Annals of Hematology & Oncology

Open Access

Austin Publishing Group

Rapid Communication

Screening for Depression in Adolescents with Sickle Cell Disease

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Received: October 01, 2020; **Accepted:** October 21, 2020; **Published:** October 28, 2020

Abstract

Background: Sickle Cell Disease (SCD) is a chronic hematologic disease. Adults with SCD are known to suffer higher rates of depression. Little is known about rates in adolescents with SCD. Our study examined prevalence of depression in adolescent SCD patients at a sickle cell clinic following integration of a depression screening protocol.

Methods: A protocol was developed to identify, screen, and refer patients. Patients ages 12 years and older were eligible for screening using the 9-question Patient Health Questionnaire (PHQ-9). Data collected included depression screen scores, age, sex, hemoglobin, hydroxyurea use, history of stroke, and previous mental health diagnosis. The study spanned May 2018 to May 2019.

Results: 52 patients were screened. Less than 10% had a prior diagnosis of depression and had an average score of 7 (+/- 3.54), compared to 4.21 (+/- 4.16; p=0.128) for those without. <10% had a diagnosis of chronic pain. 40% screened positive for depression: 65% mild, 29% moderate, and 6% severe. 1 patient expressed active suicidality. More females screened positive for depression (54% *vs*. 23%; p=0.023) and had higher PHQ-9 scores (5.96 *vs*. 3; p=0.009). There was no significant difference in PHQ-9 scores based on sickle cell genotype, hemoglobin, hydroxyurea use, or history of stroke or chronic pain.

Conclusions: Adolescent patients with SCD may be underdiagnosed for depression. Screening in hematology clinics can be valuable in identifying and referring patients. Studies involving larger cohorts are needed to determine higher risk subgroups of patients.

Keywords: Depression; Child & adolescent psychiatry; Chronic illness; Chronic pain; Pediatrics; Mental health; Sickle cell disease

Abbreviations

SCD: Sickle Cell Disease; PHQ-9: 9 Question Patient Health Questionnaire; LCSW: Licensed Clinical Social Worker; APP: Advanced Practice Provider; ADHD: Attention Deficit/Hyperactivity Disorder; ODD: Oppositional Defiant Disorder

Introduction

The impact of depression on adolescents and young adults is significant, with known increased risk for school failure, substance abuse, and suicide [1]. Data from the National Institute of Mental Health (NIMH) shows approximately 13% of adolescents in the United States were diagnosed with depression in 2017, a nearly 50% increase from 8.7% in 2005 [2]. That same year, 17.2% of high school students reported they had seriously considered attempting suicide [3]. These rates are known to be higher in chronic disease populations such as Sickle Cell Disease (SCD), in whom depressive symptoms have been linked to higher rates of hospitalization and healthcare costs [4].

SCD is the most common inherited hematologic disease, affecting approximately 90,000 individuals in the United States, the majority of whom are African-American [5]. Patients with SCD suffer from a myriad of complications that characterize this chronic disease, including severe pain and stroke. As with other chronic diseases, the prevalence of mental health diagnoses is high, with studies demonstrating rates as high as 40% in adults with SCD. However, little is known about rates of depression in adolescents with SCD; the few studies done over the last 10 years show a wide range, reporting anywhere from 4 to 46% of children and adolescents with SCD having a depressive disorder, raising concern that patients with SCD and depression may be going unrecognized or untreated [6-8]. However, it is not clear who is responsible for identifying and treating mental health concerns in this population, contributing to the growing public health crisis of mental health disorders in adolescents [9,10].

The objective of this study was to determine the prevalence of depression in adolescent and young adult SCD patients at a comprehensive pediatric sickle cell clinic following the integration of a depression screening algorithm created by a multidisciplinary team of hematologists, psychiatrists, social workers, and nurse coordinators.

Methods

Sample population and Setting

This cross-sectional study was approved by the Indiana University Institutional Review Board with exempt status. All patients of the Comprehensive Pediatric Sickle Cell Program at Riley Hospital for

Citation: Mayer J, Radwan J, Parker G, Giust J and Jacob SA. Screening for Depression in Adolescents with Sickle Cell Disease. Ann Hematol Oncol. 2020; 7(8): 1316.

Children between 12 and 21 years old who were screened between May 2018 and May 2019, the first year of the depression protocol being implemented, were included. This age group was selected as they are part of the SCD transition population who regularly interacts with the team Licensed Clinical Social Worker (LCSW), who is integral to the depression screening protocol.

