PATIENT EXPERIENCES WITH HEALTH CARE TRANSITION IN YOUNG ADULTS WITH SICKLE CELL DISEASE

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INTRODUCTION

- Sickle cell disease (SCD) is a rare disorder requiring consistent care.[1] The transition period from pediatric to adult care is a vulnerable and high-risk time for individuals with SCD with acute care utilization–emergency department visits, hospitalizations, and rehospitalizations–highest for those aged 18 to 30 years old.[2,3]
- Research shows that patient experience is positively associated with improved outcomes such as care continuity, utilization of preventive therapy, and medication adherence.[4,5]
- Thus, understanding SCD care transition experiences is critical, especially where health-related stigma and provider judgement associated with the frequent use of strong opioids for episodic vaso-occlusive pain crises make it challenging to attain optimal adult-provider relationships.[6]
- This study used **patient-reported experience measures (PREMs)** which are useful in understanding what patients observe directly for which patients are usually the best source.[7]

OBJECTIVE

This study assessed patient experiences among young adults (YAs) with SCD **after transfer to adult care.**

METHODS

Study design and data source: Prospective, cross-sectional, quantitative research design using a one-time anonymous online survey.

Inclusion criteria:

- SCD diagnosis (self-reported)
- Young adults aged 18-30 years
- At least one SCD-related adult health care provider visit after transfer to adult care.

Study outcomes and analysis

Outcomes:

- Patient-reported experiences after transfer to adult care using the Picker Transition Survey[8] with the following domains with each item assessed by 0=no problem; 1= problem:
  - Access to information, advice, and support
  - Transfer planning and involvement
  - Experiences with inpatient care
  - Experiences with outpatient clinic appointments
  - Disease self-management
- Overall quality of care of young adults with SCD after they transfer to adult care, rated on a scale of 0 (worst) to 10 (best).

Analyses: Descriptive statistics

RESULTS

Patient Characteristics (N=100)

- Mean [SD] age = 20.4 [2.8]
- Female (85.0%); Black (92.0%)
- Some college or higher degrees (71.0%)
- Unemployed (40.0%) or employed part-time (28.0%)
- HbSS genotype (52.0%)
- ≥6 ED or hospital visits (20.0%)

RESULTS

The domain with the highest overall mean problem score (0.5 ± 0.3) was Transfer Planning and Involvement, indicating overall that 50% of respondents reported problems within that domain.

Table 1. Mean and Frequency Distribution of Problem Scores for Patient Experience Domains (N=100)

