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Experiences and Perceptions on Transitioning from Pediatric to Adult Care Among Patients with Sickle Cell Disease in an NYC Hospital

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Abstract Sickle Cell Disease (SCD) is a genetic disease and a major global public health concern. The transition process from pediatric to adult care is complicated and frustrating for many patients and physicians. This qualitative, phenomenological study explored the perceptions and experiences of Physicians-In-Training (PIT) and young adult patients regarding the transition process from pediatric to adult care. A total of 12 participants (four pediatric PIT and eight young adult patients with SCD) from a hospital in New York City participated in the study. Data were collected through semi-structured interviews, which were audio-recorded, transcribed, and hand-coded into themes. The findings revealed that young adults with SCD had negative experiences and perceptions throughout the transition process. Inadequate information about the transition, poor relationships with adult providers, and long waiting times in the ER reduced the quality of care of patients with SCD. Social support during the transition process came mainly from their parents. Young adults believed that there should be a better relationship with the adult providers, and that patients with SCD and the adult clinical team should be educated about the transition process. Seventy-five percent (75%) of the PIT mentioned that transition to adult care usually starts at age 21; however, they believed that the transition process should start at age 15. They lacked knowledge about the transition process and support services for patients with SCD. They also reported hesitation of pediatric patients to transfer to adult care. They expressed concern that young adults might not be adherent to their medications and schedule their appointments when needed. The transition process should include adequate preparation, patient education, social support, communication between pediatric and adult settings, and a relationship between patients and adult providers.

Keywords: *Sickle Cell Disease, transition process, experiences, perceptions, young adult patient, pediatric physician*

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1. Introduction

Sickle Cell Disease (SCD) refers to a group of blood disorders that is inherited from parents and affects the composition of hemoglobin [1]. Individuals with this disease usually obtain double abnormal hemoglobin genes from each parent due to a mutation [2]. The mutation causes round-shaped red blood cells to change into a shape like a sickle or crescent that die prematurely. Due to this odd formation of the blood cells, the clump of cells sticks in the tiny blood vessels and blocks the normal flow of both blood and oxygen in the whole body [3,4].

The major clinical manifestations of SCD are episodes of pain throughout the body, hand-foot syndrome, swelling of the limbs of babies, frequent infections, delayed growth, vision problems, and Sickle Cell Anemia [3,4]. The two main complications of the disease are vaso-occlusion and hemolysis [5]. Other complications include pain crisis (episodes of pain), splenic and renal dysfunction, acute chest syndrome, cerebrovascular complications, infection, neurologic complications, and acute exacerbations of anemia [5,6]. Due to the complications of the SCD, some of the comorbidities that occur during childhood prolong into adulthood [7] and seem to increase as patients age.

SCD is the most prevalent inherited hemoglobin disorder around the world, especially in Sub-Saharan Africa, South America, Central America, the Caribbean, India, and some Mediterranean countries [8,9]. According to [9,10], SCD affects approximately 100,000 Americans; most of whom are Black or African American children (one in every 365 births) and Hispanic American children (one in every 16,300 births). Males and females are equally affected with SCD [9].

Patients with SCD are living longer than before [11]. The average life expectancy of SCD patients in the 1970s was about 14 years, while the average life expectancy in the 1990s for women with SCD was 48 years, and for men

it was 42 years [11]. Currently, the average life expectancy is over 50 years of age [11,12]. Increased life expectancy for patients with SCD is partly due to new drugs for treating the disease [13], screening programs of newborn children, administering prophylactic penicillin from birth to age six, the advent of the pneumococcal vaccine, transcranial doppler (TCD) ultrasound screening with transfusions to prevent stroke, chest syndrome recognition and prevention, comprehensive pediatric care, advances in supportive care, and the use of hydroxyurea [12,14].

