

Policy

Continuity of Care and Policy in Transitioning for Patients with Sickle Cell Disease

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Abstract: Policywise, comprehensive protocols and procedures must be established to help patients with sickle cell disease (SCD) transition from childhood to adulthood successfully. As such, a time-limited and specific “transitional care period” (detailing this evolution) should be created. While there is an existing policy in place in the Americans with Disabilities Act-Section 504 regarding Other Health Impairments - there is no specific procedure for patients living with sickle cell disease. Additional interventions may include community support and efforts to work with college and university health offices to better understand and interact with enrollees who live with SCD. This proposed policy includes adolescents with SCD, transitional aged patients, and college students. In addition to improving their ability to navigate in healthcare economies, this policy aims to enhance health equity. Thus, all social determinants of health should be considered.

Problem Statement: As sickle cell disease is a multilayered genetic disorder, patients living with SCD often face a myriad of challenges inside and outside of the healthcare system. Due to economic constraints, racial barriers and a segmented healthcare system, patients with SCD often lack essential resources and complete access to social determinants of health. Additional support services centering around transportation and Medicaid accessibility further complicate the availability of care. Consequently, a comprehensive approach to medical and healthcare is needed to ensure that patients receive a smooth transition from pediatric to adult care, which will aid in better health outcomes and the pursuit of health equity.

Evidence-Based Strategies to Address the Problem

Transitional Care Plan: Though biological factors account for a considerable amount of variance within the sickle cell population, many factors impact patients' disease outcomes (i.e., socio-environmental factors, including parental education and income) (Yarobi et al., 2017). Young adults who live with sickle cell may be particularly vulnerable to the effects of stress as they seek independence and pursue life goals such as higher education, a career, and beginning a family (Ameringer, Elswick, & Smith, 2014). Reports indicate that the transition from pediatrics to adult care is a high-risk period for youth with sickle cell disease (SCD). Thus, if agreed upon

by the participant, young adult patients may choose to involve their families in health care decisions. If the young adult patient has a condition that limits them from making these decisions on their own, a designated party will provide support in the decision-making process.

It is recommended that a transitional care plan occurs six months before the patient's 16th birthday. Therefore, the Continuity of Care Transition policy would ensure that patients are well prepared by 21 years of age. The following must occur to ensure the success of the program: (a) develop a transition plan, (b) a conference with the patient, parent/guardian, school representative, and medical team (c) meet with an insurance representative and others who are needed to transition the patient to adult care successfully. Also, community-based organizations are essential in partnering to provide resources to patients regarding transportation provisions that may accommodate their emergencies and medical appointments.

Financing (Medicaid and Insurance): Nevertheless, unless the client matriculates to post-secondary education or if guardianship has been placed under the state's care (i.e., foster care or adoption), Medicaid services end at 18 years of age. Hence, if the client is still in school, there should be provisions to receive Medicaid benefits. However, a change of address is required when moving out of state to attend a university. To secure financial needs, a meeting with an insurance representative is necessary. The following questions should be considered during this meeting: (a) Who should the patient call when reaching 18 years of age? (b) Whom should the patient speak with as far as available resources? (c) If the current plan ends at age 18, will the same plan be available? (d) Is it necessary to reapply once a year for a new plan (if so, how and what actions should be taken)? (e) How often should the patient speak with a Medicaid or insurance representative? (f) Whom should the patient call if personal demographic information changes to ensure continuity of services?

Transportation: Patients who find it difficult to access transportation may experience a prolonged crisis. As transportation is not always readily available, CBO (community-based organizations) may provide additional resources to expand patients' access to care.

Although "Title XIX of the Social Security Act does not specifically mandate provision of transportation as a Medicaid service, the federal regulations and interpretations of the Act may authorize states to cover transportation as either an optional service and/or as an administrative service," (North Carolina Department of Health and Human Services, 2020). Some states have "federal approval to claim transportation as an administrative service reimbursement for transportation arranged and paid [for] by the county Department of Social Services (DSS) as an agent for the state," (North Carolina Department of Health and Human Services, 2020). Regarding medical appointments, reports indicate that transitional aged SCD patients have a lower attendance rate when compared to patients living with other chronic diseases. Young adolescents with SCD may benefit from additional resources such as transportation to meet their health care needs. "Transportation will be available if the recipient receives a Medicaid covered service provided by a qualified Medicaid provider..." (North Carolina Department of Health and Human Services, 2020). "Medicaid only pays for the least expensive means suitable to the recipient's needs," (North Carolina Department of Health and Human Services, 2020). Reports show that non-medical transportation is an option for some patients. However, active Medicaid continues to play a factor for those who do not qualify for this program. Thus, the

aforementioned services may not cover patients outside the coverage area that may benefit from medical related transportation. This presents the need to establish protocols and/or procedures with Medicaid providers or other affordable options for SCD patients.

