The collaborative care model for HIV and depression: Patient perspectives and experiences from a safety-net clinic in the United States

Shannon M Fuller[1] [iD], Kimberly A Koester[1], Xavier A Erguera[1], Emma Wilde Botta[1], Fredrik von Beetzen[1], Wayne T Steward[1] and Ann Avery[2,3]

Abstract

Objectives: Collaborative care models may improve outcomes for both HIV and depression. The model includes routine screening and re-assessment of depressive symptoms as well as care coordination services delivered by an ancillary provider focused on mental health. We sought to explore patient experiences and attitudes about the services received through the collaborative care model, including measurement-based care using the Patient Health Questionnaire-9.

Methods: We conducted 17 qualitative interviews with patients in a collaborative care model implemented at an HIV primary care clinic in a safety-net hospital in the United States. Interviews were analyzed using Framework Analysis.

Results: Our findings illustrate the ways in which the collaborative care model for depression may be meaningful to patients in HIV care settings. Participants appreciated the support offered through the collaborative care model. Most participants perceived measurement-based care as useful to their providers, and an additional subset used the Patient Health Questionnaire-9 for their own self-management and awareness of depression. Over time, the collaborative care model appeared to motivate some patients to address depressive symptoms.

Conclusion: The collaborative care model may be particularly helpful to patients in the way that it reinforces how depressive symptoms can be measured and managed. Furthermore, routine screening and re-measurement for depressive symptoms using the Patient Health Questionnaire-9 hold promise as an additional self-management tool to complement other clinical and supportive services.

Keywords

HIV, depression, collaborative care, self-management, qualitative research

Introduction

People living with HIV (PLWH) experience depression at high levels. Compared to the general population (6.7% prevalence of depression), the prevalence among PLWH has been estimated at 20%–37%,[1] with some estimates surpassing 50%.[2] The deleterious effects of untreated depression are well documented,[3] and for PLWH, depression can accelerate the progression of HIV-related morbidity and mortality.[4–6]

A range of evidence-based treatment options exist for depression, including medications, group therapy, cognitive behavioral therapy, and self-management support.[7–9] Depression treatment is associated with improved adherence to antiretroviral therapy[10] and better health outcomes

for depression and HIV,[11,12] yet many PLWH in need of mental health care remain untreated or undertreated for depression.[13] Similar to the HIV care cascade, which outlines

[1]Division of Prevention Sciences, Center for AIDS Prevention Studies, The University of California, San Francisco, San Francisco, CA, USA
[2]MetroHealth Medical Center, Cleveland, OH, USA
[3]Case Western Reserve University, School of Medicine, Cleveland, OH, USA

Corresponding author:
Shannon M Fuller, Division of Prevention Sciences, Center for AIDS Prevention Studies, The University of California, San Francisco, Mailcode 0886, 550 16th St, 3rd Floor, San Francisco, CA 94158, USA.
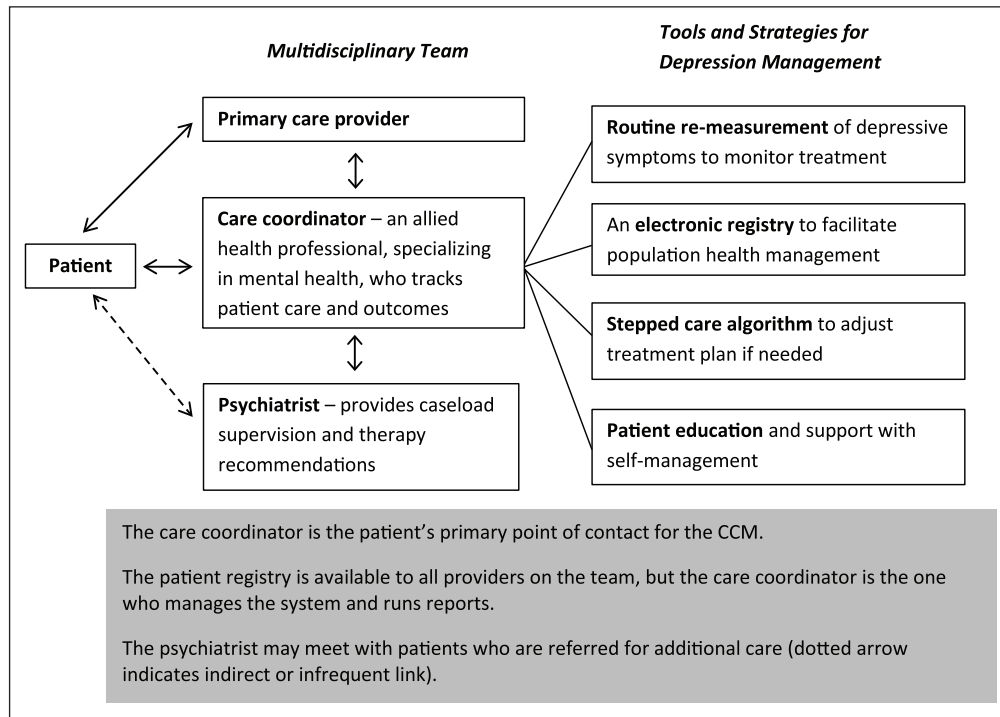Email: Shannon.Fuller@ucsf.edu