The transition process from pediatric to adult care is complex. In 2011, the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians developed professional recommendations on transition from pediatric to adult care [15], which was later updated in 2018 by Got Transition, a program of the National Alliance to Advance Adolescent Health [16]. The Six Core Elements of Health Care Transition includes: (1) creating a transition policy/guide, (2) tracking and monitoring, (3) assessing readiness, (4) planning, (5) transfer of care, and (6) transition completion. These core elements are tailored based on the type of practice that offers the transition. Therefore, there is no universal standard to measure success of the transition process. However, the Virginia Commonwealth University Medical Center [17], and St. Jude Children's Research Hospital [18], have implemented The Six Core Elements in their SCD program and have achieved success.

Many health care facilities do not have a Sickle Cell Disease transition program. At the time of this study, the hospital where the participants were recruited did not have a transition program/team for SCD patients. Challenges for patients and providers are seen at both the individual and the health system levels. Patients with SCD experience increased challenges as they transition to adult care. After the age of 18, pediatric patients need to actively participate in their health care services [7]. The challenges faced by the young adults are unpleasant experiences in the Emergency Department (ED) and shortage of knowledgeable providers about the disease after they transition [7]. In addition, providers face the challenges of adversarial provider-patient communication during a pain crisis [7,19]. There is a shortage of physicians who specialized in SCD [7,18], lack of coordination between pediatric and adult providers, and losses in health coverage [18]. Numerous researchers have indicated that there is a gap between the providers and young adults during the transition period [3,7,11,19,20,21,22]. These researchers indicated that the transition process is not uniform, and practices are inconsistent to support young adults with chronic pain after they transition from pediatric care. Therefore, it was important to understand the experiences and perceptions that are associated with the transition process to improve the health care services that are provided for patients with SCD and ultimately improve their quality of life.

1.1. Aims

The study explored the perceptions and experiences of Physicians-In-Training (PIT) and young adult patients regarding the transition process from pediatric to adult care. The following research questions were asked:

1. What are the experiences and perceptions of young adults with SCD concerning the transitioning process from pediatric to adult care?
2. What are the experiences and perceptions of Physicians-in-Training concerning the transitioning process from pediatric to adult patient care among patients with SCD?

2. Methods

2.1. Research Design

A qualitative, phenomenological approach was used to understand the lived experiences and perceptions of young adults with SCD and their physicians concerning the transition from pediatric to adult care.

2.2. Study Population

This research study was conducted at a hospital in the Bronx, New York. There were 12 participants in the study: four pediatric PIT and eight young adults with SCD. The participants with SCD were patients who received ambulatory care at the hospital. All participants were 18 years and older. Young adults were between ages 18-26 years old.

2.3. Instrumentation

The instrument used for this survey was adopted from two previous studies [23,24] with some modifications to a few of the questions. The survey consisted of demographic characteristics of the participants, and semi-structured questions that pertained to the experiences and perceptions of providers and young adults concerning transitioning from pediatric to adult care among patients with SCD. Sample interview questions for PIT included "Describe the process of getting the adolescent with SCD ready for the transition into adult care? How do you assess adolescents for their ability to self-manage pain resulting from SCD without his/her parent assistance?" Questions for young adult patients included "Describe your experience with transition to an adult provider. What were some of the challenges that you encountered as you transitioned to adult care? How would you describe the health care service that you are now receiving?"

2.4. Data Collection

Data were collected between February 2020 and April 2020. The patients and PIT were recruited from the Hematology Clinic at the hospital. A pilot study was conducted to test the instrument before actual data collection started. The researchers approached the young adults in the waiting area of the clinic, while the physicians were approached during their lunch hours and interviews were scheduled after. Patients were interviewed in an empty room of the clinic after their appointments, while physicians were interviewed via telephone. Each interview lasted approximately 20 minutes. Interviews were audio-recorded, then transcribed into a Microsoft Word document.

2.5. Data Analysis

Demographic variables were analyzed using the descriptive statistics. Thematic analysis was used to analyze the responses from individuals regarding their perceptions and experiences. The responses of the participants were organized and hand-coded based on similar themes. The themes were determined based on repeated responses to the questions.

2.6. Ethical Considerations

Permission was granted by the hospital where the study was conducted. Approval was also granted from the Institutional Review Board (IRB) at the academic institution where the researchers are affiliated. The researchers explained the purpose of the research to all participants. They also received an informed consent, which they read and signed before the interview began. Participation was voluntary.