At least two main factors should be considered in regard to transportation for continuity of care:

- (a) if the individual is seeking full-time employment in the provider's coverage area
- (b) if the individual is enrolled in a college/university.

A) For those who are seeking full-time employment and will not be attending a college/university nor leaving the adult provider's coverage area, resources should be given to the patient and the new doctor.

B) For those who are enrolled in a college/university resources regarding transportation, special permits, and emergency services should be provided from their institution. Several colleges/universities have restrictions regarding freshmen students and on-campus vehicles. At some colleges/universities, underclassmen may not be allowed to have their car(s) on campus. Hence young adults who suffer from a chronic illness and live on campus may benefit from provided transportation for medical care and non-medical related services.

The following options may be available to assist in attending appointments:

1. Paratransit in the community (which goes door-to-door and is an income-based/low-cost option) taking students back and forth to campus.
2. Uber health where patients may call and request transportation for health visits. (Physicians and/or patients may coordinate transportation and bill the health organization for transportation services).
3. School infirmaries offer on-campus options for students needing medical care and/or attention. Non-medical services may also be offered (including health education).

Vocational Rehabilitation: It is recommended that all individuals connect with vocational rehabilitation by the age of 14 for qualified income-based services. If an individual is not financially eligible for services, there is a pre-employment option if they are under a 504 plan. According to the Centers for Disease Control and Prevention's *Tips for Supporting Students with Sickle Cell Disease*, supportive services are available for individuals who have disabilities (Centers for Disease Control and Prevention, 2019). As such, vocational rehabilitation may be an important consideration for continuity of care through the following avenues:

There are 2 main categories in which a patient should consider vocational rehabilitation for continuity of care.

1. If the patient has (a) disease-related complication(s)/comorbid disorder(s):

According to the Sickle Cell Disease Implementation Consortium Dashboard, some patients with SCD also suffer from comorbidities. Per the dashboard of 2,400 patients with SCD at baseline, 58.36% reported acute chest syndrome, 27.44% reported avascular necrosis, 26.97% were diagnosed with asthma and 16.84% experienced a stroke (Sickle Cell Disease Implementation Consortium, 2019). As such, vocational rehabilitation may be an important consideration for continuity of care through the following avenues:

- a. Depending on the individual's disability, patients may apply for supportive employment services and/or assistance in transitioning to a community college or university.
- b. SCD patients who live with a comorbidity may qualify for additional services such as job shadowing and/ or assistance with the interviewing process. (These individuals are often known as high functioning and can work but a university or a community college may not be the best route. However, they are still employable.)
- c. Patients may apply for independent living services. Additionally, patients who are bound to disability benefits may receive modifications to their homes, apply for a service animal, and request additional services that may enhance their health-related quality of life.

2) If the patient chooses to attend a college/university:

According to the Centers for Disease Control and Prevention's *9 Tips to Living Well with SCD in College*, exciting opportunities and challenges can be experienced in the process of leaving home and going to college. (Centers for Disease Control and Prevention, 2019) As such, vocational rehabilitation may be an important consideration for continuity of care through the following avenues:

- 1. Students may require learning equipment such as a laptop, reading material, a communication device (i.e., a dyno box or an iPad), or any other services that may help to maintain their education and manage their new role as a student.
- 2. Students may request accommodations (i.e., virtual classes over the traditional in-person lecture). This may benefit those who experience a debilitating crisis or it may be deemed necessary for high-risk patients.
- 3. Mental health services are available for students who have an underlying health condition and/or a psychological comorbid disorder (i.e., depressive symptomatology, anxiety, and/or interpersonal sensitivity).
- a. The organization may assist students who suffer from a physical impairment in obtaining individual care services (i.e., a personal care attendant).

Conclusion/Action Steps: Patients who are transitioning from pediatrics to adult care may undergo additional stressors as they seek independence and become the sole proprietor of their health care needs. Additionally, those who have a socioeconomic disadvantage may experience fewer healthcare resources, which may result in poorer health outcomes. Hence when treating patients with sickle cell disease, one must consider the psychological and social influencers that may contribute to sensitivity. These factors pose mediators to patients coping styles, capacity, social support, and serve as explanatory variables in disability associated with pain intensity, threshold, and tolerance (Edwards et al., 2001). The proposed policy aims to address health-related stressors and barriers that may restrict patients from attending medical appointments and reaching their individual goals. In addition to providing transportation for SCD patients, we propose that patients matriculate through the proposed transition program. To promote a successful transition from pediatrics to adult care, SCD education and additional healthcare contacts should be provided. It is urgent that our fellow community-based organizations continue their efforts in creating a space for SCD patients to commune and retrieve health-related resources (i.e., vocational rehabilitation and Medicaid services). However, additional funding is needed to expand the reach of the developed initiatives and ensure that these programs are sustainable.

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