AN EFFECTIVE DIGITAL HEALTH EDUCATION TOOL THAT IMPROVES LOWER RATES OF HEALTH LITERACY REPORTED AMONGST YOUNG PEOPLE LIVING WITH SICKLE CELL DISEASE

Daniel Dexter, Bethan Williams, Jumoke Okikiolu, Honor Nicholl, Jack Kerwin, Joshua Kader, Anvind Nagra, Helen Oram, NHS; Lewisham NHS Foundation Trust; Guys and St Thomas NHS Foundation Trust; Kings’ College London; University Hospital Southampton

10.1136/bmjpo-2022-RCPCH.68

Objectives Developing health literacy is a cornerstone of transitional care (TC) programs for young people (YP) living with long-term conditions. Lower rates of health literacy correspond with a decreased likelihood of appropriate, effective healthcare seeking behaviour and worse health outcomes. UK data has found that amongst people living with sickle cell disease (SCD), young adults have the highest rate of emergency hospital admission which are associated with increased risk of mortality.

Our objective was to comparatively assess health literacy and transition preparedness of YP with SCD at different timepoints of the TC journey with the experiences of YP living with other long-term conditions (type 1 diabetes & epilepsy). We also assessed the efficacy of a bespoke, digital health education tool at improving health literacy.

Methods Ready, Steady, Go (RSG) is a NICE endorsed TC program that addresses a full range of transition parameters at specific timepoints of the patient journey.

147 YP living with long-term conditions (SCD, epilepsy and diabetes) returned age-appropriate RSG questionnaires filled at different timepoints during their transition process. 4451 unique responses were collected to questions addressing the following areas:

- Knowledge and understanding of their condition
- Treatments
- The healthcare team
- Confident self-advocacy
- Adolescent health issues
- Educational, independence and vocational domains
- Psychosocial issues
- Concept of TC.

Our clinical experience using the RSG questionnaires had shown us that unanswered questions are informative indicators of ‘help’ in areas of need. We thus elected to include questions without a response a negative indicator in our evaluation.

In response to our data, a bespoke, animated SCD transition education package was developed (figure D) and offered to YP with SCD

Results Data analysis found that at all stages of transition, YP with SCD (n=42) were less likely to report confidence in transition parameters compared to YP living with other conditions (n=105) (figure A). The difference was most pronounced in domains assessing understanding and self-administration of medication (79.9% SCD vs 89.9% other conditions). There were low reported rates of requesting and collection of repeat prescriptions (13.9% SCD vs 47.4%) (figure B). YP with SCD reported lower rates of resilience in managing bullying (26.1% vs 3.5%) and were less likely ‘feel happy with life’ (73.8% vs 86.4%) (figure C). YP with SCD were less confident in disclosing their condition to others (36.8% vs 11.8%). Regarding social support, 24% of respondents with SCD said they did not ‘know someone I can talk to when I feel sad or fed up’ vs 8.3% of YP with diabetes and were less likely to see friends outside of school.

The digital SCD educational tool was effective, demonstrating an uplift in confidence and understanding parameters from 47.8% to 84.6% after YP used the resource (figure E).

Conclusions Our data demonstrates a significant health literacy gap in YP with SCD transitioning to adult care that is larger than that seen in YP living with other long-term conditions. Targeted digital health education interventions are effective at helping to boost health literacy, engagement and confidence and should be incorporated into TC programming.