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Transforming Transition from Pediatric to Adult Care in Sickle Cell Disease: Leveraging Technology to Enhance Patient Education and Engagement

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Abstract

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By: Nneka Okeke

Sickle cell disease (SCD) has evolved from a childhood chronic illness to now a lifelong disease. As adolescents and young adults with SCD grow older, they tend to experience disease progression at a faster rate, which can lead to severe pain crises, increased risk of mortality, greater need for specialized care, and higher utilizations of healthcare services (including more frequent hospital readmissions). Given the increased disease burden as youth age, health care transition (HCT) would help ensure adolescents are well equipped to integrate into adult-based health care. The Children's Healthcare of Atlanta (CHOA), Aflac Cancer and Blood Disorders Center, is home to the largest pediatric SCD program in the United States. Within CHOA, hematologists and psychosocial providers have developed the Adolescent to Adult Sickle Cell Disease Transition Program to help with the transition from pediatric- to adult- based disease care. Due to the existing education program being in person teaching, there was a significant population that reside over two hours away from this major comprehensive center, making access to care an ongoing barrier. With social media and the use of digital technology increasing throughout the United States as well in global settings especially among young adults, creating web-based, micro learning tools to disseminate on platforms such as Tiktok and YouTube will increase engagement and disease knowledge. Given the aforementioned technological advances, the Optimizing Sickle Cell Disease Transition Engagement through: Culturally Responsive Age Appropriate and Technology Evolving Education (CREATE) study was designed to develop culturally responsive, age appropriate, and technology evolving education related to SCD and general life for emerging adults living with SCD. Within CREATE, this special study thesis aims to create one disease-based educational module to disseminate to emerging adult with sickle cell disease (EASCD). The module will be disseminated on websites and through social media platforms, accessible not only in Metro-Atlanta, but across the state of Georgia and in global countries. Technological advancement has made it possible to create web-based modules to ensures that EASCD are equipped with appropriate multi-dimensional knowledge and skills needed to engage in and navigate the adult healthcare system.

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Chapter 1. Introduction

Background

Chronic diseases are on the rise globally (Marani et al., 2020). According to the Centers for Disease Control and Prevention, 51.8% of adults who live in the United States have at least one chronic condition and 27.2% have multiple chronic conditions (Brousseau et al., 2010). Chronic conditions with onset in childhood (either congenital or acquired during pediatric age) that continue into adulthood include, but are not limited to, sickle cell disease (SCD), cerebral palsy, cystic fibrosis (CF), myelomeningocele, asthma, congenital heart disorders (CHD), and insulin dependent diabetes mellitus (IDDM). As with most chronic diseases, there are disease specific complications and/or chronic pain that either persist or progress with ageing, adding complexity and many other challenges. Complications include physical, psychological, social, and vocational challenges to surviving in adulthood (Lanzkron et al., 2018). Therefore, with increasing numbers of children with pediatric conditions surviving into adulthood, it is important for all stakeholders to ensure that adolescents and young adults who transition into adulthood and adult-based systems of care have the knowledge and skills to continue their disease management.

Sickle cell disease (SCD) is an inherited chronic blood disorder, caused by a mutated Beta (β-) globin gene that results in the distortion of red blood cells into crescent C-shape ("sickle shaped") cells under deoxygenation. (Viola et al., 2021). SCD is common among individuals in sub-Saharan Africa, Spanish-speaking populations such as Central and South America, and the Caribbean (Centers for Disease Control and Prevention 2022). In the United States, there are approximately 100,000 individuals affected with SCD; and worldwide, approximately 3 million individuals are living with the disease, with a high rate of prevalence in

sub-Saharan Africa (Viola et al., 2021). These sickle-shaped red blood cells can attach to one another and the vascular endothelium preventing blood flow through the vessels which is also known as vaso-occlusion. Vaso-occlusion can lead to severe pain (when it occurs in bone), known as pain crisis; infections; and tissue and organ damage (Matthie et al., 2016). Adolescents and young adults with SCD experience a greater rate of disease progression as they get older, resulting in severe pain crises, high risk of mortality, the need for more specialized care, and increased health care utilization (including re-hospitalization) (Sobota et al., 2011). Given the increased disease burden as youth age, there is a critical need for medical and psychosocial providers to support youth's transition from pediatric- to adult- focused health care.

Problem Statement

Health care transition (HCT) is defined as a "purposeful, planned process that supports adolescents and young adults with chronic health conditions and disabilities to move from child-centered to adult-oriented health care practices, providers, programs, and facilities" (Reiss et al., 2005). The three stages of HCT include transition preparation, transferring, and integrating to adult care (Treadwell et al., 2011). Transition is viewed as a dynamic process that has a start, middle, and end. Got Transition®, a federally funded national resource center on health care transition (HCT) posits six core elements of healthcare transition: (1) transition policy, (2) tracking and monitoring progress, (3) assessing transition readiness, (4) planning for adult care, (5) transferring to adult care, and (6) integrating into adult care (Saulsberry et al., 2019). For youth with SCD, health care transition focuses on educating adolescents about their disease (i.e., disease-based knowledge), management of their disease (i.e., disease self-management), general life (e.g., how to maintain their healthcare insurance, etc.), and health-care engagement skills and/or knowledge. In 2002, a consensus statement was approved by the American Academy of

Pediatrics on the critical steps to establish transition programming for adolescents and young adults with special health care needs (American Academy of et al., 2002). Still, over two decades later, the transition to adult-based healthcare for youth with SCD remains to be fraught with challenges and is perceived by youth and their families as disjointed (American Academy of et al., 2002). Furthermore, many pediatric SCD health care systems have seen suboptimal youth engagement in the adult-based healthcare system after they transition. Barriers to successful healthcare transition for youth with SCD include, but are not limited to, insufficient training of adult-focused healthcare providers, shortage of adult care practitioners, lack of coordination and shared systems, cost, and engagement (Lanzkron et al., 2018). The transition from pediatric to adult healthcare systems for patients aged 18-25 with SCD can be a vulnerable time, and lead to higher rates of mortality and hospital admissions. Since there is can be an increase in acute health care utilization and acute complications by emerging adults with SCD, the transfer period is a high-risk time which may partially contribute to inadequate transition readiness (Saulsberry et al., 2019). Today, over 95% of youth with SCD will survive into adulthood, but the mortality rates continue to rise during the transition period. Unfortunately, many youths with SCD are still unprepared for the transition to adult-based healthcare. Yet, incorporating technology as a modality for delivering important information that a young person with SCD should know prior to transition is one possible solution to increase engagement in the transition process. Even with local (e.g., healthcare system-based) and national initiatives, there are still gaps in enhancing transition care particularly when it comes to engaging the disengaged. Although SCD transition readiness programs, which provide practical education and vocation planning, independent living skills, disease self-management skills, and healthcare knowledge skills, exist across pediatric healthcare systems, it has been difficult to engage patients in a lasting, meaningful way. Access

to longitudinal pediatric-focused SCD care and low adherence to routine disease-related clinic visits limit the effectiveness of interventions that require the physical presence of patients in the healthcare setting (Crosby et al., 2017). With variable rates of outpatient disease-related clinic attendance and barriers to accessing disease-related care, the use of technology to provide youth with SCD with the knowledge and skills they need to transition to adult-based care will provide flexibility in utilization beyond hospital settings, such as their home, school, and waiting rooms, and direct meaningful support from family members and community based organizations (Inusa et al., 2020).