Figure 1. Collaborative care model (CCM): key components and approach.

the steps from HIV diagnosis to viral load suppression,[14] the "depression treatment cascade" depicts the stages from clinical recognition of depression to treatment initiation and, ultimately, remission of symptoms.[13] According to the cascade, an estimated 80% of PLWH with diagnosed or undiagnosed depression are not receiving adequate treatment for depression. For those who were receiving treatment for depression, only 7% were receiving adequate treatment and 5% had achieved remission.[13]

Numerous factors contribute to this disparity between need and access to depression care.[15] At a structural level, some of the challenges include infrequent screenings for depression[16] and a shortage of specialty mental health providers in the United States.[17] In the general US population, an estimated 12.5% of primary care patients had major depressive disorder, but only about half of the cases were diagnosed.[18] The gaps along the depression care cascade underscore the need for regular screening of depression (to improve clinical recognition and treatment initiation) and for better monitoring of care and treatment responses (to help more patients achieve remission of depressive symptoms).[13,18]

The collaborative care model (CCM) attempts to address these challenges by routinizing depression screening in primary care settings and using care coordinators (typically social workers or nurses) to offer specialized mental health support to patients and monitor treatment response.[19,20] Figure 1 depicts the model and its key features. The CCM consists of a multidisciplinary care team composed of a primary care provider, care coordinator, and psychiatric consultant.

Led by the care coordinator, the team uses a patient registry and standardized measurement tool to monitor patients' responses to treatment and adjust therapy as needed (i.e. measurement-based care). The care coordinator also serves as the primary contact for the patient by assisting with referrals to behavioral health services, providing health education, monitoring symptoms, and offering self-management support. Included in self-management support may be assistance with managing symptoms, setting goals, learning how to access health information and resources, and encouraging adherence to appointments and any therapy or medications.[21] *The specifics of the CCM in this study are detailed in the "Methods" section.*

The CCM may improve the health of individuals dually diagnosed with HIV and depression. Successful treatment for depression through the CCM has produced better treatment outcomes for patients with other chronic conditions such as diabetes and heart disease,[22,23] and randomized controlled trials of the model have demonstrated improvements in depressive symptoms compared to standard care.[20,24] The adaptation of the CCM for depression management in HIV primary care is nascent, but early results are encouraging. In a randomized controlled study of PLWH with depression receiving HIV care at the Veterans Health Administration (VA), the CCM exhibited cost effectiveness[25] and improved clinical outcomes for depression and HIV compared to standard care.[26] While early evidence demonstrates viability of CCM in the treatment of depression in HIV care settings, there is limited information on how PLWH actually experience the services offered through the model and how they

perceive routine screening and re-measurement for depression. We conducted an exploratory study to understand how patients experienced the changes associated with the CCM and what these innovations may mean for engagement in HIV care.

Methods

Study context

Our study is embedded within a larger mixed-methods evaluation based at the University of California, San Francisco (UCSF) and funded through the Health Resources and Services Administration's Special Projects of National Significance (HRSA SPNS). This particular initiative, the "System-level Workforce Capacity Building for Integrating HIV Primary Care in Community Health Care Settings," henceforth called the "Workforce Initiative," includes 15 different demonstration projects across the United States that have implemented new services and practices to build workforce capacity, promote more efficient delivery of care, and enhance support for patient engagement in care. The goal of the initiative is to improve HIV care continuum outcomes for PLWH and enhance the delivery of care in a variety of settings.[27] Quantitative analyses at the cross-site and site-specific levels will document the impact of these interventions on patient health outcomes. Those findings are forthcoming, pending final outcomes data from the initiative.

To understand patient attitudes and experiences in the initiative, we conducted qualitative interviews with a sample of patients in three of the participating demonstration sites between May and June 2016. We chose a qualitative approach in order to generate detailed descriptions of patient experiences in the Workforce Initiative during the early stages of project implementation. After conducting the patient interviews across the three sites in our sample, we found that the stories at MetroHealth warranted their own case study due to the unique design of the project relative to the other two sites where we had conducted patient interviews. The two sites excluded from this analysis focused on integrating HIV services and primary care, and findings from those interviews will be reported in a separate manuscript. Splitting the data in this way allows us to delve deeper into the experiences of patients engaged in a CCM for HIV and depression.

Intervention setting and CCM overview

The MetroHealth Medical Center is the public safety-net hospital system in Cleveland, Ohio, which houses an HIV primary care clinic that implemented a CCM in 2015 as part of the Workforce Initiative. The clinic is the largest provider of HIV care in Northeast Ohio, with a population of over 1600 patients. As is typical of safety-net care settings, the clinic reports high rates of poverty in the population it serves. Most patients are uninsured or on public insurance (32%

Medicaid, 22% Medicare, 31% uninsured, and 17% private insurance).

