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Review Article

Transitioning from Pediatric to Adult Care in Sickle Cell Disease: Patient and Caregiver Feedback

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Abstract

Introduction: Advances in pediatric sickle cell disease (SCD) care have resulted in children surviving into adulthood. Transition is a time when continuity of care is essential to prevent high rates of morbidity and mortality in adolescents and young adults (AYA). This descriptive study evaluated patients and caregivers' experience with transition.

Methods: Survey was conducted with AYA 20-21 years of age who transitioned from pediatric to adult care using Feedback and Post-assessment surveys.

Results: Fifty-seven AYA attended transition and 15 did not from January 2018-January 2021. Eighty-seven percent who attended felt prepared to change to adult providers with 89% having seen their adult provider since leaving pediatric care.

Discussion: The preparation received promoted self-efficacy for AYA to manage their own health care. AYA who did not attend clinic also did very well. The transition process should start early so AYA have the confidence needed to transition from pediatric to adult health care.

Keywords: Pediatric; Children; Transition; Sickle cell disease; Penicillin; Survey; Adolescents; Self-efficacy

Introduction

Sickle cell disease is one of the most common life-threatening inherited conditions affecting approximately 100,000 individuals in the United States [1,2]. Landmark advances in pediatric sickle cell care have resulted in children with sickle cell disease (SCD) surviving into adulthood and survival has increased to 95% by the age of 18 [3,4]. This is

attributed to newborn screening implementation, penicillin prophylaxis, primary stroke prevention (transcranial doppler screening), disease-modifying therapies, like Hydroxyurea, and improved comprehensive care [5]. With the increasing number of sickle cell patients living into adulthood there is a need for a successful transition program from pediatrics to adult hematology care. This is a time when continuity of care is essential to prevent high rates of morbidity and mortality in young adults. This time of transition often means patients leaving their parents' insurance and the concerns that accompany this, as well as lower medication adherence, higher hospitalizations, and acute care utilizations [6,7]. There is an abrupt rise in mortality rates between 20 to 24 years of age, and it is usually within 1-2 years after transfer to adult care [8,9]. Lack of information regarding the transition process, fear of leaving familiar health care providers and being treated as an adult, concerns about the costs of treatment and the adult provider's understanding of SCD have contributed to the rise in mortality rates due to poor transition [10].

Transitioning to the adult service is challenging not only for the patient, but for caregivers and pediatric and hematology providers. Barriers to health care transition include lack of adult specialized and interested providers, loss of health coverage, lack of patient preparedness, comorbidities, and depression [11]. The physiological, psychological, and psychosocial factors speak to the complexities of this transitional period and the importance of designing interventions aimed at addressing these barriers [12]. Poor transition also affects the health care systems by increasing pressures and workloads due to the increased use of emergency departments, increase hospitalization stays and substantially higher overall health care costs [13]. Transition programs with different interventions have tried to address the barriers and implement programs to improve health outcomes, patient satisfaction and successful transitions. The literature reports the risk of morbidity in AYA with SCD can be decrease with self-care management [14]. It is essential to establish evidence-based transition interventions to promote successful outcomes and retention in the adult hematology service.

Institution provides care to children, adolescents and young adults living with SCD. The sickle cell program is one of the largest in the United States, where approximately 15 AYA transition from this sickle cell program to adult care each year. In 2015, the subspecialty Sickle Cell Adolescent Transition Program (SCAT) was developed within the hematology division to improve patient transitions from pediatric to adult health care and improve self-care management skills, identified as an essential component to transition [15].

The purpose of this project was to evaluate patients and caregivers' feedback of the health care transition experience and evaluate patients' experiences after transitioning to adult hematology care. Goal of study was to determine if interventions are needed post transition to help patients successfully integrate into adult hematology care.