Purpose Statement

There is a need to improve the existing sickle cell disease (SCD) transition program in Metro-Atlanta, GA, (and in the state of Georgia at large) to further help engage adolescents with SCD to manage their own health as they transition to adult care. There are two designated comprehensive SCD centers in Georgia, limited to two major cities: metropolitan Atlanta and Augusta. A significant population reside over 2 hours away from these major comprehensive centers, making access to care an ongoing barrier (Treadwell et al., 2011). Creating web-based, micro learning tools for dissemination on platforms utilized by teens and young adults. Creating content for mobile applications such as Tok-tok will increase youth and their family's access to disease-related information irrespective of their location. With these goals in mind, the Optimizing Sickle Cell Disease Transition Engagement through: Culturally Responsive Age Appropriate and Technology Evolving Education (CREATE) study was designed to improve the current transition education modules utilized by a metro Atlanta children's hospital. The existing transition education modules were created to help emerging adults with sickle cell disease (EASCD) transition to adult care successfully. Unfortunately, the

existing education programs relied heavily on in person teaching and have been rendered obsolete in the past decade. Modifying educational materials and engagement strategies based on feedback from EASCD and young adults with SCD who have already transitioned to adult based SCD care and hosting this content on online/social media platforms will allow the existing transition program to 'meet emerging adults (EA) where they are.'

Specific Aims

The goal of the Optimizing Sickle Cell Disease Transition Engagement through: Culturally Responsive Age Appropriate and Technology Evolving Education (CREATE) study **is to equip emerging EASCD with the appropriate multi-dimensional knowledge and skills needed to engage in and navigate the adult healthcare system.** Within this larger study, I will be creating one disease-based educational module to disseminate to EASCD. The module will be disseminated on websites and through social media platforms, accessible not only in Metro-Atlanta, but across the state of Georgia. Furthermore, the disease-related knowledge module likely can be used in other countries with high prevalence rates of EASCD. Additionally, I will modify existing transition-related materials that are utilized within the Sickle Cell Teen Transition Clinic at Children's Healthcare of Atlanta, Aflac Cancer & Blood Disorders Center (Atlanta, GA).

Significance Statement

Advances in technology have enabled the development of web-based modules that contain sickle cell disease (SCD)-specific knowledge and transition-related skills, which can benefit in metro-Atlanta and have a worldwide impact by educating patients about their chronic health condition. Globally, more than 80% of the persons living with SCD reside in Sub-Saharan Africa, and the majority of these people live in Nigeria and Democratic Republic of the Congo

(Asnani et al., 2017). In these countries, there are no adequate pediatric- to adult- based healthcare transition programs for youth with SCD (Galadanci et al., 2014). Additionally, there are pediatric SCD clinics in lower middle-income countries (LMICs) that are independently operated with no existing connection with adult-focused care (Inusa et al., 2020). The ability to access online platforms to learn transition-related skills and obtain disease-related knowledge will help combat lack of access to SCD-specific transition programming. According to Global System for Mobile Communications Association (GSMA), there are 747 million subscriber identity module (SIM) connections in sub-Saharan Africa (Elliott, 2019). Additionally, 40% of children in Africa aged 15–24 years were estimated to be online in 2017 (Inusa et al., 2020). Given the high utilization of online services by youth within Africa, creating and freely distributing SCD-related transition information and skills via online/mobile platforms will optimize education outreach, foster self-advocacy and engagement for emerging adults during the transition from pediatric- to adult- based healthcare.

Chapter 2. Review of Literature

Overview of Sickle Cell Disease

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States (Kato et al., 2018). It is caused by a mutated Beta (β-) globin gene and primarily impacts those of African descent. This chronic disease affects 100,000 individuals in the United States. Worldwide, 300,000 babies are born with SCD every year (Kato et al., 2018). People with SCD experience a range of symptoms and complications that include tissue damage, decreased quality of life, and unpredictable episodes of acute pain (known as a pain crisis). While there has been a significant decline in the mortality rates of children with SCD over the past four decades, mortality rates among individuals with SCD over the age of 19 have increased (Hamideh &

Alvarez, 2013). Currently, the only cure for SCD is bone marrow or stem cell transplant. Gene therapy and gene editing are in clinical trial development. However, for many people, curative therapies are not an option due to the risk of severe complications (increased morbidity and mortality), the intensity of the procedure (precluding adoption in low resource countries), and a shortage of suitable donors (Ataga, 2009). Currently approved management options for sickle cell disease include both conservative measures such as drinking water, avoiding extreme weather, nutrition, and stress management, as well as disease-modifying agents like hydroxyurea, L-glutamine, Voxelotor, and Crizanlizumab.

Since the 1990s, SCD has evolved from a childhood chronic illness to now a lifelong disease that people will manage well into their 50s, 60s, and 70s (Treadwell et al., 2011). There have been several advancements in medical care such as early diagnosis of SCD through newborn screening, prophylactic penicillin, vaccinations, and disease modifying therapies like hydroxyurea (stated above). Due to these advancements, there has been a 95% increase in children with SCD surviving into adulthood by the age of 18 years (Saulsberry et al., 2019). However, the adult healthcare delivery system remains difficult for young adults with SCD to navigate, particularly after the transition period of pediatric care (Treadwell et al., 2011).