The CCM team at MetroHealth consists of HIV care providers, care coordinators, and a consulting psychiatrist. Both of the care coordinators are licensed social workers who have masters' degrees in social work (MSW) and have completed standardized, online training through the Advanced Integrated Mental Health Solutions (AIMS) Institute on the role of the care manager in the CCM, as well as general training with the consulting psychiatrist to identify depressive symptoms, diagnose psychiatric disorders, and learn self-management techniques that could be utilized by patients. The care coordinators facilitate coordination of services across the HIV and psychiatry departments in the medical facility. Although the HIV and psychiatric services are located in the same building of the hospital, historically care had been separated. By implementing the CCM, the clinic aimed to improve the management and quality of depression care in the HIV clinic by increasing access to specialty care without the need for direct face-to-face interaction between the patient and the psychiatrist.

Measurement-based care in the CCM: The Patient Health Questionnaire-9

To identify patients in need of services and monitor their care once enrolled in the CCM, the clinic uses the Patient Health Questionnaire-9 (PHQ-9), a validated tool to assess the severity of depressive symptoms.[28] The PHQ-9 consists of 9 survey items, with each answered using a Likert-type scale ranging from 0 to 3, indicating the degree to which the respondent feels that the statement applies to them. Responses are summed, resulting in a score range of 0–27, with 0–4 indicating absent to minimal depression and 20–27 reflecting severe depression. Typically, the questionnaire is self-administered, but it can be clinician-administered for patients with limited literacy.

Annually, all patients complete a shortened version of the PHQ-9 called the PHQ-2, a self-administered, two-item screening tool[29] to identify individuals with likely depression. Patients who answer positively to either of the two questions on the PHQ-2 are then instructed to complete the PHQ-9 for more detailed assessment. Patients with a PHQ-9 score of 10 or higher (the threshold for moderate depression) are referred to the care coordinator and provider for further assessment. Those patients who had an initial score of less than 10 on the PHQ-9 or a score of zero on the PHQ-2 are screened again in 12 months.

Patients with a confirmed diagnosis of depression are recommended appropriate treatment, as indicated by the severity of their depression, and are re-measured with the PHQ-9 in 3 months. Depending on severity, treatment could include some combination of support groups, psychotherapy, antidepressant medications, and self-management resources. More

specifically for the CCM evaluated in this study, self-management programs also included behavioral action planning, such as scheduling physical activity, social interaction, and pleasurable activities. PHQ-9 scores are tracked over time to monitor patient progress and guide treatment recommendations using validated algorithms for measurement-based care.[30,31]

Sampling and recruitment

We recruited patients enrolled in the CCM for in-depth interviews approximately 1½ years after the project started to ensure that participants would have had sufficient time in the intervention to be able to describe how it had influenced their care. Participants initiated CCM services at different times, but all had completed the PHQ-9 at least once and received a score ≥10. In addition, to be eligible to participate in an interview, individuals had to be (a) at least 18 years of age, (b) fluent in English or Spanish, (c) receiving HIV clinical services at the project site, and (d) currently receiving services in the CCM. Intervention staff referred potential participants to the study team, eliminating the need to share patient contact information. Potential participants were recruited by telephone or in-person using a script prepared by the research team. The script explained the purposes of the study, that is, to explore participant experiences in the CCM and the clinic as a whole. Participants were assured that their information would be kept confidential, that raw transcripts would only be available to the research team at UCSF, and that their decision to participate would not impact the care that they receive at the clinic. We prioritized recruiting patients who were already on-site for existing clinic appointments in order to minimize travel burdens. Data collection spanned one full week in order to capture a sample of patients across different providers (as most providers were not in clinic each day of the week) and to allow extra time if participants needed to reschedule. Individuals who expressed interest in participating met subsequently with the interviewer to discuss procedures and verify eligibility. All individuals who met with the study team consented to participate and were offered a US$40 gift card for their participation. The Institutional Review Board at UCSF reviewed and approved all procedures for this qualitative study. In addition, investigators at MetroHealth received approval through the MetroHealth System Institutional Review Board to implement and study the CCM as part of the Workforce Initiative.

Interview procedures

Interviews were conducted in English or Spanish by one of the three interviewers (S.M.F., X.A.E., and F.v.B.) trained in qualitative data collection and experienced working with vulnerable populations, including low-income PLWH and mental illness. All interviews and consent procedures were conducted in private spaces at the clinic. Prior to starting the interview, verbal rather than written informed consent was obtained to mitigate potential harms resulting from a breach of confidentiality, as data could be collected without study staff ever having the full names of the participants. The interviewers used a semi-structured interview guide (see "Interview domains" section), which allowed for flexibility to modify, re-order, and add follow-up questions as needed. The interviewers were instructed to maintain neutrality during each interview, so as not to bias participant responses toward being more or less favorable of the intervention or any of its components.