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Methods

This study was conducted at a large urban, pediatric hospital, which provides comprehensive hematology care to over 1500 patients with SCD from birth to 21 years. The Institutional Review Board at institution approved the study and waived informed consent. Demographic information was obtained from the electronic medical records (Table 1). As a part of standard of care for the SCAT clinic, patients and caregivers completed a Health Care Transition Feedback Survey after their last SCAT clinic visit (Table 2). Descriptive statistics were used to assess patient and caregiver experiences after completion of the pediatric SCAT clinic and changing from pediatric to adult hematology healthcare. Chi Square or Fisher's Exact tests were used when comparing categorical variables. Two sample T-tests were used when comparing continuous variables. McNamar-Bowker tests for agreement was utilized to evaluate post-assessment feedback (Table 3).

Demographics		
	Attended SCAT	**Did not Attend SCAT**
	N=57	**N=15**
Age at transition	20.84	20.86
Sex		
Female	34(59.3%)	8(54%)
Male	23(40.6%)	7(47%)
Genotype		
SB+	2(3.5%)	0(0%)
SB0	3(5.2%)	2(13.3%)
SC	6(10.5%)	2(13.3%)
SS	46(80.7%)	11(73.3%)
Currently taking Hydroxyurea	36(63.5%)	8(53%)
Chronic Transfusion	11(19.2%)	1(6.7%)
Average Number of Emergency Visits for pain in the past year	3.42	3.74
Average Number of Hospitalization in the past year	2.38	1.93
Average Number of SCAT Clinic Visits	2.77	0

Table 1: Demographics. Note: Table contains patient demographics. SCAT=Sickle Cell Adolescent and Young Adult Transition Clinic.

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		AYA		Caregiver	
Questions	**Answer**	**N**	**%**	**N**	**%**
How often did your/your child previous health care provider explain things in a way that was easy to understand?	Always	43	81.13	45	91.84
	Usually	6	11.32	2	4.08
	Sometimes	4	7.55	2	4.08
	Never	0	0	0	0
	No Answer	0	0	0	0
How often did your/your child previous health care provider listen carefully to you?	Always	44	83.02	43	87.76
	Usually	5	9.43	2	4.08
	Sometimes	3	5.66	4	8.16
	Never	1	1.89	0	0
	No Answer	0	0	0	0
Did your/your child health care provider respect how your customs or beliefs affects your care?	A lot	46	86.79%	43	87.76
	Some	4	7.55%	4	8.16
	A little	2	3.77	1	2.04
	Not at all	0	0	1	2.04
	No Answer	1	1.89	0	0
Did your/your child previous health care provider discuss with you/ your child or have an office policy that informed you at what age you/ your child may need to change to a new provider who treats mostly adults?	Yes	51	96.23	47	95.92
	No	2	3.77	2	4.08%
	No Answer	0	0	0	0
How often did you/your child schedule your/his/her own appointments with your/ their previous health care provider?	Yes	49	88.37	43	89.58
	No	4	9.3	4	8.33
	Not applicable (if child has significant intellectual disabilities)	0	0	1	2.04
	No Answer	0	0	1	2.04
How often did you/your child schedule your/his/her own appointments with your/ their previous health care provider?	A lot	42	79.25	37	75.1
	Some	5	9.43	10	20.41
	A little	4	7.55	0	0
	Not at all	1	1.89	1	2.04
	No Answer	1	1.89	1	2.04
How often did you/your child schedule your/his/her own appointments with your/ their previous health care provider?	A lot	36	67.92	37	75.51
	Some	10	18.87	10	20.41
	A little	2	3.77	2	4.08
	Not at all	5	9.43	4	8.16
	No Answer	0	0	0	0
How often did you/your child schedule your/his/her own appointments with your/ their previous health care provider?	Never	5	9.43	5	10.2
	Sometimes	11	20.75	16	32.65
	Usually	14	26.42	8	16.33
	Always	23	43.4	20	40.82
	No Answer	0	0	0	0

Table 2: Feedback survey. *The Six Core Elements of Health Care Transition 2.0 Survey.

