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A Health Service Transition to Adult Patient Care for Sickle Cell Disease

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Abstract: This paper explores the challenges related to long-term conditions, focusing on sickle cell disease (SCD) as a case study. Long-term conditions, characterized by the need for ongoing management, present a substantial burden on healthcare systems globally. A careful transition from pediatric to adult healthcare is needed for SCD. The discussion extends to the broader health service transition to adult patient care in SCD, emphasizing the World Health Organization's definition of care transitions and the necessity for an integrated healthcare service. The emphasis is on a multidisciplinary approach to medical, mental health, and educational problems. A person-centered model of care should be used more consistently to resolve these long-term condition-related challenges. To evaluate the effectiveness of new interventions in improving the transition of care from pediatrics to adult patients with SCD, continuous quality improvement strategies should be implemented and prospectively measured in younger patients. In conclusion, this study highlights the critical importance of an effective transition from pediatric to adult healthcare. The continued research of effective transition practices is essential for the future and there is still a requirement to develop pragmatic approaches to enhance research on the transition to improve the quality of healthcare for patients with long-term conditions.

Keywords: Sickle cell disease; Care transition; Multidisciplinary team; Person-centered care

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1. Introduction

A long-term condition is defined as "a health condition that requires ongoing management over a series of years or decades" [1]. The long-term condition is a significant challenge for governments and healthcare systems throughout the world and the sustainability of health services worldwide [2]. Approximately half of the people in America and 40% of the population in the United Kingdom (UK) suffer from long-term conditions [3]. According to the Department of Health and Social Care, long-term conditions are responsible for 70% of in-patient days, 78% of general practice (GP) assessments, and approximately 70% of health and social care expenditure in the UK.

The experience of living with a long-term health condition may prove to be a struggle, requiring regular medical treatments, appointments, and lifestyle modifications to manage the condition. The prevalence of long-term conditions increases while patients' expectations increase, and communities have created a complex,

ongoing need for transitional health services [3].

Sickle cell disease (SCD) is a hereditary hematological disorder resulting from abnormal hemoglobin composition due to a point mutation in the β-globin gene [4]. SCD impacts 20–25 million people worldwide, and in Africa, 50–80% of babies born with SCD are dead before five years old [5]. The United Nations General Assembly has identified sickle cell disease as a global public health issue that reflects the high morbidity and mortality rates and its extensive economic and social impacts [6]. SCD, which used to be a prevalent and fatal disease in children, is now considered a long-term condition, with the process of moving from pediatrics to adult healthcare relevant to poor outcomes [7]. SCD is a lifelong condition that requires ongoing medical management and monitoring. The most prevalent complications are vaso-occlusive crisis, acute chest syndrome (ACS), and stroke [8].

Although bone marrow transplants and gene therapy are practical and successful for significant numbers of patients, it was proposed that care would involve a continuum of primary care that is holistic and person-centered [5]. The transition from pediatric to adult healthcare can be challenging for individuals with SCD due to the complex medical needs associated with this condition. Therefore, a health service transitioning to adult patient care for SCD must consider these patients' unique and complex needs [7]. This paper will discuss the personal journey of living with SCD and the complexities of transition to adult care, focusing on the health service transition for SCD.

2. Clinical case study

The 23-year-old woman with complex SCD attended the clinic for a follow-up after being hospitalized with a vaso-occlusive crisis (VOC) and many disease complications, including aplastic crisis and asthma [7]. By late adolescence, her frequency and severity of VOC increased, often to the extent that she needed hospitalization. The doctor referred her to another clinic for a stem cell transfusion. Even though she graduated from university and started to work, her chronic pain prevented her from continuing to work full-time. Even at the age of 23, she was highly reluctant to transition from pediatrics to hematology care [7]. She was not adequately prepared during the pediatric period and was not given any special support during the transfer and adult care integration phases, which contributed to her poor self-management.

This case study highlights the importance of discussing transition early and preparing for assessment and demonstrates the advantages of a multidisciplinary team-based approach to transition [7]. Older age at the time of transition can negatively impact the transition, and early initiation of the transition process gives patients and families sufficient time to understand the adult healthcare system, identify their needs before the transition, and develop a reasonable transition plan [7]. The coordination of care among healthcare professionals involving both specialties is crucial to ensuring a successful transition. This case study has emphasized the challenges of transitioning young people with complex sickle cell disease from pediatrics to adult care. It highlights the need for a multidisciplinary approach, patient-centered care, and effective management of medical needs during the transition. These interventions support patients in preparation for the transition and ensure a successful transition process.