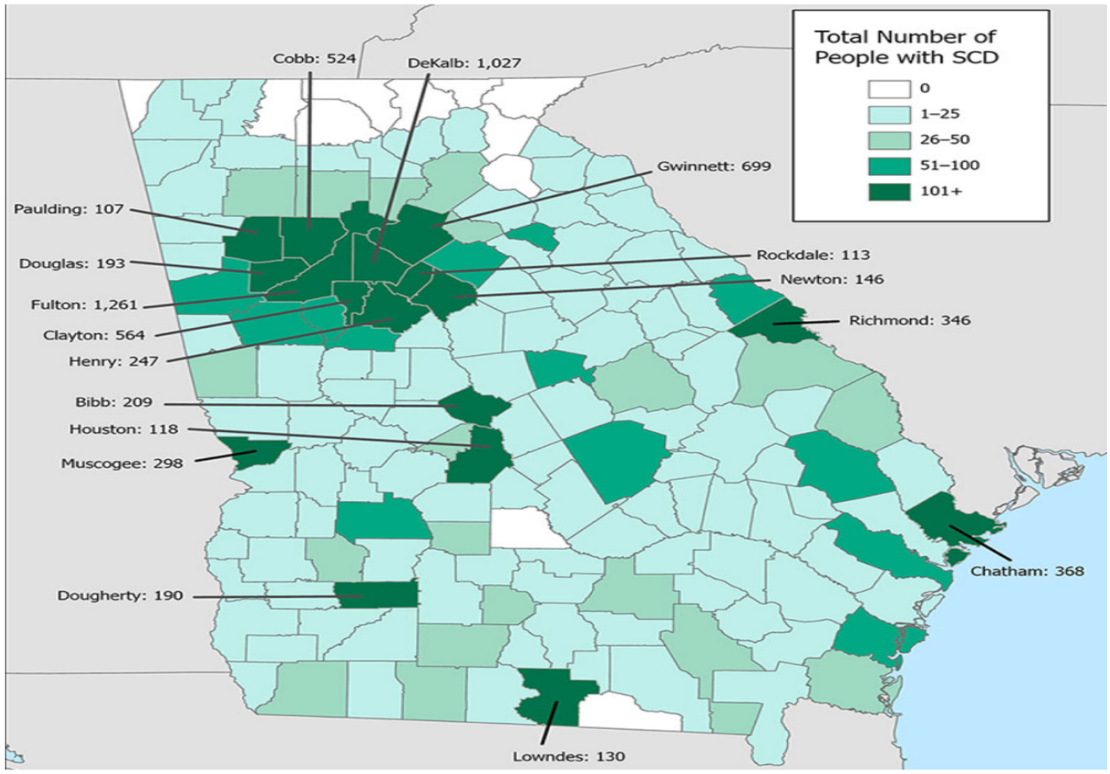
The period between adolescence and emerging adulthood is considered a particularly vulnerable time for youth with SCD. For emerging adults with SCD, learning to navigate the adult-based healthcare system and master self-management of progressive disease complications and increased pain burden are issues they face (Jenerette et al., 2014). It is important that adolescents living with SCD can manage their disease and associated symptoms to avoid progressive end organ damage, decrease morbidity, mortality and overall improve healthcare outcomes. Disease self-management can include, but is not limited to, coping mechanisms for

dealing with chronic disease, autonomy, and independence (Matthie et al., 2016). As young adults get older, challenges may arise that impact their quality of life such as managing their pain while balancing school, their chronic illness, job duties, and other important responsibilities. Across the United States, mortality rates for persons between the ages of 5 and 74 years with SCD are the highest in California and Georgia suggesting that people with SCD living in these states are in need of additional supports, SCD specialty clinics, and interventions to promote disease self-management (Paulukonis et al., 2016).

Sickle Cell Disease in Atlanta, GA

There is a high prevalence of individuals with SCD in Georgia. In 2015, the state of Georgia had one of the largest populations of individuals living with SCD (~8,017 individuals) in the United States (CDC, 2022). It is estimated that 97% of newborns with SCD are Black or African American in Georgia (Sickle cell disease in Georgia: Findings from Rush n.d.). To successfully provide patient care for individuals with SCD, there are comprehensive care centers in the state of Georgia.

Figure 1. Number of people with SCD by county of residence, Georgia 2018



The counties of Georgia have a diverse population of patients with SCD (See Figure 1). According to 2018 data from the (CDC), 45% of individuals who have SCD live in the counties of Fulton, Gwinnett, DeKalb, Clayton, and Cobb (CDC, 2022). Within the state, SCD is more prevalent in young adults aged 20-49 (46%) with the remaining 44% of individuals being 20 years old or younger and 10% being 50 years and older (CDC, n.d.). In Georgia, there are three comprehensive sickle cell centers and clinics is catered to children, adolescents, and young adults: Children's Healthcare of Atlanta, the Georgia Comprehensive Sickle Cell Center at Grady, and Public Health Outreach Sickle Cell Clinics through the Augusta University Sickle Cell Center. The Children's Healthcare of Atlanta, Aflac Cancer and Blood Disorders Center, is home to the largest pediatric SCD program in the United States. Hematologists and psychosocial providers there have developed the Adolescent to Adult Sickle Cell Disease Transition Program to help with the transition from pediatric- to adult- based disease care. This program was developed to improve specific health outcomes and teach critically important knowledge and skills to adolescents and emerging adults with SCD transitioning into the adult health system with well-structured, guided activities and modules. After pediatric patients elect to transfer their care to the Georgia Comprehensive Sickle Cell Center at Grady from CHOA, they would have access to 24-hour acute care in an outpatient setting and comprehensive primary care. The Georgia Comprehensive Sickle Cell Center partner with a community-based organization (CBO), the Sickle Cell Foundation of Georgia (SCFG). It is a non-profit organization that hosts engaging educational activities and provide services for children and adults. These support services from the clinics and community organizations help align engagement between adults with SCD, stakeholders, and local health care providers.

Approximately 2,000 pediatric patients are cared for across three pediatric hospital campuses in metro Atlanta: Children's Healthcare of Atlanta (CHOA) at Scottish Rite, Egleston, and Hughes Spalding. Studies have shown that hospital utilization rates for children aged 0-19 are approximately four hospital visits over five years. However, SCD-related hospitalizations increase in young, early, and middle adulthood (i.e., between the ages of 20 to 49), resulting in more than fifteen emergency room visits during the same time period (Sickle cell disease in Georgia: Findings from Rush, n.d.). Factors that can contribute to an increase in healthcare utilization during the transition from pediatric- to adult- based healthcare are numerous (Sickle cell disease in Georgia: Findings from Rush, n.d.). As such, developing successful transition programming can prepare adolescents and young adults to take responsibility for managing their disease after transferring to adult care.

Transition from Pediatric-to Adult-based SCD Healthcare

In recent years, it has acknowledged that the transition process from pediatric- to adult-based healthcare is a top priority for youth with special healthcare. The shift from pediatric- to adult- based health care can be a complex and traumatic experience specifically for young adults with SCD (Kinney & Ware, 1996). Health care transition (HCT) is defined as a "purposeful, planned process that supports adolescents and young adults with chronic health conditions and disabilities to move from child-centered to adult-oriented health care practices, providers, programs, and facilities" (Reiss et al. pg 112, 2005). In an ideal implementation of the process, HCT would help ensure adolescents are well equipped to integrate into adult-based health care. Transition is designed as a dynamic process of a beginning, middle, and an end. The beginning stage is preparing for the transition. The middle stage is known as transition readiness and is referred to as making important decisions and an action plan to ensure that the adolescent can

manage their own health care after the transition process has ended (Telfair et al., 1994). Since 95% of adolescents with SCD survive to adulthood, the transfer stage is significant for them as it helps to ensure they successfully transfer from pediatric to adult care for ongoing continuity of healthcare. Young adults reach the end stage of transition into adult health care when they engage in adult healthcare activities such as planning their own medical care with their provider (Treadwell et al., 2011). The standardized HCT process is based on core elements from Got Transition® www.gottransition.com, a federally funded national resource center on health care transition that recommends six core elements of healthcare transition: transition policy, transitioning youth registry, transition readiness, transition planning, transition and transfer of care, and transition completion. Transition-related tools available from Got Transition® can be customized to facilitate an effective transition process in healthcare practices and hospitals to ensure that high-quality and appropriate healthcare services are available to adolescents and young adults as they transition into adulthood (Farre & McDonagh, 2017).