Interviews lasted 60 min on average (range: 38–85 min). At the end of the interview, a questionnaire was administered to collect demographic information (gender, age, race/ethnicity, and sexual identity). Interviewers wrote field notes to record summaries and impressions of each interview. The interviewers also met each day to discuss findings from the interviews and whether or not any revisions needed to be made to the interview guide or areas of inquiry. No major changes were made to the interview guide, and the team agreed that saturation had been reached by the end of data collection. All interviews were audio recorded, professionally transcribed, and translated from Spanish to English when applicable.

Interview guide

Author K.A.K., a medical anthropologist, oversaw the development of the interview guide with authors S.M.F., X.A.E., F.v.B., E.W.B., and W.T.S. (principal investigator of the cross-site evaluation at UCSF, with a graduate degree in social psychology). Author A.A., physician and principal investigator of the study at MetroHealth, also reviewed the interview guide. To develop the guide, we drew from our experiences on prior studies where we had conducted interviews with PLWH to understand their experiences in health care and in interventions to improve retention and engagement in care.[32–35] We also created the guide based on a phenomenological approach, which focuses on studying the experiences, perceptions, and feelings among people who have gone through a certain situation or phenomenon.[36] In this case, we wanted to understand the experiences of a small sample of PLWH who were enrolled in the CCM—how they understood the intervention, how they felt about it, and what they perceived to be the impact. To contextualize the participants' experiences in the CCM, we also included questions to explore current and past experiences in health care, particularly experiences and attitudes related to HIV and mental health care. As such, we organized the interview guide into the following domains: (a) experiences with health care in general, (b) experiences with HIV care generally and at the intervention site, (c) knowledge and attitudes about depression, and (d) awareness and attitudes about the study intervention. Sample questions from the interview guide included

the following: (1) *What is it like for you being in HIV care right now?* (2) *The clinic recently started asking patients a set of questions, called a depression screening form—one of the nurses or care coordinators usually discusses this with patients. What was that experience like for you?* (3) *What has your provider told you about treatment for depression?* The full interview guide is available as a supplemental file.

Analysis

We conducted a Framework Analysis[37] to identify themes in the data. Framework Analysis consists of five major steps: (1) Familiarization, (2) Identifying a Thematic Framework, (3) Indexing, (4) Charting, and (5) Mapping and Interpretation.[37] As we describe our analytic steps in the following, we include parenthetical notation to indicate how the methods align with each of the key steps in Framework Analysis.

Three members of the study team conducted the analysis (authors S.M.F., X.A.E., and E.W.B.). First, the analysts read a subset of interviews as a group to develop a codebook useful for systematically tagging concepts found in the participant narratives (*Familiarizing and Identifying a Thematic Framework*). The codebook included both a priori and emergent codes. At least two analysts coded each interview and compared code application to ensure consistency (*Indexing*). A final coded transcript was then entered into the software program, *Dedoose*,[38] to support our analysis of the data. The analysts collaborated in writing a memo after coding each transcript to provide a brief summary of the interview as well any analytic ideas that emerged while reading and coding the data.

After coding, the team discussed and identified the following key codes to be used for analysis: "behavioral health care experiences and attitudes," "depression," "PHQ-9 screening form narrative," and "perceived impact of PHQ-9 screening form." Together, the first and third authors reviewed and summarized all interview excerpts with one or more of the key codes applied. The dyadic process of reading interview excerpts aloud and summarizing the content together enabled discussion of emergent themes and interactive interpretation of the data. We then produced analytic tables to outline the information for each participant, allowing the team to further analyze the data and refine themes across and within cases (*Charting*). The first author reviewed the memos, field notes, analytic tables, and a subset of full transcripts and wrote a comprehensive memo outlining the preliminary findings (*Mapping and Interpretation*). Other analysts and co-authors reviewed the memo and analytic tables to verify interpretations and enhance the rigor of the analysis.

Findings

We interviewed 17 patients who had been enrolled in the CCM. By happenstance, our sample yielded equal numbers of participants who identified as male (n = 8) and female

Table 1. Demographic characteristics of the participants (N = 17).

Characteristics	N (%)
Gender	
Female	6 (35)
Male	8 (47)
Transgender	3 (18)
Ethnicity	
Hispanic	7 (41)
Non-Hispanic	10 (59)
Race	
Black	5 (29)
White	5 (29)
Other	7 (41)
Sexual orientation	
Bisexual	3 (18)
Heterosexual	8 (47)
Homosexual	6 (35)
Age (in years)	
20–29	2 (12)
30–39	4 (24)
40–-49	6 (35)
50–59	2 (12)
60–69	1 (6)
Declined to answer	2 (12)

(n = 8, including two trans women). An additional participant identified as gender non-binary. Participants reported an average age of 42 years, ranging from 27 to 64 years. Of the 17 interviews, 6 were conducted in Spanish. The demographic characteristics of the overall sample can be found in Table 1.