Items	Mean[a] ± SD	Frequency Distribution of Response Choices N (%)	
		No Problem (0)	Problem (1)
Access to Information, Advice, and Support (N=5 Items)			
Before your transfer to adult services, did you speak to a healthcare professional about the move of your care to adult services?	0.2 ± 0.4	76 (76.0)	24 (24.0)
Did this person give you the advice that you needed about the transfer of your care?	0.5 ± 0.5	47 (47.0)	53 (53.0)
Did this person answer your questions or worries about the transfer of your care?	0.5 ± 0.5	54 (54.0)	46 (46.0)
Did you meet other young people who were transferring to adult services or had recently transferred?	0.5 ± 0.5	49 (49.0)	51 (51.0)
Would a social networking page or online website have been useful, for contacting other young people who were moving to adult services, for information and advice?	0.4 ± 0.5	59 (59.0)	41 (41.0)
Overall Scale Mean	**0.4 ± 0.3**		
Transfer Planning and Involvement (N=10 Items)			
Were you (rather than your family) given enough information about what would happen during your move to adult services?	0.6 ± 0.5	45 (45.0)	55 (55.0)
Were you involved in planning your transfer from pediatric (child) to adult services?	0.3 ± 0.5	69 (69.0)	31 (31.0)
Were your family or caregivers involved in planning your transfer from pediatric (child) to adult services?	0.3 ± 0.4	73 (73.0)	27 (27.0)
Were you involved in decisions about when your transfer would take place, so that timings were suitable for you?	0.6 ± 0.5	39 (39.0)	**61 (61.0)**
Did you or your family have written information about your planned transfer to adult services?	0.6 ± 0.5	42 (42.0)	58 (58.0)
Overall, did you know what the plan was for transferring your care to adult services?	0.7 ± 0.5	34 (34.0)	**66 (66.0)**
Before your care moved to adult services, were you able to visit the new place that would be providing your healthcare?	0.4 ± 0.5	63 (63.0)	37 (37.0)
Before your care moved to adult services, were you able to meet the new people who would be providing your healthcare?	0.5 ± 0.5	48 (48.0)	52 (52.0)
Before you transferred, did you have an appointment attended by both your pediatric (child) and adult healthcare providers?	0.5 ± 0.5	46 (46.0)	54 (54.0)
Overall, did you feel prepared and ready to move to adult services?	0.7 ± 0.5	35 (35.0)	**65 (65.0)**
Overall Scale Mean	**0.5 ± 0.3**		
Inpatient Care (N=2 Items)			
Did you feel comfortable and at ease staying on this hospital floor/wing?	0.4 ± 0.5	60 (60.0)	40 (40.0)
Was the floor/wing well designed for your age group?	0.4 ± 0.5	60 (60.0)	40 (40.0)
Overall Scale Mean	**0.4 ± 0.4**		
Outpatient Care (N=7 Items)			
Do you see the same doctors or healthcare professionals at your clinic appointments?	0.3 ± 0.4	75 (75.0)	25 (25.0)
Are your healthcare appointments at a suitable time that do not get in the way of school, college or work?	0.5 ± 0.5	49 (49.0)	51 (51.0)
At appointments, can you choose to have your parent or caregiver attend with you?	0.2 ± 0.4	81 (81.0)	19 (19.0)
At appointments, are you given the choice to be seen without your parent or caregiver?	0.2 ± 0.4	83 (83.0)	17 (17.0)
Do healthcare staff have enough information about your condition, treatment and medical history?	0.3 ± 0.4	74 (74.0)	26 (26.0)
Do healthcare staff treat you as an individual and listen to your needs?	0.4 ± 0.5	64 (64.0)	36 (36.0)
Do you have confidence and trust in the people that provide your care?	0.5 ± 0.5	54 (54.0)	46 (46.0)
Overall Scale Mean	**0.3 ± 0.3**		
Disease Self-Management (N=8 Items)			
Are you involved enough in decisions about your condition and treatment options?	0.2 ± 0.4	76 (76.0)	24 (24.0)
Do you (rather than your family) know what to do if your condition gets worse or if there is a medical emergency?	0.2 ± 0.4	79 (79.0)	21 (21.0)
Do you have a written summary about your condition (including details of any treatment, if necessary)?	0.4 ± 0.5	58 (58.0)	42 (42.0)
Is it easy for you (rather than your parent or caregiver) to contact your healthcare provider for advice?	0.4 ± 0.5	58 (58.0)	42 (42.0)
Have you been given enough information about how to manage your condition by yourself?	0.2 ± 0.4	82 (82.0)	18 (18.0)
Do you feel confident in managing your own condition?	0.4 ± 0.5	65 (65.0)	35 (35.0)
Do healthcare staff offer you enough information about other types of support (such as career counsellors, support at school and benefit advisors)?	0.4 ± 0.5	57 (57.0)	43 (43.0)
If needed, do healthcare staff give enough information to others (such as school, college or place of work) about your condition and how it affects you?	0.5 ± 0.5	54 (54.0)	46 (46.0)
Overall Scale Mean	**0.3 ± 0.3**		

[a]Overall scale mean = sum of proportion of problems within that domain / number of domain items; Green=low problem scores ≤0.3 Orange=high problem scores ≥0.5

The mean score for overall quality-of-care experiences was 6.8±2.4, indicating suboptimal care quality. 50% of respondents reported ratings <8.