3. A health service transition to adult patient care for SCD

3.1. Nursing care coordination

It is of utmost importance to have a coordinated approach toward caring for patients with SCD during their transition from pediatric to adult care. Care coordination is defined as "the process of intentionally organizing

patient care activities among ≥ 2 individuals (including patients) involved in patient care to facilitate the adequate implementation of healthcare services" [9]. While the healthcare profession has continued to evolve, the role of care in providing for the needs of patients has become more critical. A well-coordinated care plan that includes joint clinic appointments, shared medical records, and open communication between providers can ensure a seamless transition while maintaining continuity of care [10]. Collaboration between healthcare teams specializing in pediatrics and adult care is essential to ensure a smooth transition. Healthcare providers must work together to develop a comprehensive plan that considers the different medical requirements of each patient [11].

Nurses have a critical role in assessing patients' complex needs, especially those with multiple and often interrelated health problems. In acute care and outpatient environments, the nurse must be prepared to participate in care coordination and transition management with the patient and family to achieve improved patient results [10]. Providing care coordination to patients with complex needs first requires that each individual's health and social support needs be thoroughly assessed. This involves an essential health record and a comprehensive physician's assessment. It should also consider the individual's ability to function daily and relation to family and other social supports [12]. Lack of coordination of care may lead to fragmented and poorly planned care, which leads to underlying medication errors and potentially preventable hospitalizations. The lack of designated healthcare coordination may result in effective communication, sufficient information transfer, lack of patient and caregiver education, and limited or no access to needed services [10]. As complexity increases and the need for more robust primary care expands, the decentralization of health care services has led to people with complex needs assuming the primary responsibility for providing services for themselves and pathway guidance for providers. They experience the system needing to be more straightforward and more manageable. Healthcare assessment and coordination are becoming increasingly crucial for these patients [13]. The essential elements to assist with care coordination and transition administration involve evidence-based concepts that support patient self-management and reflect their views on values, preferences, and objectives. The healthcare professional is the patient's advocate and helps patients and their caregivers access preferred healthcare institutions, community nursing care, and medications [10]. Collaboration within the healthcare team is the fundamental basis for developing, distributing, and implementing personalized care plans [10].

According to the study by Rattler *et al.* [14], no more than 25% of carers said they had somebody to help them to coordinate healthcare provision, and around 20% said they needed additional help to coordinate care. The study also indicated multiple deficiencies in care coordination. For patients with SCD, coordination care for all necessary specialty transitions is just a tiny section of the patient's general medical care. It is more important to help patients and their family members organize activities for long-term conditions patients. These complex needs include a wide variety of services from pain management, blood transfusion, prevention and primary care issues, and compliance with chelation therapy to patient education and education of other healthcare professionals [15]. In summary, a well-coordinated care plan is essential for patients with sickle cell disease during their transition from pediatrics to adult care.

3.2. Health service transition

According to the World Health Organization [1], transitions of care are all aspects of a patient's travel and return to a specific physical destination or access to a healthcare provider to obtain healthcare services. It includes the clinical aspects of care transitions and other factors, such as patient opinion, experience, and complex needs. Young people with complex health needs and long-term conditions may need continuous healthcare support in adulthood [16]. The research has shown the significance of transitions from pediatric to adult primary care as essential in healthcare administration programs [17]. Despite the recognition of the significance of transition as a healthcare continuum for young people with SCD, it still needs an established and effective strategy [17].

For patients with long-term conditions, transitions in healthcare can be particularly challenging. Individuals with long-term conditions contact medical professionals and healthcare services in about a few hours yearly, and people with these conditions are expected to be responsible for managing their condition without assistance for more than 99% of their lives, including taking medication, monitoring symptoms, and making lifestyle adjustments [3]. To effectively address the complex needs of patients with SCD, it is fundamental to establish an integrated healthcare service that can manage the transition of care from pediatrics to adult patients. This care should address the personal needs of the SCD patient and include multidisciplinary medical and psychosocial support to ensure the continuity of care and successful transition to adults [18]. The development of independent medical care will allow people with SCD to receive the medical support necessary to manage their condition, improve their quality of life, and prevent complications associated with SCD. When a person with SCD is young, it is the parent or other adult caregiver's responsibility to administer the child's health and medical healthcare needs. They will schedule doctor appointments and manage treatment plans to reduce the severity and incidence of pain crises and other SCD-related health problems [19]. According to the NHS [20], In order to adequately prepare young adults and their families, it is essential to begin preparing for this transition as early as possible, usually around age 14. Moreover, the transition can be organized with other services, such as social services and education. As young people with SCD move into adulthood, the responsibility transfers from caregivers to the young people themselves. During the transition, young people with SCD also shift their healthcare providers from pediatricians to adult healthcare providers [19]. As with many other chronic childhood diseases, the transition from pediatrics to adult care can be difficult for a young person with SCD [7]. When transitioning from a pediatrics-centered model of care to an adult-centered model of care, it is essential to ensure that the highest levels of healthcare quality are not disrupted to achieve and maintain excellent health and social outcomes.