The CCM was generally well received by the patients we interviewed. This overall finding can be explained through three major themes identified in our analysis. Among participants, the drivers of acceptance and engagement in the model included (1) *Trust in provider and perceived value of using the PHQ-9 for depression assessment*, (2) *Recognition of the clinic's care and attention placed on mental wellbeing*, and (3) *Encouragement and support through the CCM to address symptoms of depression*. We describe each of these themes in more detail in the following sections.

To minimize the risk that clinic staff or providers could identify any participants, we present all demographic data in aggregate and use pseudonyms throughout the manuscript. Our analysis did not reveal notable differences in how participants responded to the CCM according to age, gender, or race/ethnicity, and therefore, we decided that redacting such descriptive information from each case featured in the following would not compromise our ability to represent the findings.

1. *Trust in provider and perceived value of using the PHQ-9 for depression assessment*

Most participants felt that the information elicited by the PHQ-9 was instructive to the provider and helped to insure proper treatment. One participant, Eric, explained, *"It's a way of [the provider] knowing how I feel … I don't analyze it. It's not the SAT,"* referring to the Scholastic Achievement Test taken by US high school students seeking admission to college. As was typical of other participants who expressed a similar attitude about the questionnaire, Eric trusted that his provider could interpret the measurements from the PHQ-9 and make appropriate recommendations for care.

General attitudes and prior experiences with depression also influenced responses to the PHQ-9. Specifically, a number of participants invoked language that appeared to normalize their experiences of depression, a tone that also carried into their narratives about the purpose and utility of the PHQ-9. Manuela, for example, did not recall completing the PHQ-9, yet expressed enthusiasm for the concept of routine screening and re-measurement after it was described to her: "*That's the best thing … because these days, I think everyone suffers from depression.*" In addition to knowing friends and family who suffered from depression, she also described undergoing periods of depression several times a year and reported taking antidepressant medication for about a decade.

A few participants reflected indifference toward the PHQ-9. These participants may have understood the medical utility of the questionnaire, but did not convey overt enthusiasm about it. Carl exhibited this neutral attitude. When asked about his experience with the PHQ-9, he shared, "*It was nothing. It was just something I felt like I had to do.*"

Two participants expressed skepticism about the PHQ-9's ability to reflect their own symptoms of depression; however, this did not appear to impede their overall interest in the CCM. In the following quote, Colin described his skepticism toward some of the specific items in the PHQ-9:

> *I'm always honest with the questions, you know. And then I started feeling like, I think my lack of interest on paper seems really bad. Because although I may have a lack of interest in doing something, to me I won't say I'm depressed. I personally will say I'm just being lazy because I can be really lazy at times and don't feel like doing nothin.' Like, I just literally want to lay down and watch TV and eat. Some people call that a form of depression. And it may be true for some people, but for me, I find comfort in it. I like it.*

Colin seemed amenable to answering the questions on the PHQ-9 honestly because he understood that it would prompt further conversation with the doctor or care coordinator. Although he had a relatively recent history in this particular clinic, he described several years of experience in behavioral health care, which seemed to enhance his comfort in having these conversations with members of his new care team. He mentioned that he was currently seeing the psychiatrist and the care coordinator and reported taking an antidepressant medication that he felt was working well.

Only one person voiced discontent about the PHQ-9. Robin reported numerous admissions to psychiatric hospitals and believed that answering the questionnaire honestly would result in involuntary commitment to inpatient psychiatric care. When asked about the PHQ-9, Robin responded,

> *If you don't want help, you're not going to tell the truth on it. And especially with the psych part, you're not going to be truthful if you don't want to go to the psych ward because they're going to ship you right out to the psych ward. And that's just a bunch of s—. I hate psych wards … That's why a lot of people, and personally me, I don't usually tell the truth on those forms.*

Underpinning the range of attitudes toward the PHQ-9 was the role of trust. Based on the stories shared by our participants, we conceptualized trust as the degree of confidence placed in the PHQ-9, care team, and health system. What seemed to distinguish Robin's case from others was the lack of trust in how the information gleaned from the PHQ-9 would be used, resulting in unwillingness to answer the questionnaire honestly. The other participants, by contrast, reported high levels of trust in their providers and in the larger medical system. This baseline prevalence of trust seemed to pave the way for acceptance of the PHQ-9 and other aspects of the CCM. Most participants believed that it was important to be truthful with the care team and described comfort being candid with the clinic staff. Will conveyed this sentiment clearly when he said, "*You've got to be truthful with the doctors … That's the only way you can get the proper care you need. And they make it so you're comfortable with being truthful with them.*"

2. *Recognition of the clinic's care and attention placed on mental wellbeing*

The CCM was often well received by patients in part because of the way that it signified genuine concern and caring from providers and staff. A number of participants observed that the clinic had dedicated more attention to the importance of mental health, and they welcomed this change. For many, the increased attention sent a message reinforcing their beliefs that the clinic really cared about them, as exemplified by a statement from Carl, notably someone who was indifferent toward the PHQ-9 itself. When recounting his experiences with the CCM team, Carl said, "*I like the fact that they are real thorough and see how you're doing … They actually seem genuine and caring and just want the best for you, for your health.*" Another participant, Michelle, described how she noticed the clinic becoming "more supportive" in the provision of mental health services through the new CCM:

> *They ask me, do I need anything? Do I need a counselor or any of that? They started doing that every time I come up here to see my doctor. And it's good that they got them doing that. Because some of us probably do need it. Right now, it just seems like they got a good team working together … I'm glad they're doing it*

that way now. Because it seems like they've become more supportive over the years.

