Identifying Social-Behavioral Health Needs of Adults with Sickle Cell Disease in the Emergency Department

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Contribution to Emergency Nursing Practice

- This study is the first to identify social behavioral risk factors for persons with sickle cell disease (SCD) during an ED visit. The identification of these risk factors increases our understanding of the complex needs of persons with SCD who seek care in the emergency department.
- Emergency departments can identify internal and external resources to implement a standard screening and referral process that would identify patients with SCD who have social-behavioral health risk factors.
- Screening tools should include the following elements: depression, anxiety, and barriers to insurance, filling prescriptions, and accessing transportation to routine clinic appointments.
- Emergency nurses, social workers, care managers, and physicians can easily complete the short screening tool.

Abstract

Introduction: Sickle cell disease (SCD) is a complex illness with many social-behavioral co-morbidities. The aim of this project was to describe unmet social-behavioral health needs for adults with SCD who presented to the emergency department for treatment of vaso-occlusive episodes (VOEs).

Methods: A descriptive study using 1:1 interviews during an ED visit for a VOE was conducted; a brief social behavioral health screening interview guide was used. A convenience sample of adults with SCD treated in the emergency department for a VOE were eligible for inclusion.

Results: We conducted 147 interviews over 14 months. Patients reported transportation and/or scheduling difficulties with clinic appointments in one third of the interviews. Four major themes emerged: clinic appointment barriers, medication barriers, other care barriers, and social-behavioral issues. A majority of patients (53%) reported being brought to the emergency department by a family member at their current visit. Patients cited having insurance coverage issues in more than one quarter (27%) of the interviews. Difficulties in obtaining prescriptions were cited as a result of a financial copay (17%), transportation (11%), and pharmacy (9%) issues. Almost one third of patients (29%) reported feeling depressed, and 20% reported feeling anxious.

Discussion: Many patients with SCD who are treated in the emergency department have social or behavioral health risk factors. Emergency departments have an opportunity to screen and refer patients for follow-up. Future research should investigate referral outcomes and their effect on ED and hospital use.

Key words: Sickle cell disease; Social behavioral health; Emergency department

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Sickle cell disease (SCD) is the most common genetic blood disorder in the United States, affecting approximately 100,000 persons, primarily African Americans.[1] The complex pathophysiology results in a wide range of medical complications, including vaso-occlusive episodes (VOEs; previously referred to as vaso-occlusive crises), stroke, pulmonary embolism, loss of vision, and acute chest syndrome. For these reasons, many patients with SCD require treatment in an emergency department.[2] Because of the significant disease burden, persons with SCD have a much shorter life expectancy when compared with the general US population. The median age of death, in 2005, for men and women with SCD was 38 and 42 years, respectively,[3] whereas it is 72 and 78 years, respectively, for African American men and women in the general population.[4] Severe painful episodes (VOEs) and medical complications are the most common reasons for ED visits (Table 1).

TABLE 1
Psychosocial assessment tool results (n = 147 ED visits)

	No. or mean	%
Primary source of outpatient SCD care		
SCD clinic	115	78
Primary care	8	6
SCD and primary care	12	8
Other	10	8
Time since last clinic appointment		
<1 mo	77	52
1-3 mo	42	29
>3 mo	12	8
Missing	16	11
Barriers to clinic appointments		
Transportation	50	34
Scheduling difficulty	20	14
Source of transportation to ED visit		
Family member	78	53
Friend	14	9
Self	11	8
Public transportation	13	9
Other	9	6
Missing	22	15
Missed work due to pain (employed n = 47)	23*	16
Had issues with obtaining prescriptions		
Financial copay	25	17
Transportation	16	11
Pharmacy	13	9
Insurance coverage issues	39	27
Feeling depressed	43	29
Feeling anxious	30	20

ED, Emergency department; *SCD*, sickle cell disease.
103 of 147 (64%) of participants had difficulty of some sort with prescriptions.
* 49% missed work because of SCD.

In addition to the physical toll the disease exacts, SCD is often associated with a complex social-behavioral health burden, such as lower quality of life, a decline in peer and family relationships, decreased academic performance, and increased incidence of behavioral health co-morbidities.[5] The prevalence of depression and anxiety has been reported as 27% and 6%, respectively.[6] Patients with SCD often report feelings of isolation as a result of the disabling nature of the disease, which contributes to feelings of uselessness and helplessness.[7] These psychological changes are documented early in the development of the disease in the pediatric population, with findings that youth with SCD have a greater risk for anxiety, depression, aggression, and delinquency.[8] Persons reporting depression and anxiety also reported more daily pain, as well as poorer physical and mental well-being.[9] In short, the burdens of SCD can affect physiological, psychological, and social well-being.[10] It is likely that these factors may affect health care utilization.

Because of the frequent medical and social behavioral health co-morbidities, it is not surprising that persons with SCD may experience high health care use; the most common reasons for ED visits is the treatment of debilitating pain caused by a VOE.[11] In 2006, persons with SCD in the US had an estimated 232,382 ED visits, resulting in 68,410 hospitalizations and an estimated cost of $2.4 billion.[12] By way of comparison, that same year, the number of hospital admissions per 100 persons with congestive heart failure was