoughts that you would be better off dead or of hurting yourself in some way	Well understood; often associated with experiences of HIV and triggered memories of the time of HIV diagnosis	Interpreted correctly by almost everyone who articulated it