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Question	Percent of agreement	Test	P value	Conclusion
1	83.30%	Bowker's Symmetry Test	0.1718	Agreement
2	81.30%	Bowker's Symmetry Test	0.3618	Agreement
3	78.70%	Bowker's Symmetry Test	0.8013	Agreement
4	91.60%	McNemar's Test	1	Agreement
5	91.30%	McNemar's Test	1	Agreement
6	63.00%	Bowker's Symmetry Test	0.2482	Agreement
7	74.50%	Bowker's Symmetry Test	0.9698	Agreement
8	60.40%	Bowker's Symmetry Test	0.6934	Agreement
9	85.40%	McNemar's Test	0.7055	Agreement
10	69.60%	McNemar's Test	0.285	Agreement
11	89.40%	McNemar's Test	0.1797	Agreement
12	72.30%	McNemar's Test	0.7815	Agreement

Table 3: Feedback Survey comparison. *The above Null hypothesis is that there is marginal homogeneity in the 2 by 2 table (agreement). Since all p values are greater than 0.05, there is insufficient evidence of disagreement between parents and AYA for each of the question.

Follow-up post-assessment surveys were conducted with the transitioned young adult three months after transition to adult hematology health care, via telephone, to assess their utilization of the adult sickle cell health care system. Post-assessment questionnaires were also conducted with patients who did not attend SCAT clinic (Table 4).

Results

Demographics

Over the past 4 years (2016-2020),57 patients who attended the SCAT Clinic transitioned to adult hematology care and 15 patients transitioned to adult care without attending the clinic. The average age of transition was 20.84 for those who attended SCAT clinic, and 20.86 for those who did not attend. Of the patients who attended the SCAT clinic 34 (59%) were female and 23(41%) were male. Most of the patients seen in the SCAT clinic had Hb SS disease (46, 81%), 6(10.5%) Had SC, 3(5%) had SBo and 2(3.5%) had SB+ Thalassemia. AYA not seen in the clinic were Hb SS (11,73.3%), Hb SC (2,13.3%) and SBO (2, 13.3%). Those seen in the clinic who were taking hydroxyurea (36,64%) differed only slightly from those who were not seen in the clinic (8,53%). Eleven (19%) of the patients who attended the SCAT clinic were receiving

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chronic transfusions and only 1 patient who did not attend received chronic transfusion. The AYA who attend the SCAT clinic had an average of 3.42 emergency visits for pain in the past year and those who did not attend clinic had 3.74 emergency visits for pain. (Table 1)

	Attended SCAT		Did Not Attend SCAT
		N=53	N=12
Do you feel you were adequately prepared to transfer?	Yes	46(86.8%)	10(83.3%)
	No	5(9.4%)	2(1.6%)
	No Answer	2(3.7%)	0(0.0%)
Do you feel you were adequately prepared to transfer?	Yes	46(86.8%)	10(83.3%)
	No	5(9.4%)	2(16%)
	No Answer	2(5.6%)	0(0.00%)
Have you seen an adult provider since you left Children's?	No	4(7.5%)	2(16.7%)
	Yes	47(88.6%)	10(83.3%)
	No Answer	2(3.8%)	0(0.00%)
Are you satisfied with the care you've received?	No	3(5.6%)	3(25%)
	Yes	45(84.9%)	9(75%)
	No Answer	5(9.4%)	0(0.0%)
Are you on Hydroxyurea?	No	21(39.6%)	7(58.3%)
	Yes	32(41.6%)	5(41.6%)
Do you take as prescribed?	No	1(3.1%)	0(0.0%)
	Yes	30(93.8%)	5(100%)
	No Answer	2(6.3%)	0(0.0%)
Were you on Chronic Transfusion therapy at Children's?	No	37(69.8%)	9(75.0%)
	Yes	14(26%)	2(16.7%)
	No Answer	2(3.8%)	1(8.3%)
Are you currently on Transfusion Therapy?	No	39(78%)	10(83.3%)
	Yes	14(26.4%)	1(8.3%)
	No Answer	0(0.0%)	1(8.3%)
Have you been hospitalized since transferring to adult care?	No	29(50.0%)	8(66.7%)
	Yes	22(41.5%)	3(25.0%)
	No Answer	2(3.8%)	1(8.3%)

Table 4: Post Assessment Survey.