Participants consistently endorsed the support from the care coordinator who was assigned to them through the CCM. They felt that they could turn to this person for help when needed and often appreciated how the care coordinator would reach out proactively to check on them or remind them about appointments. Like Pete, as quoted in the following, participants frequently described how they could trust the care coordinator:

She always gave me a first impression that, "I'm not going to judge you. We don't judge here." And that allowed me to say, "You know what? You can let your guards down and you can talk about how you really feel." So, that's how I feel sometimes when I'm with her. I feel I can trust her.

Through their own personal experiences and through education from their providers, most participants were cognizant of the risks associated with unmanaged depression and thus appreciated how the CCM aimed to mitigate these issues. For example, Will, a participant who reported recent initiation of antidepressant medication, described a family history of depression and had lost a relative to suicide. He had also witnessed the deaths of other friends with HIV, noting that "*they stopped taking their [HIV] medication because they were just depressed.*" Will understood that part of the motivation for the CCM was the potential it had to improve adherence to HIV treatment and represented one of the few participants who articulated this purpose of the intervention so clearly. When asked what his provider had told him about the symptoms of depression, Will explained,

He told me that you can lose interest in a lot of things. Your weight can go up and down. Either lose your appetite or gain an appetite. You just don't want to be around anybody. Don't want to take your medication. Which is important. That's why they really try to treat depression here … because when you get depression you don't want to take your medication. You don't want to do anything. So they try to fix that.

3. *Encouragement and support through the CCM to address symptoms of depression*

The CCM appeared beneficial both for patients who were already aware that they had depression and for patients who were newly diagnosed through the PHQ-9 screening tool. In this section, we outline how long-term exposure to the CCM supported patients who were at various stages with their interest in receiving treatment for depression.

Pete was one participant who recalled a strong motivation to engage in mental health care prior to implementation of the CCM and appreciated the ability to avail himself of these new services. After his recent incarceration, he learned that his anger issues—which he attributed to his incarceration— could result from mental health conditions. He also learned that receiving appropriate treatment could waive his charges, in addition to helping him manage his emotions. While these factors initially motivated him to seek mental health care, he appeared to find further validation and support through the CCM. In the following quote, he described his shift in attitude and personal realization that he needed mental health care:

With me fighting the case, being incarcerated, a lot of the people was telling me, "Go handle your anxiety. Go seek mental therapy" and stuff like that. So, I started reaching out more and started realizing, "You know what? I've got to take grasp of the opportunity to see why is it getting to this level where if I'm not being persistent in my mental healthcare. I don't want it to take me to that dark place again." […] I'm like, "Wow, you really need help." So, that's what made me start coming down. I'm getting more intense with me receiving help. Before that, I was always against it. Now, I'm like, "You know what? I need this [the services from the CCM] for myself."

Pete also explained that by working with the care coordinator he has learned about different methods of self-care, such as reframing negative self-talk, socializing with friends, and seeking out art therapy. In the following quote, he described the self-management component of the CCM:

[The care coordinator] gave me a collaborative work study—a program sheet where it has a list of things. Like, I check off on Wednesday "Did I accompany somebody today? Did I wear something that I liked today? Did I do something nice for a person today?" And I'll check it off. That's part of the assessment that she gives me sometimes just to keep me on track with me doing my mental therapy.

When asked how he felt about the self-management exercise described above, he said, "It changes the way I see [depression], and it gives me better options of how I can deal with it."

Some participants also described using the PHQ-9 as a tool for self-management or reflection. Though they did not invoke the term "self-management," they discussed using the PHQ-9 to track their symptoms of depression over time. Sarah, who disclosed that she was currently suffering a period of major depression, described her experience completing the PHQ-9 as, "*It was neat, but it was sad. I mean, it made me take a look at myself. And I didn't really realize how depressed I was.*" The interviewer inquired how many times she had filled out the questionnaire, and though she did not recall the exact number of times, she went on to explain that she did not mind completing it on each occasion, as it allowed her to take an active role in monitoring her symptoms:

[Completing the PHQ—9] doesn't bother me because it helps me. I don't mind doing stuff like that. I really do not mind doing stuff like that. So, if they do it every time, then that's a good thing. Bring it. Seriously—because it helps me. I'm like, "Oh, OK. Well, that's improved," or, "This is not improved," or, "This has gone bad," you know.