Screening

The 9-question Patient Health Questionnaire (PHQ-9) is a validated screening tool in both pediatric and adult populations with good sensitivity and specificity [1,11]. A screening protocol was created by a multidisciplinary team to identify, screen, and refer SCD patients as needed (Figure 1). Eligible patients were identified prior to the clinic day. When the patient checked in to the sickle cell clinic, the PHQ-9 screen was introduced to the patient and caregiver by the Medical Assistant (MA). The patient would complete the questionnaire while waiting for the physician or Advanced Practice Provider (APP). The questionnaire would then be scored by the LCSW, physician, or APP. The results would then be reviewed with the patient.

Scores of 4 or less were equivalent to minimal to no depression. Scores of 5-14 were mild to moderate depression. Scores 15 or higher were severe depression. Any patient who scored >0 on question 9 (thoughts of death) was screened for suicidal ideation with the Columbia Suicide Severity Rating Scale. Based on the results, either no intervention, supportive counselling, a referral for therapy, or a referral to child psychiatry would be facilitated by the LCSW. An immediate Child Psychiatry consult was performed for anyone with active suicidal ideation.

Data collection and analyses

In addition to PHQ-9 score and follow-up intervention, demographic data including age and sex, as well as disease characteristics such as SCD genotype, hemoglobin at the time of the visit, hydroxyurea use and adherence, history of stroke, diagnosis of chronic pain, and previous mental health diagnosis were collected from the electronic medical record (EMR). Adherence was defined by patient reported use of >70% of doses in the last one month, which is part of usual documentation in the EMR at each clinic visit.

Univariate analyses using t-tests for continuous variables and chi-square or Fisher's exact tests for categorical variables were done to compare demographic data and disease characteristics between patients with a positive PHQ-9 screen (score of 5 or higher) and those with a negative PHQ-9 screen. Regression analyses were used to evaluate the association of PHQ-9 scores with remaining demographic and disease characteristics. Sex and age were the only variables significantly associated, and therefore, used in a regression analysis as independent variables.

Results

Fifty-two patients were eligible for screening during this 12-month period, all of whom participated. They ranged in age from 12 to 19 years old and half were female (Table 1). 44% of participants had been prescribed hydroxyurea, though only 43% of these patients were considered adherent with their regimen. Only 6 (11%) patients had a history of stroke. 5 patients (<10%) had a previous diagnosis of depression, 4 of whom were taking antidepressants at the time of this study. Less than 10% had a diagnosis of chronic pain.

The overall average PHQ-9 score was 4.48 (+/- 4.16). Those with a prior diagnosis of depression had an average score of 7 (+/- 3.54), while those without had an average score of 4.21 (+/- 4.16; p=0.16). The average PHQ-9 score for those with any mental health diagnosis (anxiety, depression, ADHD, ODD) was 6.2 (+/-0.66, p=0.128).

40% of patients screened had scores positive for depression (score 5 or greater), 65% of whom had mild (scores 5-9), 29% moderate (scores 10-14), and 6% severe (15 and up) with 1 expressing active suicidal ideation. 75% of those who screened positive had no prior mental health diagnosis. More females screened positive for depression than males (54% *vs.* 23%; p=0.023). Females were also noted to have statistically significant higher PHQ-9 scores than males (5.96 *vs.* 3; p=0.009), even when controlling for age. However, there were no statistically significant differences in PHQ-9 scores based on age, even when controlling for sex. Additionally, there was no statistically significant difference in PHQ-9 scores based on sickle cell disease genotype, hemoglobin at time of screen, hydroxyurea use or adherence, history of stroke, or history of chronic pain.

18 of the 20 patients who scored positive for depression were referred for mental health services. The other 2 patients were already established with mental health resources. However, of the 18 patients who were provided mental health referrals, two patients and one guardian(s) refused mental health resources due to feeling it was unnecessary.

Discussion

More than one-third of adolescents in the United States live with a chronic medical disease [12], which can impose significant stressors on daily life, leading to higher rates of depression than the general population [6,13]. The bidirectional relationship between chronic illness and psychiatric disorders can make diagnosis and treatment of both more difficult [14]. Whereas depression can arise from the difficulties of living with a chronic illness, so too can mental illness worsen the somatic complications of patients. Our study showed a significantly high rate of positive depression screens in adolescents with SCD, the majority of whom had no prior history of depression. Additionally, females were more likely to screen positive for depression than males, with statistically higher scores than their male peers, indicating a possibility of more severe depression in females.