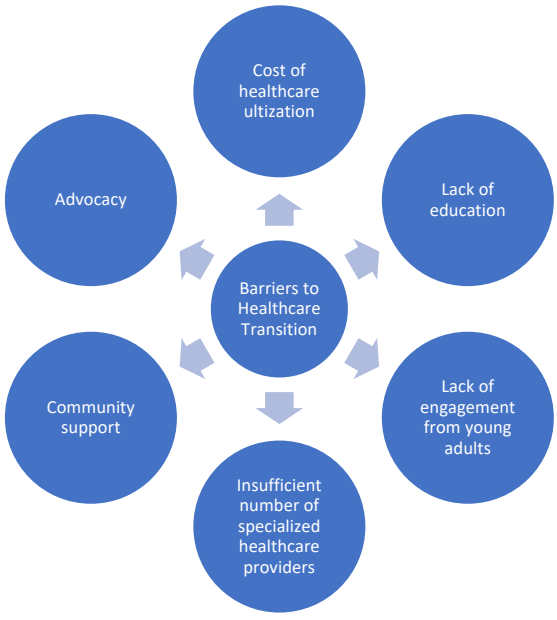
The period of emerging adulthood is a pivotal time for youth with chronic health conditions. This transition allows them to build adult relationships, maximize lifelong functioning and well-being, experience independent living, obtain skills in self-supportive medical care, and create social support. The necessity for integrated transitional procedures to support adolescents and young adults with chronic diseases as they transition from pediatric to adult health care has been acknowledged by providers in the United States and around the world (Callahan et al., 2001). The American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and the American Society of Internal Medicine approved a consensus statement in 2002 on ensuring that the medical profession is taking initiative steps to develop a family-centered, continuous, comprehensive, coordinated,

compassionate, and culturally competent health care system for young adults with special health care needs (American Academy of et al., 2002). Following the consensus statement, in 2016, the American Society of Hematology created a toolkit to standardize and modernized the transition process for patients with SCD and other hematological diseases with the goal of maximizing lifelong functioning and high-quality appropriate health care services that will serve individuals as they move from adolescence to adulthood (Inusa et al., 2020). Although there is national guidance on ways to improve the transition process, young adult patients' needs for comprehensive healthcare services during and following transition are still sub-optimal.

Barriers to Transition from Pediatric-to Adult-based Healthcare

Transition preparedness among adolescents and young adults is low due to many barriers. Figure 2 shows the barriers to successful healthcare transition outcomes including the cost of healthcare utilization, an insufficient number of specialized healthcare providers, lack of engagement from young adults, and difficulties with care arrangements between pediatric and adult health systems (Sakurai et al., 2022).

Figure 2. Barriers to Healthcare Transition



According to the 2018 National Survey of Children's Health: HCT, only 16.2% of children with childhood-onset chronic conditions acquire the knowledge and skills to transition to adult care, (Child and Adolescent Health Measurement Initiative, 2018). Overall, in the United States, 18.9% of youth with special health care needs (SHCN) obtain services such as self-managements skills, transition clinics jointly staffed by pediatric/adult physicians, and patient/family support systems and education, compared to 14.2% of youth without special SHCN (Child and Adolescent Health Measurement Initiative., 2018). This data shows there is a low percentage of youth with SHCN receiving health care services to ensure positive long health outcomes. The lack of preparedness can have an impact on patients' ability to efficiently self-manage their disease. Patients being unprepared to transition into adult care may be due, in part, to not being engaged during the transition process. Because of unfortunate encounters in the emergency department and poor relationships with providers, patients can have a difficult time engaging with the adult healthcare system. This can contribute to low outpatient disease-based clinic attendance rates. Furthermore, loss of insurance coverage (Medicaid) during the same period fosters uses of the emergency rooms in lieu of outpatient primary provider/hematologist well care, health maintenance visits (Sheppard et al., 2023). As a result, this can hinder young adults from receiving the necessary care to manage their disease and disease-related complications (Saulsberry et al., 2019).

Without adequate care to treat their disease and minimize disease-related complications, hospital admissions and emergency department utilization can increase exponentially. Many young adults will experience more pain-related episodes between the ages of 18-39 years (Yusuf et al., 2010). From 2000 to 2016, there was a 40.6% increase in the number of hospital inpatient stays among young patients aged 18-34 with SCD, and most of these hospitalizations were due to

pain (Fingar et al., 2006). Increased pain-related hospitalizations may be due to insufficient access to primary medical care, lack of transfer summaries when switching from a pediatric to adult-based provider, lack of confidence from physicians treating patients with SCD, and poor communication between pediatric-based and adult-based healthcare teams on when they should initiate care with an adult-based provider before leaving pediatric care (McPherson et al., 2009). In addition to the transition period being a high-risk time for negative health outcomes, it can also be a time of increased healthcare costs. Furthermore, there is limited review of healthcare costs for SCD to commercial health insurance, which only covers one-third of SCD patients, and their healthcare costs may vary which can cause an increase of healthcare utilization (Sheppard et al., 2023). For example, a SCD-related inpatient stays totaled $811.4 million in 2016, with an average length of stay of 5 days (Fingar et al., 2006). Lastly, there is a high rate of mortality among young adults with SCD during the transfer period. In comparison to older adults, the young adult mortality rate quadruples between the ages of 20 to 49 (Shankar et al., 2005). Overall, these barriers to healthcare access have contributed to an inadequate transition process to adult-based healthcare, further propelling a decline in health during the transitional period. Leveraging use of technology and social media platforms can minimize barriers related to disease knowledge and self-advocacy to transition and increase skills needed to successfully transfer to adult-centered care.

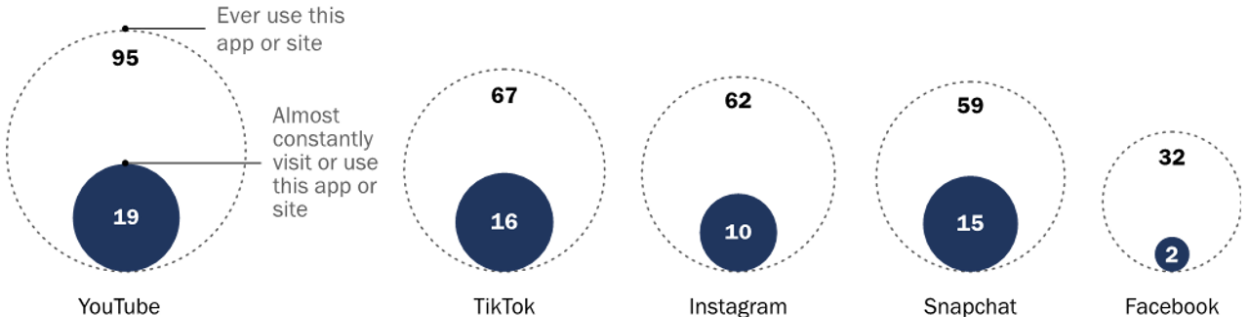
Use of Technology and Social Media For Patient Engagement

The prevalence and use of digital technology are spreading throughout the United States as well in global settings. Young adults use online platforms and social media to gain knowledge on health-related educational material, to learn more about health concerns, and to learn about their chronic disease(s) (UNICEF, 2017). In Africa, 40% of youth (age 15-24) in low- and

middle-income countries were online in 2017 and 91.9% of these youth spent more than 5 minutes per day online. Of the youth who spent more than 5 minutes online per day, 69.4% were online more than 30 minutes per day looking at health-related content and 36.6% spent more than 1 hour per day on the internet looking at health-related information (Park & Kwon, 2018).