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How could your child's health care provider have made the move to an adult health care provider better for you and your child?
There was nothing more CNMC could have done. Transition went smoothly. "You all did great". Very prepared (n=30)
You help her to do things like make appointments, know medications.
Transition was very easy
The transition clinic was an excellent resource and beneficial to my son.
Have her start going to the adult provider 1-2 more times before transition.
Before they transition to the adult provider, it would have been helpful to have a representative from the new site present at CNH to make the transition seamless.
Would like to stay at Children's, extend the age at Children's to 26.
I think that the transition to adult care was well explained.
Overall done well. Medical Records all sent to Adult Provider.
Made more specific where she could go. Problems with who would take her insurance. Too much unplanned.
Overall Done well. Medical Records all sent to adult provider. Maybe 1 year before they transfer and their records.
Not the same care at adult care provider.
Give him a better referral for a better doctor.
Not really. Be at children's forever.
The support my daughter received was very helpful. The pandemic slowed some things down but with the help of the transition team, my daughter got a lot of the questions she asked answered to transition.
They could have sent more of her medical information to the adult provider before transitioning, but good job
More information on insurance changes as an adult. Social Security switched him to Medicaid.
Wasn't aware of need for extra help after switching insurance
Transition Clinic was very helpful. Researchers were reluctant to leave. Emergency doesn't fast track adults like Children's.

Table 5: Caregivers Responses.

Feedback survey

Fifty-three (93%) of AYA who attended the SCAT clinic completed the health care transition feedback survey for youth and 49 caregiver dyads completed the survey (Table 2). Forty-three (81%) AYA and 45 (92%) ($p>0.05$) caregivers responded that their previous health care provider always explains things in a way that was easy to understand. Forty-four (83%) AYA and 43(88%) caregivers responded that their previous health care provider always listened carefully to them during their appointments. Most AYA (46, 87%) felt that their health care provider respected their beliefs and customs and 43 (88%) caregivers responded similarly. Fifty-one (96%) AYA and 47(96%) caregivers felt their previous health care provider discussed with them the office policy that informed them at what age the AYA may need to change to a new provider who treats mostly adults. Forty-nine (88%) AYA responded that

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the provider talked with the without a caregiver present. Out of the 48 caregivers who responded, 43(90%) reported that the provider talked with the AYA without them in the room. Most (42,79%) AYA reported their previous health care provider actively work with them to gain skills to manage their own health and health care, which was comparable to how the caregivers responded (37,75%). Thirty-six (68%) AYA responded that the providers actively work with them a lot to think about the future, while 5(9%) responded some. Only 23(43%) of the AYA always scheduled their own appointments, 14 (26%) usually did and 11(21%) sometimes schedule their own appointments. with their previous health care provider. This was analogous to the 20(41%) caregivers who responded that the AYA always scheduled their own appointments and 8(16%) respond usually and 16(33%) responded sometimes. Comparably, 5(9%) AYA and 5(10%) caregivers responded that the AYA never made their own appointments. Both the AYA (47,89%) and caregivers (45,92%) agreed that their previous provider explained the legal changes in privacy, decision-making, and consent that take place at age AYA is 18. Most, 41(89%) AYA and 40(96%) caregivers also responded that their previous health care provider actively worked with them to create a written plan to meet their health goals and needs. Twelve (23%) AYA responded that this did not happen, and 7(14%) caregivers agreed this did not happen as well. Forty-eight (77%) AYA and 47(96%) caregivers responded that the health care provider created and shared the patient's medical summary with the AYA. Finally, 39(76%) AYA and 35(71%) caregivers responded that that their previous health care provider provided them with information about community resources. All the questions that were answered by the AYA and caregivers when compared showed agreement ($p \geq 0.005$) (Table 3). There were four questions that only the caregivers were asked about the transition process. Forty-four (90%) caregivers knew how their child would be insured as he/she became an adult. Forty-three (88%) reported the health care provider assisted in identifying a new adult provider for the AYA to transfer to. Thirty-five (71%) caregivers responded that the adult health care provider had the medical records before the first visit and 5(10%) didn't know. At least half (25,51%) of caregivers felt that their AYA was very prepared to change to the adult health care provider, 19(39%) felt the AYA were somewhat prepared and 2(4%) felt the AYA were not prepared.