3. Results

The demographic data of the young adult patients with SCD revealed that most of the participants were females (seven out of eight). All participants with SCD were between the ages of 22-26 years old and were Black or African American. Three out of four PIT were females, white, and all were between ages 18-45 years (Table 1).

Table 1. Demographic Characteristics of Participants

Participants	Characteristics	Categories	Number (%)
Young Adults with Sickle Cell Disease (SCD)	Gender	Male	1 (12.5)
		Female	7 (87.5)
	Age	22-26	8 (100)
	Race	Black/ African American	8 (100)
Physicians-In-Training (PIT)	Gender	Male	1 (25)
		Female	3 (75)
	Age	18-30	2 (50)
		31-45	2 (50)
	Race	White	3 (75)
		Asian	1 (25)

3.1. Experiences of Young Adults with SCD Regarding Transition

Two themes emerged from the responses of the young adult patients regarding their experiences during the transition process (Table 2):

1. Unpleasant experience with the healthcare they received.
2. Received social support

3.1.1. Unpleasant Experiences with the Transition Process

Throughout the transition process, patients with SCD had unpleasant experiences, such as long waiting times in the emergency department, poor communication with doctors who treat adult patients, and they reported that doctors seem not to care about or understand them. The experiences of young adult patients: *"I would say longer wait times in the Emergency Room, because I guess, they don't know, if they don't feel like my emergency is as urgent as everybody else's*." Another patient explained *"…and oftentimes they were not willing to work with me and they weren't willing to give me the treatment that I needed to get my pain under control in order to be discharged promptly."*

Young adults with SCD also mentioned that there was poor communication from the physicians regarding the transition process and that the adult hematologists were not friendly. A young adult patient stated: *"There was no talk about transition…I was just passed on to an adult hematologist… no conversation developed around it at all."* Another patient remarked *"…there was no guideline or pamphlet or any type of orientation, it was just …we were thrown into adult care."* These sentiments were mentioned by three other young adults.

Some of the patients found it difficult to transition to adult care. One patient mentioned: *"I had to go to various hospitals and found one that is best suited for the proper care, that I needed…..so, I found something that's further away that is better equipped to work with me."* After they had transferred from pediatric to adult physicians, they mentioned that their interactions with the adult physicians were not as friendly as their pediatric physicians. The experience of an adult patient: *"My experience wasn't really pleasant; the adult provider, not as friendly and concerned as my childhood provider."*

3.1.2. Support During Transitioning

Despite the negative experiences, some of the patients with SCD got some support during the transition process. Most of the young adult patients received support from their parents (particularly their mothers). One patient mentioned: *"My parents helped me in finding an adult provider."* Another mentioned *"…. only my mom helped me."* Other patients mentioned that they got support from a social worker who helped them to find an adult doctor, and two patients mentioned that they joined support groups. One participant expressed *"…I met with a Social Worker…he helped me out with a lot of resources."* Two other participants revealed…. *"Oh, I just… like my parents really help me, my mom. Now, I'm a part of Candice's Sickle Cell group, like getting a better understanding though the transitioning phase to the program,"* while the other mentioned *"I joined Bronx Care (support group)."*

3.2. Perceptions of Young Adults with SCD Regarding Transition

An overarching theme that emerged from the data was that young adult patients were dissatisfied with the health care system. They believed that there should be a better relationship with the adult providers, and that both patients with SCD and the adult clinical team should be educated about the transition process. One-half of the patients were not satisfied with the healthcare services that they received. One patient expressed *"…. this horrible, just horrible…."*

