

# Exploring Health-Related Quality of Life and Health Behaviours in Children with Sickle Cell Disease



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# Introduction Part I: Health-Related Quality of Life (HRQL) and Sickle Cell Disease (SCD)?

QoL is defined by the World Health Organization (e.g. WHO-QOL Group, 1995) as *“the ‘individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”*.



## Ascertaining HRQL

- HRQL is often obtained using questionnaires where children report having a lower perceived HRQL compared to their healthy peers (e.g. Panepinto & Bonner, 2012a).
- There appears to be limited HRQL research involving qualitative methodology in this population besides e.g. Panepinto et al., 2012b; Thomas, & Taylor 2002.
- Drawing and semi-structured interviews is the most prevalent method of engaging young children (e.g. Driessnack, & Furukawa, 2012).



## Introduction Part II: Health Behaviours

Clinical manifestations;  
psychosocial factors;  
impaired HRQL.



Health behaviours  
e.g. high protein diet;  
hydration;  
avoiding excessive  
exercise.



## Research Aim

- To explore the HRQL and health behaviours of children with SCD, including any differences between their current and ideal self, compared to that of their healthy siblings.

## Method

- Semi structured interviews facilitated by children's drawings of their perceived and ideal selves;
- 18 children with SCD ( $M=8.56$ ,  $SD= 2.18$ ) & 14 healthy siblings ( $M=8.89$ ,  $SD=2.49$ ) aged 5 to 12 years;
- Preliminary findings from thematic analysis of the data.



# Overview of the Data

## Three of the emerging themes:

- Discrepancy between current and ideal selves
- Influences on health behaviours
- Awareness and Secrecy



## Discrepancy between current and ideal selves: part I

**Current, a child with SCD:** “Because of my condition and my bones in my back and my legs, not like other people’s bones. So I can’t do cartwheels.” *(Jamila, 6 year’s old)*

“Look, my friends arms are up, really really high. I can’t do that...My mum tells me not to do anything dangerous. So nothing fun!” *(David, 9 year’s old)*

**Ideal, a child with SCD:** “I’m feeling good because I’m running and I can’t really run and sometimes I go slow, when I’m with my friends.” *(Leon, 5 year’s old)*

“sickle’s part of me” *(Jay, 12 year’s old)*



## Discrepancy between current and ideal selves: part II

**Current, a healthy sibling:** “Because my little brother can’t play football outside because he has Sickle Cell and because he can’t be in the cold and because I have to be with my mum or dad if I’m outside and they’re busy working, cleaning, cooking and so yeah.” *(John, 12 years old)*

**Ideal, a healthy sibling:** “Well I would like to um go on more trips, I mean we do go but maybe more trips but with [my sister] and mum as well not just me....Anywhere! Just trips outside to any place really, just outside because we can be in the house a lot...” *(Ibrahim, 10 years old)*



## Influences on health behaviours

**A healthy sibling:** “Mum and dad tell me to do PE because it makes me healthy and it makes me grow up more.” (*Faith, 7 years old*)

**A child with SCD:** “I have to drink water, I do have to drink water, but when other people ask for water she [the teacher] don't give it to them, but when I ask for it she does.” (*Caitlin, 9 years old*)



## Awareness and Secrecy

**A child with SCD:** “No, I want to be like my friends and I don’t want people being mean to me...Because I’m different and they can get my condition...Eh, um, mum said, um can’t they?”  
*(Mark, 7 year’s old)*

**A healthy sibling:** “Yeah yeah it was they thought I just wanted attention well I do! Because [my brother] always gets it whenever he has a crisis, ohh it’s such a big deal we have to run to the hospital and we have to do this and it drags on and on and like he does a one to ten scale and first his pain is ten and after a few days it’s still a ten when it’s actually a five because I know him!” *(Elizabeth, 12 year’s old)*



## Conclusions

- Greater discrepancy between the perceived and ideal selves of healthy siblings compared to children with SCD in some areas of HRQL; i.e. in the social domain, but not in the physical domain of HRQL.
- Parents are overprotective of children with SCD in relation to the activities they do, so a more balanced approach may help them.
- Parents need more advice about how health behaviours can affect SCD, which could then be passed on to schools.



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**ALL PARENTS AND PATIENTS ATTENDING THE EVELINA  
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**Thank you.**

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