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TO THE EDITOR:

Evaluating self- vs interviewer-administered screening for depression in sickle cell disease

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Sickle cell disease (SCD) is a hereditary blood disorder impacting around 100 000 Americans, predominantly those who are from socioeconomically disadvantaged backgrounds.[1,2] Among adults living with SCD, there is a high prevalence of depression, affecting 20% to 57% of the population, which is even higher than the general population, affecting only ~8% of adults.[3-8] Depression among adults with SCD adversely affects the overall quality of life, acute visits, SCD outcomes, and survival.[9-12] National guidelines recommend annual screening for depression in adults with SCD.[13] However, many people are reluctant to seek help and underreport symptoms of depression due to stigma.[14-17] In SCD, stigma is accentuated due to other compounding factors related to both their race and the need for opioid medications to treat pain,[18,19] which may further limit depression symptom disclosure. Therefore, without regular and effective screening strategies, depression might remain unrecognized and untreated and contribute to poor outcomes in adults with SCD.

One standard screening tool for depression is the 9-item Patient Health Questionnaire (PHQ-9), which can be self-administered or conducted by health care providers or clinic staff.[20] The PHQ-9 is a 9-item questionnaire scored from 0 to 27 with scores ≥ 5, ≥ 10, ≥ 15, and ≥ 20 representing mild, moderate, moderately severe, and severe depression, respectively.[20] However, the most effective method of administering this screening tool to individuals with SCD is unknown, and different methods of administration might result in more false-negative depression symptoms screens. Thus, this study aimed to identify rates of depression in an adult SCD cohort receiving routine outpatient PHQ-9 screening before a visit with a primary care provider and test the hypothesis that self-administered PHQ-9 screening would yield more positive screenings for depression than verbal PHQ-9 administration by clinic nurses.

This study was part of a more extensive, single-site, prospective study to evaluate the impact of a patient-centered medical home with an integrated primary care provider for adults with SCD. This study was conducted at the Ohio State University Wexner Medical Center Comprehensive Sickle Cell Clinic and was approved by the Institutional Review Board. The study was conducted in accordance with the Declaration of Helsinki. Adults aged ≥ 18 years with any type of SCD were recruited between 1 January 2021 and 31 March 2023. Participants were given computer tablets to self-administer the demographic surveys and the PHQ-9 and were also verbally asked the PHQ-9 by the clinic nursing staff. McNemar tests were computed for differences among the proportion who screened positive for depression between the 2 strategies, and exact binomial tests were used for discordant individual item scores on the self-administered vs interviewer-administered questionnaires. A paired t test was calculated to determine the differences in PHQ-9 scores by the mode of administration. Analyses were performed using R (version 4.3.0).

Table 1. Distribution of scores and severities between the self-administered PHQ-9 and the interviewer-administered PHQ-9 among the 38 participants

| PHQ-9 question	Self-administered (n = 38) Mean score (SD)	Interviewer-administered (n = 38) Mean score (SD)
Over the last 2 weeks, how often have you been bothered by any of the following problems?		
1: Little interest or pleasure in doing things	0.76 (± 1.02)	0.42 (± 0.83)
2: Feeling down, depressed, or hopeless	0.71 (± 1.01)	0.34 (± 0.74)
3: Trouble falling or staying asleep, or sleeping too much	0.97 (± 1.01)	0.55 (± 0.89)
4: Feeling tired or having little energy	1.21 (± 1.23)	0.81 (± 1.01)
5: Poor appetite or overeating	0.60 (± 0.85)	0.29 (± 0.77)
6: Feeling bad about yourself or that you are a failure or have let yourself or your family down	0.50 (± 0.95)	0.29 (± 0.77)
7: Trouble concentrating on things, such as reading the newspaper or watching television	0.71 (± 1.01)	0.58 (± 0.98)
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	0.13 (± 0.34)	0.05 (± 0.23)
9: Thoughts that you would be better off dead, or of hurting yourself	0.10 (± 0.51)	0.13 (± 0.41)
Total	5.71 (± 6.09)	3.47 (± 4.91)
PHQ-9 score: depression severity, n (%)		
0-4: none-minimal	20 (53%)	30 (79%)
5-9: mild	10 (26%)	4 (10%)
10-14: moderate	3 (8%)	2 (5%)
15-19: moderately severe	3 (8%)	1 (3%)
20-24: severe	2 (5%)	1 (3%)

Although 52 adults completed both the self-administered PHQ-9 and interviewer-administered PHQ-9, a total of 14 were excluded because they did not complete both modes of assessment on the same day. Of the 38 included participants, 36 (95%) received the interviewer-administered PHQ-9 first. Mean participant age was 30.66 years (standard deviation [SD], 10.06 years); 58% were females; 95% were Black (95%); 53% had hemoglobin (Hb) SS or HbSβ[0]thalassemia, and 47% had HbSC or HbSβ[+]thalassemia. Of these 38 participants, 18 (47%) scored ≥5 (a positive screen for depression) on the self-administered PHQ-9, whereas 8 (21%) scored ≥5 on the interviewer-administered PHQ-9 (P < .01). Everyone (n = 8) who scored ≥5 on the interviewer-administered PHQ-9, also scored ≥5 on the self-administered PHQ-9.