Further confounding the picture of chronic disease and mental health in SCD, is the coexistence of chronic pain in SCD. Studies estimate 20-30% of adult SCD patients with comorbid depression suffer from chronic pain, which negatively impacts quality of life and increases healthcare utilization, though there is limited research regarding this in pediatric SCD [7,14-20]. Additionally, mental health concerns such as depression and anxiety are also known to be increased post-stroke, a common complication in SCD patients [21,22]. Interestingly, in our study, there was no statistically significant overlap between positive screens or higher PHQ-9 scores with history of chronic pain or stroke. However, the number of patients with chronic pain and/or stroke in our sample was small compared to national estimates, and therefore, may not be adequately assessing for a true statistical relationship.

With such a high incidence of depression in adolescents with SCD, the question remains who should be responsible for depression screening for this population. In 2009 and again in 2016, the US Preventive Services Task Force recommended that all adolescents 12–18 years be screened for depression with adequate supports in place to diagnose and treat patients [23]. In the 2004 American Academy of Pediatrics (AAP) Periodic Survey, 80% of pediatricians believed they were responsible for screening for mental health disorders, including depression. However, in the 2013 Periodic Survey, only 67% of pediatricians surveyed inquire about or screen for depression [24]. In our study, 40% of patients who were screened had scores positive for depression, and yet nearly 75% of these patients had no prior diagnosis of mental health concerns. This suggests that adolescents with SCD are not adequately having their depressive symptoms identified by primary care providers, with whom much of the responsibility for depression screening has been placed. The importance of depression screening in the subspecialty clinic in addition to primary care is further underscored when placed in the context of adolescents with SCD most commonly reporting a specialist as their primary physician [25].

Using a multidisciplinary team, we were able to develop a screening protocol that allowed for timely and consistent scoring and referrals, and permitted implementation of depression screening into a subspecialty clinic. Critical to its success, the algorithm utilized resources and personnel already available, as a typical appointment in the comprehensive SCD clinic for the transition population includes time with the provider (physician or APP), transition nurse coordinator, and LCSW. Additionally, selection of a depression screen with high sensitivity and specificity for a depressive disorder allowed for quick identification of patients [11]. By creating a role-defined, integrated way of screening patients for depression, the clinic was able to readily identify at-risk patients with minimal change to the usual workflow in the clinic.

We recognize that while screening for depression in this high-risk population is necessary, and our study demonstrates a way in which this can successfully be done in a subspecialty clinic, identification of a mental health problem does not necessarily assure follow-up assessment or treatment. Although this study referred patients with positive PHQ-9 screens for formal psychological or psychiatric evaluations, accessing behavioral health care after referral is often low. Even patients with a prior diagnosis of depression in our study were not necessarily established with a mental health provider (3 of 5 patients). One study in pediatric primary care reported the follow-up rate with a mental health referral appointment was 61% and even lower, at 45%, for a first time identified mental health problem. In addition, care at 6 months was limited to only one mental health visit for the majority of the patients [26]. Insurance, transportation, time away from work, limited services, trust in other healthcare systems, and stigma are cited barriers to accessing behavioral health care [27-29]. Further, in rural neighbourhoods or neighbourhoods with a higher percentage of African Americans, primary care providers were less likely to have geographically proximate behavioral health services [30]. The use of in-school counseling can lessen this burden; however, this still requires an off-site initial intake visit, and is not a universally available resource.

Further complicating this issue is communication between providers. Bourguet et al, discusses how referring primary care physicians only receive feedback on half of their referrals to specialists and receipt of feedback most often happened when the referral physician communicated to the specialist at the time of consult [31]. The communication during referral to behavioral health may be hindered, especially in community mental health centers, when patients are not often assigned to a therapist and/or prescriber until an initial assessment evaluation has been completed. Given the strong evidence demonstrating increased mental health concerns in SCD and the association of mental health concerns and outcomes in SCD, the barriers to referral and communication between the hematologist and mental health provider are important to address. Unfortunately, these are not unique or novel challenges to this particular geographical population and argues for consideration of collaborative mental health services within the specialty clinic.

Conclusion

Our study demonstrated a higher prevalence of depression in adolescents with SCD than the general population, with rates similar to those reported for adult SCD patients. We also demonstrate the ability to perform regular depression screening in a comprehensive SCD clinic and believe it should be an essential component of comprehensive SCD care. Future studies involving larger cohorts should evaluate follow-through of mental health referrals, as well as analyze subgroups of patients with SCD, such as those with chronic pain or a history of stroke, who may be at higher risk for depression and necessitate earlier or more frequent screening.

Acknowledgement

We would like to thank the patients in the Riley Hospital for Children Comprehensive Pediatric Sickle Cell Program for their willingness to be active participants in their care.

Funding

This work was supported by the Agency of Healthcare Quality (AHRQ) Learning Health System (LHS) (1K12HS026390-01).

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