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Biographic disruption in families of a child with Short Bowel Syndrome: A sibling perspective

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Background

- This unique study explored how being a sibling of a child with Short Bowel Syndrome (SBS) impacts an entire family and the resultant biographic disruption (social experience of living with a chronic illness).
- SBS is a serious and rare condition affecting about 2 per million in the EU, that is not often researched from a social perspective.
- SBS occurs following extensive removal of the small bowel, leading to mal-absorption and intestinal failure with life-changing consequences, and typically long hospital stays.

Method

- The study used a mixed-methods design comprising diary keeping and interviews with parents and siblings over 11yrs. For children between 4-11yrs, electronic tablets, hosting the ‘Digitising Children’s Data Collection’ (DCDC) application were used to record children’s answers digitally from four complementary methods.
- Framework analysis was used to analyse the interview data.
- Data from the DCDC application was analysed in multiple ways: thematic analysis was used for voice files, pictures, and drawings, while basic frequency calculations were carried out on the questionnaire data.

Results

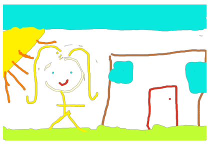
- 6 families participated fully, which included 5 siblings, 2 older and 3 younger siblings.
- Siblings had varying degrees of understanding about SBS, and reported that it impacted on them more as they got older and recognised the biographic disruption to a larger extent (e.g. missing out on activities) or caring responsibility (e.g. being aware of medication needed).
- The impact was also changeable depending on how old the child with SBS was, or the need for medical appointments.

  > “*we have to take special medication with us when we go anywhere*” and “*we have to make sure he is ok to do things*”;

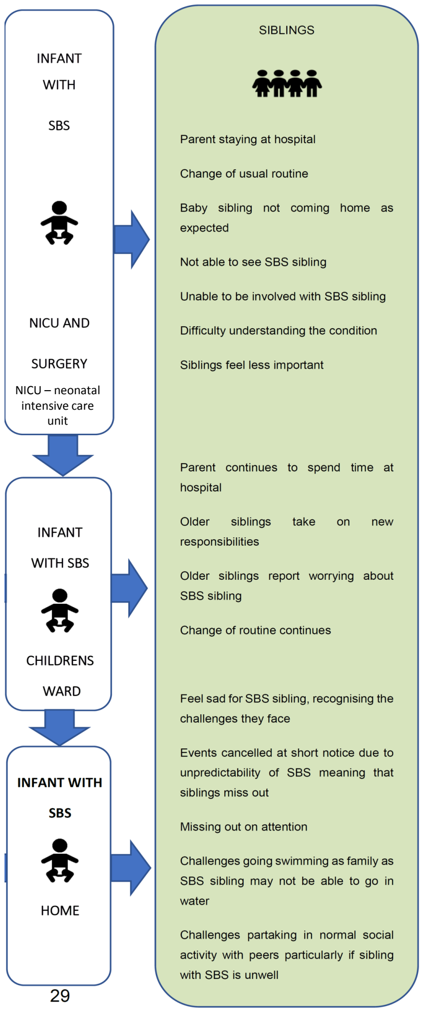
- Siblings also had a wider awareness, e.g. the impact on their parents, and their wish for things that would help themselves or their sibling. Whilst they all talked favourably about their sibling, even the younger siblings were aware of some of the impact of SBS on the family.

  > “*by making him not have that problem with him*”
  > “*his bum work*”
  > “*There is a massive upheaval. Your life does change and I think it can make you a little bit self centred but not. When my mom was in hospital I remember feeling…I feel like I’m going to cry…I remember feeling like, not as important*”.

- For example on a number of occasions one of the siblings talked about wanting to go swimming more (“*like when we go swimming we have to plan it first because he needs a double nappy on him so*..”), play outside or have less responsibility (when they were older) (“*…He’s not mine and we don’t orientate that way, but I spend every day with him. So the things that affect my mum affect me the same. But its different, because obviously I am older, and I am his sister I get to go…whereas she doesn’t get to go …*”).



Graphic showing the themes around the experience and impact over time of being a sibling of a child with SBS



Discussion

- SBS is a complex condition that often produces a range of challenges for those born with the condition, and their families.
- This small study shows that there is a need for greater integrated working and increased dialogue between sectors to recognise that the impact goes far beyond medical challenges and causes social biographic disruption that extends to the family.
- This study highlights the importance of engaging siblings of all ages to understand and respond to their lived experience, which differs from their parent’s needs, and those of their sibling with SBS. at different stages of their lives.

Acknowledgments

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