As technology advances, people interact more frequently with social media through their cellphones, tablets, computers, and other electronic devices. Specifically, teens and young adults have more knowledge in the tech environment as it relates to using mobile and social platforms to obtain information and participate in interactions. More than 80% of young adults with SCD have access to a computer or mobile phone, as well as other electronic devices (Crosby et al., 2017). The Pew Internet Project survey found that 96% of young adults in US between the ages of 18-29 were internet users, 84% used social networking sites, and 97% had cell phones (Anderson & Rainie 2022). In Figure 3, as of April 2022, YouTube and Tik-Tok were the most popular social networks used by adolescents between the ages of 13-17 years old, as shown in Figure 3 (Anderson & Rainie 2022).

Figure 3. Social Media Usage Among Teens (13-17 years old) in 2022



Digital interventions provide an opportunity for patients and health professionals to engage with and disseminate health information in a variety of areas such as health, wellness, and chronic illness. Additionally, digital content may increase awareness of SCD among healthcare providers and the general public, provide information on disease self-management and potential complications, provide information on disease-related specialists, and education on potential treatment options (Inusa et al., 2020).

Barriers to delivering SCD-related and general information to EASCD prior to their transition to adult-based health care include disengagement, low-in person show rates to medical appointments, poor provider communication, lack of support from healthcare providers, and inadequate education from providers (Josephson, 2016). Given the varying success rates for SCD-focused pediatric- to adult- based healthcare transition programs, creating web-based/social media content will allow for greater reach to provide education on disease-related self-management strategies and transition-related skills and knowledge (Inusa et al., 2020). Since transition preparedness from pediatric- to adult- based healthcare typically occurs between the ages of 13-17 years, incorporating web-based educational tools and mobile health will potentially allow patients with SCD to increase the knowledge and skills they need to transition to adult-based healthcare through highly salient mediums (e.g., TikTok, Instagram, etc.).

Additionally, digital interventions provide flexibility in utilization beyond hospital settings, such as in the home, school, and waiting room during medical visits (Inusa et al., 2020). Due to limited access to comprehensive SCD centers in Georgia, creating web-based/mobile apps will allow healthcare providers and community-based organizations to reach emerging adults (EA) where they are despite their location. Lastly, web-based/mobile applications may improve existing sickle cell transition programing in metro Atlanta, GA, and in the state of

Georgia as it may increase adolescents' engagement in their disease-related healthcare and increase their knowledge and skills as they transition to adult care.

Two U.S.-based, pediatric hospitals have utilized web-based tools to increase patient engagement in their transition to adult-based healthcare programs or to provide general disease-related knowledge. First, the Sickle Cell Transition E-Learning Program (STEP) was designed by pediatric SCD providers at St. Jude Children's Research Hospital (Memphis, TN). STEP is a 6-module web-based tool to increase transition readiness for young adult with SCD (Saulsberry et al., 2020). Researchers found a positive relationship between the number of completed STEP modules and disease knowledge among youth with SCD. When youth with SCD completed more than three modules, their disease knowledge scores were significantly higher than those who completed less than three STEP modules (Saulsberry et al., 2020). Secondly, the Children's Hospital of Philadelphia (CHOP) Cancer Center has also leveraged social media to help educate adolescents and young adults with cancer about their disease, promote disease self-management, and promote adherence. Professionals at CHOP found that disseminating educational topics on general health and adherence on Tik-Tok was rapid, low cost, and reached more viewers than any single instructional effort (>30,000 views total) (Psihogios et al., 2022).

Overall, utilizing technology-based, mobile platforms can improve disease-related knowledge, symptom tracking, patient-provider communication, and treatment delivery (Nazareth et al., 2018). The implementation of web-based technology will optimize education-related outreach and engagement for emerging adults and likely help to close existing gaps in healthcare utilization, lower mortality rates, and improve health outcomes during the transition from pediatric- to adult- based healthcare.

Reducing Barriers: The CREATE Study

The Optimizing Sickle Cell Disease Transition Engagement through: Culturally Responsive Age Appropriate and Technology Evolving Education (CREATE) study was designed to improve the current transition-related education modules utilized by a children's hospital in metro Atlanta, Georgia. The study's primary objective is to improve the engagement of emerging adults with sickle cell disease (EASCD) in the transition process by identifying and filling gaps in the current education programs by creating new educational modules and disseminating on teen preferred media platforms. Creating patient-centric, culturally responsive transition education and engagement material and disseminating them in formats and on platforms that are preferred by EASCD will allow providers and community-based organizations to "meet them where they are." Therefore, the study's goal is to equip EASCD with the appropriate multi-dimensional educational and disease knowledge skills needed to engage in and navigate the adult health care system. The educational and engagement materials that the study creates will be disseminated on websites and through social media platforms in 2023 and 2024; and CREATE researchers aim that the materials will reach EASCD not only in metro Atlanta, but across the state of Georgia and potentially have a US-wide and global reach (other low resource countries with a high prevalence rate of SCD)

Chapter 3: Methods

Project Design

The CREATE study was designed with the goal of developing culturally responsive, age appropriate, and technology evolving education related to SCD and general life for emerging adults living with SCD. To this end, the project would utilize a sequential exploratory mixed

(SEM) methods approach which will include conducting a needs assessment followed by the development and dissemination of educational materials. The needs assessment will use focus group discussions and a survey to determine what (a) SCD- and general life- related skills and knowledge content and (b) methods of dissemination and engagement are best suited for present-day emerging adults living with SCD. The data from the needs assessment will inform the design of the educational materials. The Emory University Intuitional Review Board (IRB) has reviewed and approved this study.

The SEM approach used within the CREATE study is comprised of four phases, including a preliminary phase 0, within which this thesis work was concentrated.

Phase 0: this phase was focused on creating preliminary educational content on topics determined to be necessary for all SCD patients preparing to transition from pediatric-to-adult-based healthcare, specifically on the topic of pain management. I created one educational video on pain management for young adults with sickle cell disease via TikTok. Since TikTok is one of top used platform among young adults, I have used that platform to create an educational video on pain management. While the young adults watch the TikTok video, I have formulated closed-ended questions based on the video's educational material to evaluate their learning.

Phase I: this phase constitutes the qualitative component of the formative research for CREATE. It will include six (6) focus groups to be held in person at the Sickle Cell Foundation of Georgia. During each focus group, participants will be asked about (a) the knowledge and skills needed prior transitioning from pediatric- to adult- based healthcare and (b) how the aforementioned knowledge and skills should be delivered to youth.