With survival rates for patients with SCD increasing, the transition from pediatrics to adult life becomes critically important and requires ongoing management to ensure a complete and seamless transition of care [21]. Preparing for transition will enable them to make a positive transition of care to an adult care provider and continue to receive sufficient, regular care to stay healthy [19]. Multidisciplinary integrated pediatrics and adult care improves clinical outcomes for patients with SCD by providing care coordination and prevention services. It is essential to prepare a young person with SCD for transition.

3.3. Multidisciplinary team

Patients suffering from SCD have complex healthcare, psychosocial, and educational needs that demand a coordinated, multidisciplinary approach to their care. The multidisciplinary team is an essential component of the transition process because it brings together a series of healthcare professionals from different disciplines to work together to meet the varied needs of patients with SCD, and they cooperate to provide holistic and coordinated care for patients with complex medical conditions within a coordinated structure [5]. The holistic needs of patients are met through multidisciplinary coordination across systems among a group of stakeholders, including pediatricians, hematologists, other clinicians, and community practitioners [5]. Some of the complex needs typically associated with SCD include pain management, infection prevention, stroke prevention, and management of organ damage. Multidisciplinary teams have the professional knowledge and skills to deal with the various needs of SCD patients. For example, the hematologist is responsible for managing the medical treatment of SCD, such as prescribing hydroxyurea and managing pain crises. Nurses educate and support patients and families, including self-management strategies and symptom monitoring. The psychologist provides counseling and support to patients and families, addressing mental health challenges [5].

In addition, people with SCD may experience social and emotional challenges, such as depression and

anxiety, which may impact their ability to effectively manage their health [18]. According to Powell *et al.* [22], the study demonstrated that after implementing a multidisciplinary care team intervention to manage uncomplicated pain episodes associated with SCD, including a personalized care plan with nursing team meetings and the establishment of a focused pain management plan, a significant reduction in emergency treatment use and acute admissions was found. The multidisciplinary team approach provides an opportunity to address the diverse needs of patients with SCD, focusing on promoting self-management and improving health outcomes. Therefore, healthcare systems must prioritize the evolution and operationalization of multidisciplinary care models to resolve the complex needs of patients with SCD during the transition to ensure continuity of care and optimal health outcomes [6].

4. Experience of living with sickle cell disease

The long-term condition affects the quality of life and does not disappear. It is a condition that has to be endured for the rest of the life or until a cure is found. It affects not only the patient, but also their family, friends, and those around them. These conditions bring physical discomfort to patients and affect their psychological state and social life [23]. On average, individuals with long-term conditions spend only a few hours per year in the company of healthcare professionals. They manage daily life alone or with relatives [14], such as dealing with complex needs, medication treatment plans, and lifestyle changes. Recent research underscores the need for a biopsychosocial perspective to care that attends to the physical manifestations and psychosocial effects of sickle cell disease [20].

Patients with SCD experience pain management. A study in the UK of adults with SCD found that the condition adversely influenced their physical condition [3]. The long-term condition has a substantial influence on the patient's health. Pain is one of the primary issues in sickle cell disease. Poor management of painful crises may lead to an increased frequency of crises, leading to chronic pain, repeated hospitalizations, and depression [24]. Pain profoundly affects a patient's quality of life, functional capacity, and health care utilization. In Mkoka and Nkingi's study [5], it was observed that some participants would feel severe pain on a daily routine, while other participants would feel intermittent pain, and the severity of the pain can range from moderate to severe. Moreover, all participants described self-medication with analgesic tablets as pain relief. Pain management for SCD is usually managed with medication (e.g. opioids, NSAIDs, and paracetamol) or relaxation therapy, hypnosis, heat, ice, or acupuncture for pain relief. If the condition is not effectively treated and managed, these physical conditions will be prolonged and may become progressively worse.