Self-administered questionnaires indicated higher rates of positive depression screening and more severe depression (Table 1). Mean PHQ-9 scores were higher with the self-administered PHQ-9 (mean, 5.71; SD, 6.09) than with interviewer-administered (mean, 3.47; SD, 4.91) (difference, 2.24; 95% confidence interval, 1.13-3.35; P < .001). On the first 2 questions of the PHQ-9, which are necessary for the diagnosis of major depression, more participants reported higher frequency of having little interest or pleasure in doing things on the self-administered than on the interviewer-administered questionnaire (n = 11 [29%] vs 2 [5%]; P = .02), and more reported higher frequency of feeling down, depressed, or hopeless (n = 12 [32%] vs 2 [5%], P = .01) The last PHQ-9

question, which asks about suicidal thoughts, had similar scores between the 2 routes (P = 1.0) (Figure 1). The minimal difference in the suicide item is likely due to the rarity of suicide in SCD, which was also evident from the very low scores among our participants (mean score, 0.10). Results were consistent in the corresponding analyses for the 14 excluded participants; there was a similar proportion of discordant answers between administration modes, and the direction trend of discordance was unchanged.

Although PHQ-9 screening in a primary care setting for the general population suggests that self-administered and interviewer-administered depression screening provide equivalent results,[21] our results suggest that verbal administration of depression screening among adults with SCD may identify fewer adults with depression symptoms and less severe symptoms than via self-administration. Potential reasons for why this might have occurred is that self-administration might promote a deeper self-awareness of symptoms and less concern about the stigma, especially because stigma for mental health is more common among African Americans.[22] Our study suggests that identifying an optimal strategy to screen for depression, potentially by self-administration only or by a combination of self-administration with follow-up, is crucial in this population with a high burden of depression, because depression can ultimately affect the quality of life, SCD outcomes, and mortality. Optimal screening is critical because medical professionals can offer further support, including

Figure 1. Distributions of score difference (self-administered minus interview-administered) by PHQ-9 item.
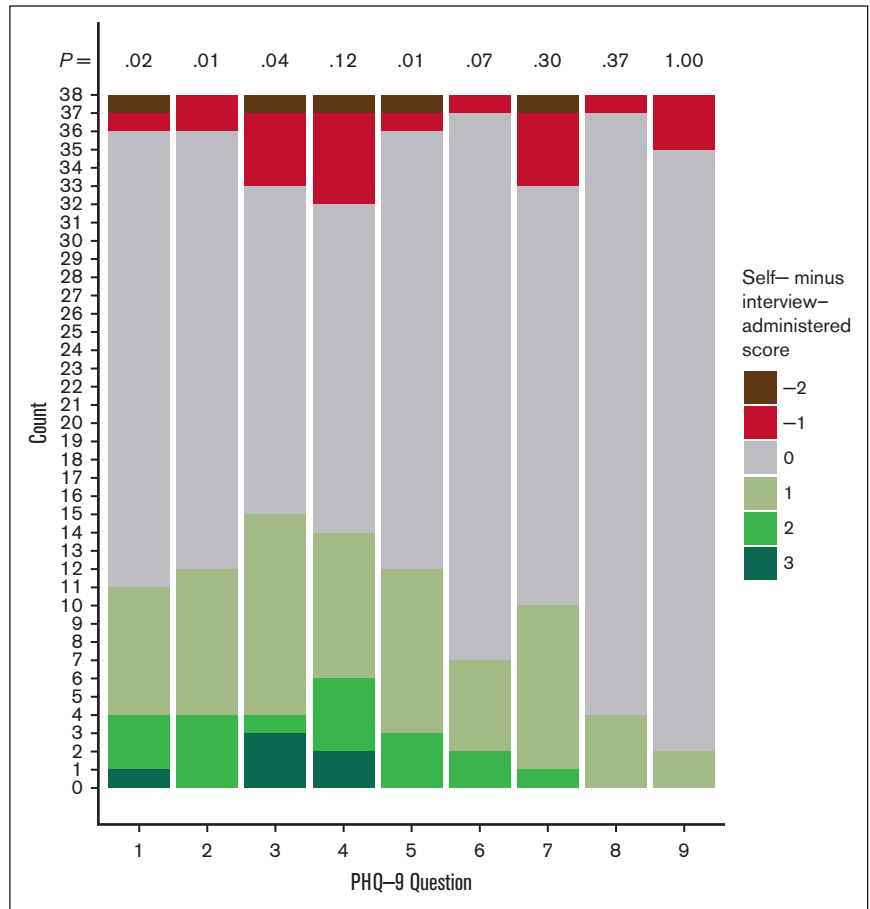
referrals to behavioral health and more effective treatment for those with depressive symptoms, and potentially improve their outcomes.

This study was limited as it was a single-center study, and only those who presented in the SCD clinic were included, which could limit generalizability. Another limitation is that the ordering of interviewer-administered vs self-administered was not randomized and based on clinic flow. Because the majority received the self-administered PHQ-9 after the interviewer-administered PHQ-9, the additional time, readministration, and reflection of their symptoms may have contributed to score differences. However, multiple studies on the validation of the PHQ-9 demonstrated that the test-retest reliability of the PHQ-9 is excellent[20,23,24], meaning that asking the questionnaires at different times within 2 weeks resulted in similar scores on the PHQ-9. Therefore, asking these questions at other time points is unlikely to make a difference, and the results we found were unlikely related to the order in which they were administered but by the administration method. Finally, although some individuals may have screened positive for depression, it is essential to note that the PHQ-9 test is a screening test, and not all individuals may be ultimately diagnosed with depression. The diagnosis should be confirmed using the Diagnostic and Statistical Manual of Mental Disorders, fifth edition, criteria if the screening is positive. However, a lack of a positive screening may miss this crucial diagnosis. Future multicenter studies for optimal strategies to screen, diagnose, and manage depression among adults with SCD are needed.

In summary, this study is 1 of the first to demonstrate that the method of depression screening administration is important to consider when screening for depression symptoms in adults with SCD so that all of those with symptoms can be identified and receive appropriate mental health services.

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