Phase II: this phase constitutes the quotative component of the formative research for CREATE. A survey regarding media preferences in teens and emerging adults will be conducted. Based on

the focus group responses, the themes of media preferences and digital engagements patterns of participants will be generated in a short survey. Questions in the survey ask about social media platform participant use on a regular basis, platforms usage to obtain information about health, and specific apps used for SCD, among other parameters.

Phase III: assessment, development, and implementation of transition education tools. Based on re-occurring themes gathered during the focus groups and surveys on participants' perceptions of educational gaps, needs, and media preferences, there will be a total of eight (8) educational modules being disseminated on websites and social media.

Phase 0: Preliminary Content Development and Testing

To accomplish the overall project's aims, I co-created one new transition education video on pain management to disseminate to young adults with sickle cell disease via existing online platforms and/or social media. Since TikTok is one of top used platform among young adults, it was selected as the channel to disseminate the content in this phase. The video was coupled with a set of closed-ended question, to be delivered before and after watching the content to assess patient learning. Additionally, I will modify existing transition-related materials that are currently being utilized within the Sickle Cell Teen Transition Clinic at Children's Healthcare of Atlanta, Aflac Cancer & Blood Disorders Center (Atlanta, GA). Once all of the educational modules are finished, a pilot group of 40 youth aged 16-21 with SCD will be recruited from the Aflac Cancer & Blood Disorder's Clinic at Children's Healthcare of Atlanta to complete the pre-test, watch the educational modules on transition, and take the post-test.

In addition to creating new content, I modified existing transition-related materials that are currently being utilized within the Sickle Cell Teen Transition Clinic at Children's Healthcare of Atlanta, Aflac Cancer & Blood Disorders Center (Atlanta, GA).

Developing the TikTok Video

For this special project, I created a TikTok video geared towards emerging adults (aged 16-21) transitioning from pediatric care to adult care, focused on the topic of pain management strategies. I have information from existing SCD-related literature and source educational content such as the Centers for Disease Control and Prevention guidelines to create an overview of pain/medication management, triggers and signs, and treatment for pain. After cultivating information on pain management, I wrote a script for the TikTok video about (a) what contributes to pain for people with SCD and (b) how to manage SCD-related pain. The script was revised by my committee chair, committee co-chair, and committee member. The video detailed the importance of collaborating with a health care provider on an overall pain management plan and non-medicine strategies for pain management. CREATE is about creating culturally relevant educational materials and I tailored the language to the audience by avoiding technical and medical jargon terminology. I have used subtitles on video as well as emojis and images to capture the audience attention throughout the video.

The video will eventually be available for viewing by individuals with SCD (a) who receive care at Children's Healthcare of Atlanta, (b) who receive care at the Grady Comprehensive Sickle Cell Center, and (c) across the globe as the video will be disseminated on various online social media platforms and channels, including the website scinfo.org, and other online social media platforms to help emerging adults with sickle cell disease (EASCD) transition to adult care successfully. For the time being, the video will be on a holding, temporary account until all the modules have been created and reviewed and vetted by the participants of the focus groups as thematically accurate. The video is the property of the Aflac Cancer and Blood Disorders Center at Children's Healthcare of Atlanta (Atlanta, GA) and one

educational tool that will be integrated into transition to adult-based healthcare programming for youth with SCD who receive care at the Center.

Developing the Knowledge Assessment Quiz

To assess knowledge delivered through the video, youth will take a pre-test prior to watching the TikTok video and a post-test afterwards. I created a short quiz with two questions that are based on the educational material in the video. The questions asked about the following: 1) Stress is one of the triggers for sickle cell disease (Responses: True or False), and 2) Is breathing technique a good way to manage your sickle cell pain? (Responses: Yes or No). I used closed-ended questions to easily measure changes in disease knowledge within their answers.

After the young adult watch the modules, they will have a QR code to transfer them to their personal REDCap ID to answer pre-and-post survey questions. The video will eventually be monitored and evaluated to analyze changes in disease knowledge by completing the pre-and-post questions. The Emory School of Digital Scholarship (ESDS) will access and monitor the website to see which young adult access the video and if they watch the full video. The content of the Tik Tok video and the pre- and post- test questions specific to this video are in Chapter 4.

Revising Existing Transition-related Materials

In addition to creating the TikTok video, I made an infographic document with information on the SCD transition program at CHOA from the original SCD Teen Transition Clinic materials. Also, I modified the introductory letter for parents and adolescents that details the purpose of the SCD Teen Transition Clinic and gives information on the Clinic format to indicate services offered. Along with the introductory letter, I re-formatted the SCD Teen Transition Policy document. The SCD Teen Transition Policy is to prepare parent/caregiver to move their 18-year-old teen to adult care by providing opportunities to learn how to be more

impendent in caring for his/her disease. Lastly, I re-organized the Sickle Cell Disease Knowledge quiz to be more aesthetically pleasing to youth. Of note, the Sickle Cell Disease Knowledge quiz is typically given to adolescents with SCD during the SCD Teen Transition Clinic to measure their (a) disease-related and general health knowledge and (b) disease self-management. The aforementioned materials will be utilized during the SCD Teen Transition Clinic within the Aflac Cancer and Blood Disorders program (Children's Healthcare of Atlanta, Atlanta, GA).

Chapter 4: Deliverables

Source Educational Content: Overview of Pain/Medication Management

Sickle cell disease (SCD) is an inherited chronic disorder that that affects red blood cells. Under low oxygen, it causes the red cells to be deformed into sickle shapes, which makes the body destroy them earlier than normal giving rise to anemia. It is also characterized by severe pain episodes (known as pain crises) and other organ complications as patients age. The most distressing symptom of SCD to persons living with the condition is pain. The intensity, unpredictability, and recurrent nature of pain is due in large part to red blood cells becoming stiff, sticky, distorted (i.e., in a crescent, banana, shape), and clumping together. Specifically, the sickled-shaped red blood cells prevent blood flow through the vessels by being attached to one another. These blocked blood vessels can cause pain that ranges from mild to very high and lasts for any length of time (*Living well with sickle cell disease : self-care toolkit*). Thirty (30) to forty (40) percent of adolescent and adults living with SCD experience chronic pain (Sil et al., 2016). Acute pain episodes can occur in infants and increase more as an individual gets older which can lead to the development of a chronic pain condition (Brandow & DeBaun, 2018). The

period between adolescence and emerging adulthood is considered a particularly vulnerable time for youth with SCD and the increasing frequency of pain episodes and emergence of chronic pain are the most challenging aspects of this time period. Therefore, pain management is vital for individuals living with SCD as it helps to reduce suffering improve functioning and improve quality of life. Pain management strategies are tailored to the individual with SCD. Pain management strategies for persons with SCD include, but are not limited to, medications, nutrition, hydration, exercise, stress reduction techniques, vaccinations, and blood transfusions (CDC, 2022). Furthermore, it is important to understand the triggers that contribute to pain onset, signs that indicate pain is present, and treatments to effectively manage pain.

