Identification of Knowledge Gaps in Adolescents with Sickle Cell Disease

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Background

- Transition from pediatric to adult health can be a time of increased morbidity and mortality for those with sickle cell disease (SCD).[2,8]
- Disease specific knowledge is only one aspect of transition planning and preparation.[3]
- Adolescents want to know more about symptoms, symptom management, and triggers/prevention.[4,7]
- Young adults who have transitioned recommend educating oneself, becoming autonomous, and taking responsibility for one's SCD.[4]
- Providers have also indicated the need for adolescents and young adults to have a better understanding of complications and how to practice good health maintenance behaviors.[5]
- Much of the SCD education has shown improvements in knowledge and some sustained over time.[1,6]
- Improving adolescents' SCD knowledge base may improve confidence and self-management skills.[1]

Methods

- Setting: outpatient hematology clinic at the Children's Hospital at Montefiore, Bronx, NY
- Adolescents aged 12-17 years with any SCD genotype
- **Primary aim** was to assess SCD knowledge in six domains via an online anonymous survey:
  - Genetics
  - Pathophysiology
  - Triggers/prevention
  - Symptoms/management
  - Complications
  - Treatment
- **Secondary aim** was to create tailored education based on the results of the online survey.

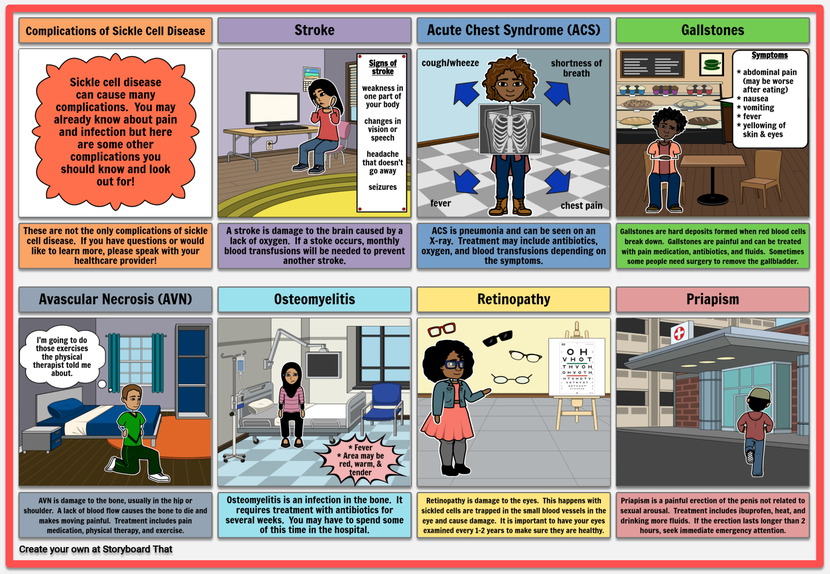
Results

- ~10% survey response (17/178 participants)
- All participants completed the full survey, no missed questions
- Mean score for all adolescents was 75%
- Range of scores between 44%-94%
- Domains with weakest score:
  - **Complications 49%**
  - **Treatment 55%**

Mean Scores by Age in Each SCD Domain

	Genetics	Patho-physiology	Triggers/ Prevention	Symptoms/ Management	Complications	Treatment
All ages	88%	88%	82%	86%	**49%**	**55%**
12 years (n=1)	67%	100%	100%	67%	33%	100%
13 years (n=4)	83%	83%	75%	83%	42%	25%
14 years (n=3)	100%	89%	89%	78%	33%	78%
15 years (n=3)	100%	100%	89%	100%	78%	67%
16 years (n=4)	83%	83%	83%	92%	75%	50%
17 years (n=2)	83%	83%	67%	84%	0%	50%

Targeted education provided via a storyboard to be distributed at clinic appointments



Implications

- The results of this project reflect the literature: Adolescents are lacking basic knowledge about some aspects of SCD.
- Identification of knowledge gaps provided direction for tailored education in the areas of disease complications and treatment.
- The most effective media for education and the setting in which to deliver it has yet to be determined but…
- Printed material will provide a starting point for teaching and discussions during clinic appointments.
- Future research should focus on the effectiveness of such education and what impact it may have on the transition planning process and the patients' successful transition to adult health care.

Conclusion

Lack of disease knowledge and self-management skills have been identified as one of the barriers to a successful transition of care. Education focused on current knowledge gaps may assist in building a strong foundation of disease knowledge in these adolescents. Providing this education early in the transition process may improve their understanding of SCD and an improved knowledge base can promote better self-management skills and may enhance the transition process.

References

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