Caregiver responses

Caregivers provided feedback on how the SCAT clinic team could have improved the transition process for their AYA (Table 5). Most felt the transition went smoothly and the support the AYA received was helpful. One caregiver felt seeing the adult provider more than once before transition would be helpful, a few had insurance concerns, and some would prefer not to leave pediatric care.

Post assessment survey

Three months after AYA transitioned to adult care they were called for follow up and 65 AYA responded to the post-assessment survey. Those who did not attend SCAT clinic were also called. (Table 4). Forty-six (87%) AYA who attend SCAT felt adequately prepared to transfer, 47(89%) AYA had seen their adult provider since leaving their

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pediatric provider, and 45(85%) were satisfied with the care they were receiving. Ten out of the twelve AYA who responded and did not attend SCAT had seen their adult provider and felt adequately prepared and 9(75%) were satisfied with their care. Of note, the SCAT clinic did help these AYA find an adult provider and sent their medical records before the first visit. Only 32(42%) patients who were seen in SCAT clinic were continuing to take hydroxyurea, and 5(42%) of those who were not seen in SCAT clinic were taking Hydroxyurea. Fourteen (26%) AYA were on chronic transfusion in Pediatrics and were all still on transfusion after transitioning to adult care, compared to the 2 AYA on transfusion who had not been seen in SCAT clinic and 1 was still on chronic transfusion. Of the 51 respondents, 22(42%) AYA who were seen in SCAT clinic had been hospitalized since leaving CNH and 3(25%) who had not been seen in SCAT clinic had been hospitalized.

Discussion

The literature supports the need for educational intervention to improve transition skills in adolescents with SCD [16]. There are positive correlations between self-efficacy during transition and positive patient outcomes in the SCD population [17]. Study demonstrates that the SCAT clinic provided education and promoted self-efficacy for AYA to manage their own health care.

Overall, most participants in study reported a positive transition experience transitioning to adult care. However, there is room for improvement in patient preparedness earlier in the transition process in hopes to lessen fear and anxiety related to leaving their pediatric facility. We recognize the need to start the transition process earlier than the age of 18, so that AYA can begin early preparation to self-manage. Studies have shown that discussion of transition to adult care should start as early as 13 years of age. See the need to share more community services to provide additional support during and after transition to adult health care. In the process of starting transition preparation at the age of 12. Most caregivers felt their AYA were ready, however, the timing of transition to adult care should be determined in part by both the AYA's and parent's perceived readiness [18].

Also, essential for a successful transition program is the follow up experience after they are in the adult hematology system. Nearly 90% of young adults reported establishing an adult hematology home. Research showed that transition may be improved if pediatric hematology centers assist and verify adult provider contact [19]. Program assisted in identifying an adult hematologist and provided a comprehensive medical summary for the adult provider, regardless of whether they attend the SCAT clinic. Due to the ongoing communication between the AYA in Program after transition were able to support them during a crucial time to prevent lost to follow up. This was also instituted regardless of SCAT attendance. Although not captured in data, there were AYA who did not return to their adult provider after the first clinic visit. During program's follow up, able to identify them and assist to reconnect them with their adult provider or help them gain access to another adult hematology provider. There was outreach to the adult hematologist if they were having issues in establishing continuity of care for the AYA. Feedback from caregivers

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is an essential part of the transition process. Most caregivers were pleased with the process and felt their AYA were well prepared. However, the close attention must be pay to other concerns, though few, to continue to improve the transition experience and hopefully ensure the AYA remains connected to their adult provider. Having the caregiver present in a least one SCAT visit can help to address concerns surrounding insurance issues and whether a medical summary was sent to the adult provider prior to the visit, which is always done but caregivers may not be aware of this practice.