Source Educational Content: Triggers & Signs

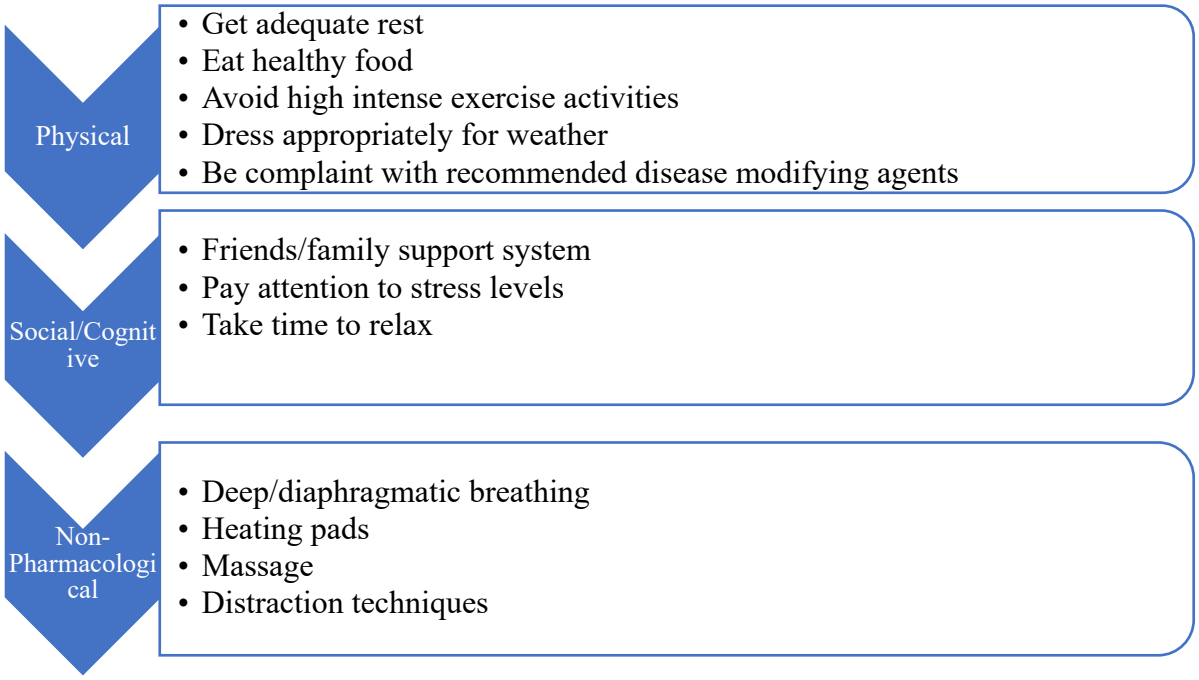
There are common triggers of pain-related episodes that individuals with SCD may experience. Pain-related triggers include, but are not limited to, physical or psychological stress, cold weather, loss of fluids (dehydration), and stress. Some signs that an individual is under stress are when they are unable to focus, they feel worried, and/or they feel irritable. This can occur when an individual has a lot of tasks to complete at the same time, relationship issues, problems at school and work, and etc. (*Living well with sickle cell disease : self-care toolkit*). Cold weather is associated with pain crises among individuals with SCD. Due weather changes, the blood vessels constrict, allowing less blood to flow through the body. This increases the likelihood of the red blood cells becoming sickled and a pain crisis occurring (Brandow et al., 2013). Lastly, dehydration can occur when your body loses more fluid. Signs of dehydration include dizziness, lightheadedness, fatigue, and headache; and dehydration can occur when sitting out in the sun for too long without drinking the adequate amount of water and individuals doing extensive workouts. Sickle cell-related pain varies from person to person, and it can occur

in any area of the body such as the abdomen, joints, (hip), chest, back, and any other bones. It is important to acknowledge the symptoms and triggers of a pain crisis so that one can engage in effective disease self-management and intervene as soon as possible.

Source Educational Content: Treatment and Prevention of Pain

Since SCD-related pain can be very unpredictable and severe, developing an individualized, comprehensive pain management plan with a healthcare provider is very important (Brandow & DeBaun, 2018). The first part of such a plan is to try as much as possible to prevent pain crisis from occurring; and secondly, the person should be instructed in how to manage pain when it does happen. Figure 4 shows different pain management strategies for individuals who are experiencing a pain crisis. These strategies are also incorporated in the TikTok video.

Figure 4. Pain Management Strategies for Individuals Experiencing a Pain Crisis



To reduce the risk of pain episodes, it is important to get adequate rest, eat a healthy diet, avoid activities that are risky and high intensity (not well tolerated), and avoid stress. Also, it is

important to dress warm in cold weather and carry an extra layer. Also, there are daily medications, disease modifying agents that may be prescribed by a medical provider to modify the underlying pathophysiology of the disease. Improved adherence with these can help reduce pain (and other complications). For example, hydroxyurea is one of the most common drugs used to reduce pain-related hospitalizations among individuals with SCD (Segal et al., 2008). In addition to lifestyle behaviors and their impact on pain, there are social and cognitive components to pain that people with SCD should attend to, for example, building a good support system that includes friends and family can help manage stress and help in time of need. Different techniques that individuals can utilize to manage pain include non- pharmacological strategies like heating pads, deep/diaphragmatic breathing, massage, light physical activity (as tolerated), and distraction techniques (*Living well with sickle cell disease : self-care toolkit*). Overall, developing a personalized, preventive plan to minimize pain-related triggers and to address pain once it occurs is important for all persons with SCD.

TikTok Script

Hey everyone, my name is Nneka, and I'm here to talk to you about sickle cell disease pain and pain management.

Did you know that people with sickle cell disease often experience intense pain?

Yup! That is true!

People with sickle cell disease experience intense, unpredictable, and recurrent pain due to their red blood cells becoming stiff, sticky, and C-shaped. These sticky, sickle-shaped blood cells can cause serious health problems such as pain.

Triggers for sickle cell disease-related pain, can include stress, changes in weather either hot or cold, and not drinking enough water. In hot weather, you can get dehydrated which leads to

slower flow through the blood vessels; and in cold weather, the blood vessels tighten up, become narrower (or constrict) all leading to an increase in red blood cell sickling.

But don't worry, there are MANY strategies to manage sickle cell pain!

A disclaimer, I am not a medical provider. I have gathered information from a medical website. Please consult with your primary doctor for more information.

When you first experience signs of pain, you should do some self-talk to calm down your nerves while drinking water to stay hydrated. The second step is to do breathing techniques. I will show you: as you close your eyes, breath in and out as you count to 10 slowly. The third step is to follow a pain plan that is personalized for you from your doctor. And this plan could include medications that should be taken in the order that your doctor states.

Lastly, please call your sickle cell provider if you cannot manage your pain at home using your pain plan, have fever, and/or difficulties breathing. Remember to always take care of yourself, stay strong, and you're a warrior!