Table 2. Experiences of Young Adults with SCD Regarding Transition

Themes	Subthemes	Responses	Examples of Responses
Unpleasant Experience	Long ER Wait Times	4	*"I would say longer wait times in the Emergency Room, because I guess, they don't know, if they don't feel like my emergency is as urgent as everybody else's."* *"…I wait like hours or more than hours."*
	Poor Communication about Transition	5	*"There was no talk about transition…I was just passed on to an adult hematologist… no conversation developed around it at all."* *Another patient remarked "…there was no guideline or pamphlet or any type of orientation, it was just …we were thrown into adult care."*
	Doctors Don't Understand or Care About Them	4	*"...they don't pay attention to you, you know, when my IV is beeping, they don't care."* *"I felt like they [hematologists who treat adult patients] didn't understand me…. or how to manage my sickle cell disease and to give me the respect that I feel like I deserve as a patient."*
Social Support	Family	5	*"My parents helped me in finding an adult provider."* *"…. only my mom helped me."* *"Oh, I just like my parents really help me, my mom.*
	Other sources	3	*"…I met with a Social Worker…he helped me out with a lot of resources."* *Now, I'm a part of Candice's Sickle Cell group* *"I joined Bronx Care (support group)."*

In terms of improving relationships, the patients felt that all physicians (pediatric and adult) who provide care for patients with SCD should communicate so that the adult physicians will have a better understanding of the patients' health status. A young adult patient stated: *"….if they [patients] have problems [with adult care], to possibly speak with their pediatric team……or try to get back the [pediatric] team to meet with the adult team…..so that, they can better understand what is good for that particular patient."* Another patient mentioned: *"They [pediatric side] should have done education with me to know what Sickle Cell is…. what causes of Sickle Cell… education for the team who's prepared for the transition."* Another patient stated: *"I felt like they [hematologists who treat adult patients] didn't understand me…. or how to manage my sickle cell disease and to give me the respect that I feel like I deserve as a patient."*

3.3. Experiences of Pediatric Physicians-In-Training Regarding Transition

Four themes emerged from the responses of Physicians-in-Training regarding transition (Table 3):

1. Transition to Adult Care Starts at Age 21
2. No knowledge of the transition process
3. Unaware of Support Services for transition
4. Pediatric SCD patients Hesitant to Transfer

3.3.1. Transition Starts at Age 21

Three of the four Physicians-in-Training stated that patients with SCD usually transition to adult care beginning at age 21. However, one physician mentioned that the process is sometimes delayed depending on the sub-specialty clinics. A pediatric PIT stated: *"… up to age 21, and … some of them have sub-specialty including Hematology, you know, sometimes that can be delayed a bit later…."*

3.3.2. No Knowledge of Transition Process

Most of the PIT mentioned that they lacked knowledge on the transition process and were not directly involved in the process. For that reason, the pediatric residents were unable to provide information regarding the involvement of others in the process, except for one pediatric hematologist. A pediatric PIT stated: *"I have never been involved in the process of transitioning from adolescent to adult care."* The other pediatric PIT stated: *"Pediatric hematologist is involved…. Not sure who else would be involved in that transition."*

3.3.3. Unaware of Support Services for Transition

All PIT were unaware of support services for adolescents who are transitioning from pediatric care to adult care. A pediatric resident stated: *"...I don't think we have a program that helps with the transition."*

Table 3. Experiences of Physician-In-Training Regarding Transition

Themes	Responses	Examples of Responses
Transition Starts at Age 21	3	"…I would make the transition at 21 years of age, but I would try to start the transition at least a couple of years before…". …" up to age 21, and … some of them have sub-specialty including Hematology, you know…"
No knowledge of Transition Process	3	*"I have never been involved in the process of transitioning from adolescent to adult care."*
Unaware of Support Services for Transition	4	*"...I don't think we have a program that helps with the transition."*
Hesitant to Transfer to Adult Care	3	*"I think maybe it might be hard for them to build that relationship with the new provider especially in a disease like sickle cell where it impacts your whole life. They might, you know formulate a relationship with the nurses they used to that setting. So, it might be hard to then transition their care to a whole new set of team members. So yeah, I think the lack of trust and the continuity might be another challenge as well for them."*

3.3.4. Pediatric SCD Patients Hesitant to Transfer

Most of the pediatric PIT explained that SCD pediatric patients were hesitant to transition to adult care. Hesitancy might be due to fear of the unknown, being comfortable with their pediatric team, and making decisions for themselves such as scheduling the own appointments. One pediatric PIT mentioned *"I think maybe it might be hard for them to build that relationship with the new provider especially in a disease like sickle cell where it impacts*

your whole life. They might, you know formulate a relationship with the nurses they used to that setting. So, it might be hard to then transition their care to a whole new set of team members. So yeah, I think the lack of trust and the continuity might be another challenge as well for them."