Implications for practice

Transitioning from pediatric to adult healthcare can be a stressful time for both AYA and caregiver. In addition to assessing transition readiness and providing disease education, there is a need to determine the effectiveness of the transition program from the AYA and caregiver's perspective. Including the caregiver in the first transition session can do much to educate both about the process, address any concerns or misconceptions and get buy in from both AYA and caregiver. It may also be a good idea to include the caregiver at the last transition clinic visit as well, to summarize the content learned, review transition plans and address any lingering concerns. Having the AYA visit the adult provider prior to transition has been well received by all parties and has proven helpful in allaying uncertainties, anxieties, and fears. This should also be a consideration, as feedback results from caregiver responses suggested that transition patients visit their identified adult hematology facility at least twice before leaving pediatric care. More than one visit with the adult provider may allow more time for patients to become familiar with the new provider and facility before transitioning and ensure their comfort with the provider. The transition clinic may also be enhanced by partnering more with neighboring adult hospitals to ensure a warm patient hand off. Developing a "transition day" event and inviting adult hematology providers to speak at the SCAT clinic and discuss services offered, as well as allowing patients to become familiar with the adult provider, may reduce anxiety and fear with attending their first adult appointment. Moreover, telemedicine has emerged and can also play a role in bridging the gap, allowing the pediatric provider to attend the patient's first adult hematology visit remotely. For patients who have significant disease severity, the use of a telemedicine visit with the patient, pediatric provider, and adult hematologists can ensure effective communication between teams. A combined pediatric and adult clinic visit should also be considered. More research is needed in these areas.

There were limitations to this study. It was conducted at a single site, which may limit generalizability of the findings. The generalizability is also limited by the small sample size in the group that did not attend SCAT clinic (n=15). Due to mix matched groups, statistical significance could not be determined between those who attend SCAT and those who did not. The Post Assessment Survey was created by the SCD team and lacks validation. Although most AYA and caregivers completed the surveys, some did not, therefore do not have their input. Findings were also limited by measurements

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of self-report, which can lead to bias in reporting.

Successful transition from pediatric to adult heath care depends on many factors. Incorporating a team approach to the process, establishing a relationship with the new adult hematology provider, and individualizing the transition program to fit the unique needs of the AYA is important for a successful transition program as the time of transition is a time of increased morbidity and mortality [20].

The results of this findings suggest that most AYA who attended SCAT clinic felt well prepared for the transfer to adult hematologic care. Transition educational modules and material were presented in an age-appropriate manner, as the majority of AYA stated their pediatric health care provider explained things in a way that was easy to understand.

Patients who attended SCAT clinic also had fewer emergency room visits for sickle cell pain than those who did not attend. This finding suggests and is confirmed by the literature that disease severity and multiple hospitalizations may lead to poorer transition outcomes if patients are unable to receive transition education and support due to their ongoing acute medical needs [8,21]. Follow up after transition has proven to be essential and cannot be overemphasized. Further research is needed in follow up to determine transition programs' effectiveness and AYA survival rates. Researchers found that those who did not attend SCAT clinic also did well, possibly due to SCD team identifying an adult provider and ensuring the provider had their medical summary and providing follow up assessments. Starting the transition process earlier can also help AYA begin the process of self-management sooner and hopefully by the time they reach adulthood they are not afraid of the process. Not captured in the data is the graduation ceremony provided to AYA after SCAT clinic completion. They are presented with a certificate of graduation and ring the 'Victory Bell", signifying SCAT completion. This helps AYA and caregivers to view transition as another developmental milestone, not a "kicking out of the program" and hopefully will help them welcome entry into adulthood.

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