After watching this video, you will receive a link to answer the post questions survey. This is one of eight modules video that you will be watching. After you complete the 8 modules you will receive 100 points which then you will receive a $50 Amazon gift card.

You can scan the QR code link to complete a teen clinic experience questionnaire to learn more about how CHOA can support you in teen clinic. Thank you for watching this pain management video!

TikTok Video

A link to the TikTok video on pain management

https://drive.google.com/file/d/1ezPko4Jxv8cr8UbFVco4SrsIMF0rvG2b/view?usp=drivesdk

Pre-and-Post Test Questions

1. Stress is one of the triggers for sickle cell disease (Response: True or False)
2. Is breathing technique a great way to manage your sickle cell pain? (Responses: Yes or No)

Chapter 5: Discussion

Summary of Main Thesis Deliverable

The importance of developing a structured and multidisciplinary transition program from pediatric to adult care for young adults with sickle cell disease (SCD) can improve on their disease self-management, overall health and disease-related well-being, and decrease their mortality during young adulthood. Unfortunately, there are barriers to implementing healthcare transition to adult-based care programs for youth and young adults with SCD; and these barriers can contribute to lack of engagement in adult-based healthcare once a young person ages out of pediatric-related disease care. Barriers to successful healthcare transition for youth with SCD include, but are not limited to, education, insufficient training of adult-focused healthcare providers, shortage of adult care practitioners, lack of coordination and shared systems, cost, and engagement (Lanzkron et al., 2018). Out of all the barriers to improve patient readiness to transition to adult-based healthcare, the current special project focuses on improving education and engagement among adolescents and young adults with SCD. Disease-based knowledge and disease self-management are important parts of any healthcare transition program, and inadequate knowledge can prevent adequate transition outcomes.

Current literature has demonstrated that educational interventions, in particular, transition to adult-based healthcare programming within pediatric healthcare facilities, have been effective in improving transition outcomes for adolescents and young adults with chronic health

conditions such as SCD, diabetes, and cystic fibrosis. Previous transition programs have utilized education programs such as books, templates, in-person care clinics, social media/short videos, and role play. Nonetheless, the cycle of disengagement, loss to follow-up in the adult-based healthcare setting (after the last pediatric healthcare appointment), increase in acute health care utilization (e.g., emergency room usage) during the young adult period, and acute complications continue to abound. Although the traditional in-person and/or paper-based methods of delivering disease-related education are easy to implement, gaps remain in enhancing transition care particularly among the disengaged, those who reside in rural areas, and/or those who do not engage in routine disease-based healthcare (Calhoun et al., 2019). In recent studies, the utilization of web-based technology has been shown to improve disease-based knowledge among adolescents with SCD. Leveraging use of social media platforms for education and engagement has rapidly evolved to everyone, particularly for adolescents who tend to socialize on and obtain health-related and/or other information via social media outlets. Due to the proliferation of social media use among children, adolescents, and young adults, the CREATE study was developed to adapt existing in-person, paper-and-pencil, and web-based SCD-related education to align with technological advancements and improve engagement and disease-based knowledge among emerging adults with SCD. The existing transition-related educational materials were developed by medical and psychosocial providers with the Aflac Cancer and Blood Disorders Center at Children's Healthcare of Atlanta (Atlanta, GA). Overall, the study will focus on developing culturally responsive transition educational materials and increasing engagement of emerging adults with SCD in the healthcare transition process. One way in which the CREATE study will accomplish the aforementioned goals will be to utilize various web-based technology platforms, in particular, social media sites such as YouTube, TikTok, Snapchat, Facebook, and Instagram.

Among these platforms, TikTok is one of the most widely used by adolescents and young adults. Therefore, for the current special project, I created one educational module script on pain management that was used to create a TikTok video. The TikTok video will be disseminated on different social media platforms and on a free-standing website that is managed by the Aflac Cancer and Blood Disorders Center at Children's Healthcare of Atlanta (Atlanta, GA). The overall goal of the pain management TikTok video was to help emerging adults with SCD develop disease-related self-management skills and increase patients' self-efficacy as it relates to managing one of the most common symptoms of SCD. Furthermore, the video will improve access to disease-related education for youth with SCD who reside in the United States and worldwide.

Limitations

There are several limitations to my current special project. First, I only created one educational module/video to address a large component of SCD-related care, in particular, pain management. Therefore, other disease-related and general information and aspects of disease self-management need to be developed into modules. Secondly, there are many other barriers to successfully transitioning to adult-based health care for youth with SCD that are beyond the scope of the CREATE study and this special project. One such barrier is access to specialized hematological care for young adults with SCD who reside in rural or underserved areas. Another barrier is adding a policy on health care coverage after ageing out of pediatrics. Lastly, the relatively short length of TikTok videos (e.g., typically less than sixty (60) seconds) limited the amount of information I was able to include on pain management. However, the brevity of the video may be more palatable to emerging adults as they are accustomed to viewing both educational and non-educational content via this modality. As such, the short length of the video

might ensure that the emerging adults are engaged and retain the information. Since the video will be disseminated on the organization website, another barrier will be reaching emerging adults who are not connected to care or have dropped out of care due to lack of insurance.

Future Directions

In an effort to provide SCD-related information in short, engaging formats to emerging adults with SCD, the CREATE study plans to create additional TikTok videos that discuss other sickle cell complications such as infections, acute chest syndrome, and organ damage. Specifically, this would expand the micro-learning among emerging adults to "meet them where they are." The additional videos on other SCD-related complications would also be hosted/housed on the website that is maintained by Children's Healthcare of Atlanta. By hosting the videos on the aforementioned website, they could be accessed by adolescents and young adults in Georgia counties that have high prevalence of SCD. Additionally, from the information in the videos, handouts (or infographics) could be created for patients and their families. Translating these materials into different languages, particularly languages that are widely spoken in African, Caribbean, and Middle Eastern countries would allow for dissemination to individuals in other countries.

Implications

Social media has rapidly evolved and is widely available to people across the globe. Particularly, adolescents use social media to connect and communicate with each other and obtain information on aspects of themselves (e.g., chronic health concerns) and the world (in general). Social media platforms have functions that allow for the creation, sharing, and exchanging of user-generated content which is a great way to engage adolescents. Given the aforementioned technological advances, the Optimizing Sickle Cell Disease Transition

Engagement through: Culturally Responsive Age Appropriate and Technology Evolving Education (CREATE) study was designed to improve the current transition education modules utilized by a pediatric hospital in metro Atlanta (Georgia) and to help emerging adults navigate the adult healthcare system. Information on how to manage SCD-related pain was used to one out of the eight transition-related educational modules for the CREATE study. The module included pain management strategies to help with the acute and/or chronic pain that can occur among those with SCD. The web-based modules can educate adolescent and young adult persons with SCD on their chronic condition. Disseminating the modules and videos on the pediatric hospital's SCD-specific website will align with emerging adults (EA) use of social media to learn information about themselves and the world. Furthermore, the modules and videos can be viewed by adolescents and emerging adults with SCD in the US and across the globe.

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