Another participant, Michelle, who recalled completing the PHQ-9 twice, recounted how the questionnaire gave her "good insight." She described her initial, long-standing resistance to depression treatment and how she had recently become more amenable to recommendations from her care team. When asked about her experience with the PHQ-9, Michelle replied,

It just gives you a good insight. It keeps me updated, if they feel like I may need help, or if I should go and get some counseling or something [...] Because I was depressed for a long time there. But I'm stubborn and I didn't want to take none of the medicines. And I was fighting them on it. And I found out that, you know, you don't always have to be depressed—there's different types of depression, too. They told me that. So, you don't always have to be depressed. You could get depressed over weird things, like what you ate, or something. Things that are going on in your life, how strong you can handle it. And if you don't feel like you can handle it, they got the support groups for that, too. I don't want to be in none of the support groups, but I think it's good that they started them.

Repeated exposure to the PHQ-9 seemed to build awareness of or reinforce awareness about depressive symptoms. It also helped patients better understand the purpose of the screening tool. For example, Will stated,

You wonder why at first, "why are they asking me this?" Now I understand why they ask you those questions because [depression] could affect whatever health problem you might be having. That they might run a test and say "well I wonder why this?' Maybe it's because he's depressed or something." So I see why it's important now.

Will exemplified a clear case of someone for whom the CCM as a whole appeared to influence engagement in care for depression. He explained that he had some initial concerns about side effects when his provider first suggested antidepressant medication, specifically how it would interact with antiretroviral therapy. In a decision that unfolded over an unspecified amount of time, he indicated that he now supported the provider's recommendation to start taking an antidepressant. Though he did not state so directly, it appeared that the combination of the repeated measurements with the PHQ-9, his own personal experiences witnessing the effects of untreated depression (described in Theme 2), and the conversations with the CCM team may have encouraged his willingness to try a new treatment plan that could improve his symptoms and wellbeing.

Discussion

In this study, we sought to understand the experiences of HIV patients who had been engaged in a CCM for treatment of depression. We found that the majority of participants in our sample were satisfied with the new program and with completing the PHQ-9 to screen for and re-assess depressive symptoms. For some participants, the CCM encouraged them to try new therapies for depression. Our findings have important implications for the integration of HIV and depression care and perhaps for other types of chronic care models where patient engagement is instrumental.

Most participants recognized the benefits of depression screening and monitoring. Through prior experiences with mental health care and/or education provided through the CCM, many patients understood that depression was a relatively common yet treatable condition, and that there were risks associated with untreated depression. Furthermore, those who embraced the clinic's adoption of routine screening and re-measurement for depression believed that the PHQ-9 elicited useful information for their providers.

These attitudes were shaped by how participants thought their providers would use the responses obtained from the PHQ-9. Trust—in one's care team and in how the information from the PHQ-9 would be used—appeared to play a significant role in influencing how participants responded to and engaged in the CCM. This finding was not surprising given the abundance of medical literature affirming the importance of trusting patient–provider relationship in promoting treatment adherence and engagement for a variety of conditions.[39,40] Furthermore, other studies have highlighted how trust is especially valuable in the context of HIV and depression care due to the stigma associated with both HIV and mental illness.[33,41,42] A number of interventions have aimed to improve patient–provider trust, yet a large-scale Cochrane review shows conflicting evidence of efficacy.[43] Further research is needed to identify how best to improve trust between patients and providers. Such approaches would likely need to be tailored to the particular patient population and its subgroups as well. For example, a trust-building intervention for someone with entrenched distrust of the medical system would likely be designed differently than an intervention geared toward a patient new to behavioral health care.

Irrespective of their feelings about the PHQ-9, however, participants liked the CCM approach overall. Even those who were indifferent to the PHQ-9 embraced other components of the model, such as working with the care coordinator and engaging in group therapy or other treatment modalities recommended by the CCM team. Appreciation for the CCM seemed to be largely influenced by the model's ability to reflect provider concern for patients and coordinate care across different disciplines, echoing other literature that demonstrates how patient-centered medicine promotes satisfaction and engagement in care.[44] The general positive response to the CCM was also likely influenced by the fact that a number of participants indicated prior awareness of depressive symptoms before the intervention began. These characteristics could also explain why we often heard patients express appreciation that the clinic was taking extra steps to care for those facing depression. Although it proved challenging to identify those among our sample who were

newly identified with depression as a result of the screening form, even among participants who already knew that they had depression, the PHQ-9 and the larger CCM appeared to be meaningful in the way that it provided access to new services and reinforced the importance of mental health care.

Our findings also revealed the value of long-term exposure to the CCM, including the re-measurement component using the PHQ-9. Over time, the program appeared to motivate some patients to address depressive symptoms. For example, some participants described initiating new forms of treatment or coping strategies, which, based on the timing, likely resulted in part from the intervention. It appeared that the process of completing the PHQ-9, along with additional conversations with the medical staff, might have enhanced patients' receptivity and self-efficacy[45] to try alternate therapies if their depressive symptoms had failed to improve. If the CCM improves patient engagement in depression care for PLWH, as our findings suggest, then it may in turn support engagement in HIV care by reducing the barriers associated with depression.[46]

Systematic re-measurement with the PHQ-9 could also assist providers in promptly identifying depression recurrence. More than half of individuals who experience one episode of major depression have a second episode.[47] Re-measurement could also help patients gain more awareness of the symptoms of depression, so that they too may be better equipped to detect the signs of an emergent problem or a need to revise their current care plan.