3.4. Perceptions of Pediatric Physicians-In-Training Regarding Transition

Two themes emerged from the responses of the Physicians-In-Training regarding transition:

1. Poor self-management skills of SCD patients
2. Early start of the transition process

3.4.1. Poor Self-Management Skills of SCD Patients

Seventy-five percent of PIT felt that the main challenge was getting young adults with SCD to adhere to their medications, which seems overwhelming for the patients at times. The opinion of a PIT: *"an adolescent may not feel that they can stay on top of that (medication)."* One PIT mentioned that scheduling an appointment might be a difficult task for young adults with SCD as they transition to adult care: *"scheduling that next appointment doesn't happen as early as it should and that's one of the big ways that they can fall through the crack."*

3.4.2. Early Start of the Transition Process

To make the transition process easier, PIT recommended that early preparation in transition should start when the patient with SCD is about 15 years, and the process should involve the adult physician who will be providing care. A PIT stated: *"…it should start early. I think talking to them [the adolescents] about the transitioning of care, that it will be happening; prepare them for it, and …. having the adult team involved at an early stage."* Another PIT mentioned: *".....at least one or two joint appointments with both myself [pediatric Hematologist] and whatever the provider [adult physician] they are going to be switching over."*

Table 4. Perceptions of Physicians-In-Training Regarding Transition

Themes	Responses	Examples of Responses
Poor self-management skills	3	*"An adolescent may not feel that they can stay on top of that (medication)."* *"Scheduling that next appointment doesn't happen as early as it should and that's one of the big ways that they can fall through the crack."*
Early Start of the Transition Process (including the adult hematologist)	3	*"…it should start early. I think talking to them [the adolescents] about the transitioning of care, that it will be happening; prepare them for it, and …. having the adult team involved at an early stage."* ".....at least one or two joint appointments with both myself [pediatric Hematologist] and whatever the provider [adult physician] they are going to be switching over."

4. Discussion

The study focused on the experiences and perceptions of patients with SCD as well as PIT who provided care to patients with SCD. Young adults mentioned that their experience during the transition process was overall unpleasant. Among the reasons for unpleasant experiences were inadequate or no information given, an unfriendly attitude of adult providers, and difficult or hard-to-deal-with persons in adult care. Many young adult patients also revealed communication gaps between them and their adult providers. In previous studies [7,11,25], the authors revealed that adult patients were unable to understand the expectations as they transitioned to adult care and that they should be fully aware of the next phase of treatment for their health. Some elements of a successful transition process are to have knowledge of the disease and the transition process, proper communication among everyone who will be involved, and resources. Before transitioning from pediatric to adult care, patients should be given The Six Core Elements of Health Care Transition as it relates to SCD as a standard of care. Implementation of these core elements have resulted in significant decrease from pediatric to adult care abandonment, decrease in time of transition between pediatric and adult care [18], and increased rate of matriculation to adult care [17,18]. This information should be delivered by their pediatricians. However, the hospital that we recruited participants for the study did not have a program, therefore, the extent to which any of the core elements was adopted is unknown. If patients with SCD are not knowledgeable about who their next doctor will be and how they can get services, access to care could be delayed, which could lead to potentially life-threatening situations. The researchers explained that being informed about the transition process could reduce anxiety and improve self-efficacy skills [7]. In addition, the providers or health care team should be able to assess patients' self-efficacy skills in managing their disease because they are likely to have reduced support from their parents as they transition from pediatric to adult care.