Figure 1. Overall Quality of Care Experiences (N=100)

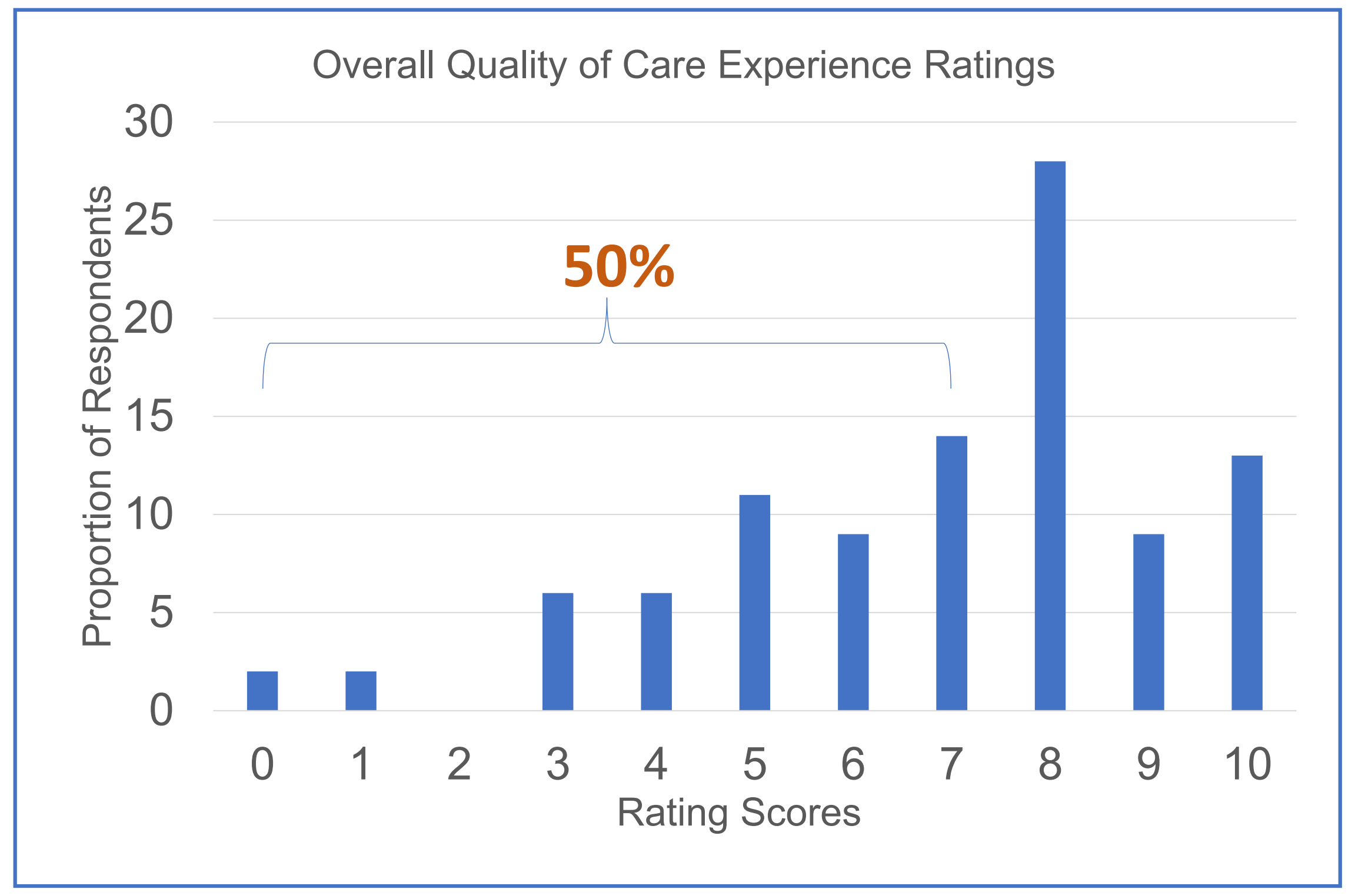

Figure 2. Word Cloud of Free Text Responses for Areas for Improvement in Care Delivery