Overall, our findings suggest that the CCM gave patients a sense of control of their depression. Participants who described using the PHQ-9 as a self-management tool by promoting self-reflection, increasing awareness of symptoms, and providing a metric to track their own progress over time made this point especially clear. Similarly, in a qualitative study of patients in general care clinics in the United Kingdom, some patients requested the PHQ-9 to monitor their progress and liked that the score provided a "tangible" measurement of their depression.[48] Even if our participants did not use the PHQ-9 in this way or express a desire to do so, the CCM may have demystified what it meant to be in care for depression and reinforced the idea that depression could be managed effectively. An enhanced sense of control over depression would be extremely valuable for patients, as such beliefs are known to have protective effects. Research has shown that perceived control over one's environment, known as an internal locus of control,[49] is associated with better mental health and wellbeing.[50,51]

There is wide interest in encouraging self-management due to its potential to improve patient engagement in care and health outcomes for chronic conditions,[52] including HIV[53] and depression.[9] Promoting self-management may also reduce costs on the health care system.[54] However, supporting patient self-management can be difficult in safety-net settings[55] and in HIV care,[53] especially when patients are living with multiple chronic conditions.[56] Despite these challenges, evidence suggests that patients in safety-net settings are interested in self-management support, but that it is crucial to provide patients with a range of tools available in different formats, for example, web-based, phone, and in-person.[57] Our findings reaffirm that patients may be interested in self-management techniques, and the unintended role of the PHQ-9 as an adjunctive self-management tool warrants further exploration.

With the CCM consisting of multiple key components, it is difficult to identify the relative importance of each feature of the model.[19] However, a meta-regression study of the intervention components found that routine screening and measuring of depressive symptoms, having case reviews with a psychiatrist, and hiring care managers with a mental health service background were predictive of improved depression symptoms in primary care settings.[58] Our study contributes to this growing body of literature on the CCM for HIV and depression[59] by adding insight from a qualitative, patient-level perspective. Our findings reveal how the measurement-based component of the model, when paired with other CCM components, can help patients build the willingness and vision for addressing depression.

While re-measurement with the PHQ-9 seemed to produce a positive response among most of our participants, prior to the interviews we wondered whether patients would feel disgruntled about answering the same set of questions repeatedly. We did not hear this sentiment reflected in any of our interviews, though it is possible that the interviews were conducted too early to detect such measurement fatigue. Further study is needed to understand the long-term effects of regular re-measurement in this population.

Finally, it is important to remember that the CCM explored in this study took place in the context of a workforce development initiative. There are substantial strains on the availability of mental health specialists,[17] as well as concerns about the future capacity of HIV primary care providers.[60] The CCM helps to address these constraints in the healthcare workforce by allowing allied health professionals (e.g. care coordinators) to work at the top of their licenses, thereby transferring some of the tasks from the providers and streamlining services across departments. Participants consistently endorsed the support offered from the care coordinators. Though our sample size is small, our findings suggest that the changes in staffing structure inherent to the CCM may be acceptable to a number of patients and may foster engagement in care for both HIV and depression.

Limitations and further study

This was an exploratory study based in one clinic; therefore, caution should be taken in generalizing these findings to other settings as well as to the larger clinic population. Given that we did not interview patients who had declined services through the CCM or disengaged from care, our sample may be more representative of patients in the clinic who are relatively

well engaged. We also relied on project staff to refer interview participants to us, which may have introduced sampling bias if staff were more likely to refer participants that they knew had positive experiences in the CCM. To mitigate any potential sampling bias, we assured program staff that findings would only be shared in aggregate and that participant experiences would not be traced back to any specific providers.

Furthermore, being a small-scale, qualitative study, we did not aim to explore differences in CCM engagement along racial, age, or other demographic characteristics. Studies with larger sample sizes and appropriate designs could explore those differences and determine whether there are any significant correlates for providers or other clinic staff to consider when implementing the model. Our findings help to delineate some of the potential ways that patients can respond to and use the PHQ-9 and how they may perceive the CCM overall.

Conclusion

Participants interviewed as part of this study had generally positive attitudes toward the CCM, which were fundamentally shaped by the trust that patients placed in their providers. Particularly resonant aspects of the intervention included re-measurement with the PHQ-9 and the supportive role of the care coordinator. The PHQ-9 as a monitoring tool is a promising strategy for encouraging greater self-management and engagement in services to address depression. Our findings suggest that that the CCM is perceived as an acceptable, meaningful strategy that may improve health outcomes for patients dually affected with HIV and depression.

ORCID iD

Shannon M Fuller [iD] https://orcid.org/0000-0001-6070-8172

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