Fifty percent of adult patients faced long wait times in the Emergency Room (ER). These findings were consistent with previous studies [3,11,20,24,26]. A possible explanation is that there are usually long wait times in emergency departments of city hospitals because they are mostly crowded. Also, urgency of treatment might depend on the severity of pain that they are experiencing in the emergency department.

Young adults with SCD wished they were directed to or provided with support services to better manage their condition. Most of the adult patients received support from their parents (mainly moms) during and after the transition. However, other patients received support from nurse practitioners, social workers, and social support groups. Young adults, parents, and providers should play an integral part of successful transition to adult care. Creating a support mechanism (team) and sources of social support for patients with SCD may ease the uncertainties of the transition process. SCD patients should be given information on community-based organizations that they can join to get additional support if

needed. These may subsequently improve the experience with patients and their adult physicians.

The results of this study revealed that pediatric PIT lacked knowledge of the transition process. Their main concern was having no direct involvement in the process. A possible explanation for the lack of involvement of pediatric PIT in the transition process is that at the present time of the study, there was no transition team in place at the hospital.

Patients with SCD wished that they and their adult providers were better educated about the transition process. Similar findings were reported in previous studies [7,25]. According to [27], there are a limited number of doctors who trained to properly treat patients with SCD. Therefore, SCD patients should be knowledgeable about their disease so they can educate their adult providers about the disease. Better understanding of the disease and the transition process will allow patients with SCD to be more comfortable with their adult providers [25]. These concerns if not addressed, may lead to a slower transition process as patients with SCD may return to their pediatric physicians for care, or they may become frustrated and not get the care they need. They will eventually rely on urgent care, which they seem to fear.

Pediatric PIT expressed that SCD pediatric patients were hesitant to transition to adult care. They explained that these patients have built a relationship with the pediatric providers and other clinicians, and they may not trust a new provider or their team with their care. They also mentioned that transitioning to adult care means finding a new location and more importantly, this transition comes with more responsibilities such as scheduling appointments and being proactive about their health. This finding was consistent with other researchers [7,28]. These findings suggest that it is important to plan for the transition from pediatric to adult care and to involve everyone (patients, caregivers, and the clinical team) in the transition process. A team approach could possibly reduce apprehension in patients and provide a clearer path to transition to the next phase of treatment for patients with SCD.

5. Limitations

This study has some limitations. Firstly, the study utilized a convenience sample and participants were selected from one hospital. Thus, the results on the experiences and perceptions of young adult patients with SCD and pediatric PIT should be interpreted with caution. Secondly, the researcher did not have the opportunity to interview physicians who provide care for adult patients with SCD due to the COVID-19 pandemic.

6. Recommendations

Research has shown that implementation of The Six Core Elements of Health Care Transition in a SCD program have improved transition outcomes [17,18]. Therefore, the researchers recommend that the hospital provide a team of health care professionals who are dedicated to serve the young adult patients with SCD. This team should be involved in the early transition process and should implement The Six Core Elements of Health Care Transition to provide education about SCD and the transition process, explain to patients the importance of adhering to their medications, ensure that patients are assigned an adult provider, and provide support services to patients before they transition to adult care. The researchers also recommend that the hospital should ensure that physicians or hematologists be on call to assist patients with SCD when they get to the emergency room. Future studies should consider collecting data from all involved in the transition process (SCD patients, pediatric and adult hematologist, other clinicians, social workers, and care givers).

7. Conclusion

The research study allowed both pediatric Physicians-in-Training and adult patients to express their experiences and perceptions in transitioning from pediatric to adult care. One overarching theme that emerged from this research is that adult patients with SCD are unhappy with the healthcare service they received after transitioning to adult providers. In this study, several challenges were identified from the responses of pediatric residents and young adult patients, such as existing communication gaps between pediatric team and adult team, the communication gap between young adult patients and adult providers, lack of education-based transition, inadequate support services for pediatric patients, and negative experience in the emergency department. These challenges could result in reduced quality of care, hence poor health-related quality of life for adult patients with SCD.

Abbreviations

PIT: Physicians-in-Training
SCD: Sickle Cell Disease
COVID-19: Coronavirus Disease 2019

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Conflict of Interest

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