- **Main Themes:** lack of empathetic providers, poor treatment/stigma, poor provider collaboration, long wait times in the emergency department
- Based on the frequency distributions across all five domains, **>60% of respondents indicated problems with the following questions**:
  - *Were you involved in decisions about when your transfer would take place, so that timings were suitable for you (transfer planning and involvement)?*
  - *Overall, did you know what the plan was for transferring your care to adult services (transfer planning and involvement)?*
  - *Overall, did you feel prepared and ready to move to adult services (transfer planning and involvement)?*
  - ➢ These indicate areas for improvement in planning, involvement, and preparation for transfer to adult care.
- The **lowest overall mean scores** were reported for the Outpatient care (0.3 ± 0.3) and Disease self-management (0.3 ± 0.3) domains, indicating fewer problems (overall 30% of respondents reported problems) within those domains.

DISCUSSION

- Our work is important in including the voice of YAs **post-transfer** to the existing literature, which has primarily focused on the pre-transfer and transfer periods.
- As reflected in our study, many YAs report problems with involvement in planning their transition and insufficient preparation for transfer to adult care.
- Even after transfer to adult care, most YAs feel unprepared to integrate into adult care.
- Assessments of transition preparation and readiness should be included in transition programs and revisited over time, to develop individualized interventions for YAs during and after transfer to adult care.

LIMITATIONS

- Selection bias as recruitment was primarily through Rare Patient Voice, which may have led to a study outcome that is not representative of the general SCD population.
- Recall bias may also be a limitation as participants may have transferred several months or years prior to survey administration.
- Sample size of 100 may have been a limitation, but it was within the range of other surveys involving SCD.

CONCLUSION

- **Suboptimal overall patient experiences of YAs with SCD after transfer to adult care** highlight areas for quality improvement in the transition process.
- The high proportion of respondents who reported problems with **transfer planning and involvement** indicates the impact of transition preparation and planning on quality of care. Interventions targeted towards improving patient experiences with transfer planning are recommended in this population.

REFERENCES

1. Hamideh D, Alvarez O. Sickle cell disease related mortality in the United States (1999-2009). Pediatr Blood Cancer. 2013;60:1482-1486. doi:10.1002/pbc.24557
2. Blinder MA, Vekeman F, Sasane M, Trahey A, Paley C, Duh MS. Age-related treatment patterns in sickle cell disease patients and the associated sickle cell complications and healthcare costs. Pediatr Blood Cancer. 2013;60(5):828-835. doi:10.1002/PBC.24459
3. Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. JAMA. 2010;303(13):1288-1294. doi:10.1001/JAMA.2010.378
4. Black N, Jenkinson C. Measuring patients' experiences and outcomes. BMJ. 2009;339. doi:10.1136/bmj.b2495
5. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. 2013;3:1570. doi:10.1136/bmjopen-2012
6. Jenerette CM, Brewer C. Health-related stigma in young adults with sickle cell disease. J Natl Med Assoc. 2010;102(11):1050-1055. doi:10.1016/S0027-9684(15)30732-X
7. Matthew P, Manary MSE, Boulding W, Staelin R, Glickman SW. The patient experience and health outcomes. New England Journal of Medicine. 2013;368(3):201-203. doi:10.1056/nejmp1213134
8. Picker Group. Children and young people patient toolkits. Accessed July 26, 2024. https://picker.org/how-we-can-help/care-experience-tools/licensable-toolkits-2/children-and-young-people-patient-toolkits/#collapse10070

We would like to thank Rare Patient Voice for supporting data collection efforts for this project.