The social functioning of people with long-term illnesses may be affected by the constraints imposed by the long-term condition. In the research conducted by Thomas and Taylor [6] in the UK, 17 young people with SCD were surveyed in several focus groups. It discovered that SCD influenced their education, employment, independence, and relationships. Patients with long-term conditions may critically influence an individual's learning experience. A study in Nigeria also agreed with this viewpoint; the majority of participants identified a generally negative perception of SCD and expressed problems with education, employment, and health care [25]. Most participants reported being absent from studies and exams in school since frequent illnesses of SCD. As a result of the disease, some participants interrupted their studies completely [24]. Another study showed that 60% of patients reported frequent absences from school, and 52% believed that their disease negatively impacted their academic performance [26]. Other participants shared their worries regarding the state of the economy, with some mentioning that they had lost their jobs due to SCD conditions. People with SCD may experience fatigue due to anemia or other disease complications. This fatigue can affect an individual's ability to concentrate and complete work-related tasks. Furthermore, it stigmatizes patients in the workplace after disclosure of

their disease condition [24]. In the study by Osunkwo *et al.* [27], almost half of the participants had experienced depression. The employed patients indicated that SCD significantly influenced their performance, as 57% of patients decreased their work duration, and 47% considered leaving their job [26].

Complications related to SCD can make a significant difference in a patient's activities of daily living, ranging from affective and physiological health to relationships and work. The complex need for improved management of SCD will improve the patient's quality of life at home and school/work, may improve emotional health, and have a positive economic impact.

5. Person-centered care model in SCD

Person-centered care (PCC) is central to enhancing the lives and health of the growing population of children, adolescents, and adults suffering from long-term conditions [28]. A person-centered model of care should be used more consistently to resolve these long-term condition-related challenges. Healthcare professionals should recognize patients as experts on their conditions and listen to their complex needs [1].The PCC model requires a more specific effort to achieve the undeveloped potential of patient-directed care by increasing the availability of targeted information, education, and training, along with access to new technologies and support from peers and the community [15].The McCormack and McCance PCC theoretical framework focuses on the therapeutic relationship between healthcare professional and clients (**Figure 1**).

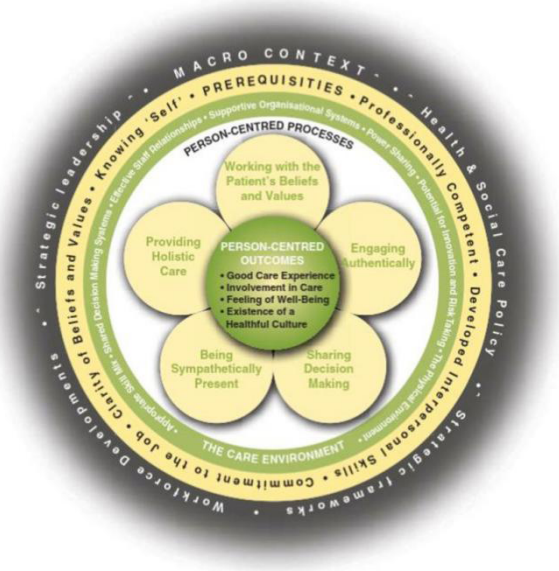

Figure 1. Person-centered practice framework

According to the PCC model, treatment and care should consider the patient's needs and preferences. Patients with sickle cell disease should have the opportunity to work with their healthcare professionals to make educated decisions regarding healthcare and treatment [9]. Person-centered care in sickle cell disease may involve developing an individualized care plan that resolves the patient's complex needs and objectives. This may include medication management, pain management, and other interventions to manage various symptoms and complications of sickle cell disease. Overall, person-centered care is essential for SCD to recognize each patient's complex needs and preferences and promote optimal health outcomes for individuals with this complex condition.

6. Conclusion

As survival rates improve, an important time in transitioning from pediatric to adult lifespan for adolescent SCD patients is when ongoing support is needed to ensure healthcare continuity [29]. The preparation for the transition should be assessed before the transition of care to ensure that each young adult is developed and ready to accept full responsibility for the care of the young adult and is adequately prepared. Monitoring the progress of young adults over several years will enhance the assessment of the success of the adolescent transition program. A multidisciplinary team approach to transitioning health services to adult patient care is essential for these patients with long-term conditions. Transition programs are complex and effective collaboration is needed to achieve maximum results, especially for people with long-term conditions [30].

The effective transition from pediatrics to adult health services for young adults with sickle cell disease is the foundation for treating and managing their complex needs and the key to improving the quality and quantity of their survival [31]. Therefore, more research and efforts need to be focused on improving healthcare transition resources and establishing personal-centered care for patients with SCD [32]. To evaluate the effectiveness of new interventions in improving the transition of care from pediatrics to adult patients with SCD, continuous quality improvement strategies should be implemented and prospectively measured in younger patients. The continued research of effective transition practices is essential for the future and there is still a requirement to develop pragmatic approaches to enhance research on the transition to improve the quality of healthcare for the patients with long-term condition.

Disclosure statement

The author declares no conflict of interest.

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