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Reflection on biographic disruption in families of a child with short bowel syndrome (SBS): a diary study

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Background

SBS is a rare, serious and complex condition whereby half or more of the bowel has been lost, is unable to function, or has been surgically removed. Infants undergo emergency surgery and need ongoing medical intervention to survive. A pilot study found significant 'biographic disruption' (the social experience of living with chronic illness) in those caring for a child with SBS (Whitely, 2014) and recommended further research to understand the impact on patients and their families.

Research Questions

- How does living with a child with SBS impacts on the family in terms of social, financial and psychological aspects?
- How do families cope with their children's illness?
- How do parents and siblings feel when they are first told about the diagnosis?
- How do families understand the condition and it's prognosis?

Methods

A mixed method study design, which included parents and siblings of a child with SBS keeping a diary over a 2-week period. Diaries are a familiar and readily available tool that can capture daily records of lived experiences, events, appointments, feelings and attitudes (Blythway, 2012). Diary-keeping can help participants to recollect experiences over a period of time that can be discussed and explored further in an interview (Corti, 1993), and is considered one of the most reliable methods of obtaining information.

- Blythway B., (2012) The Use of Diaries in Qualitative Longitudinal Research. Timescapes Methods Guides Series, Guide No. 7.
- Corti L., (1993) Using diaries in social research. Sociology at Surrey, Issue 2.
- Whitely L. (2014) Paediatric Ultrashort Bowel Syndrome: Parent perceptions on care and family biographic disruption. Unpublished report, supervised by Mr. Antonino Morabito, Consultant Paediatric and Neonatal Surgeon, Royal Manchester Children's Hospital

Key themes: Challenges

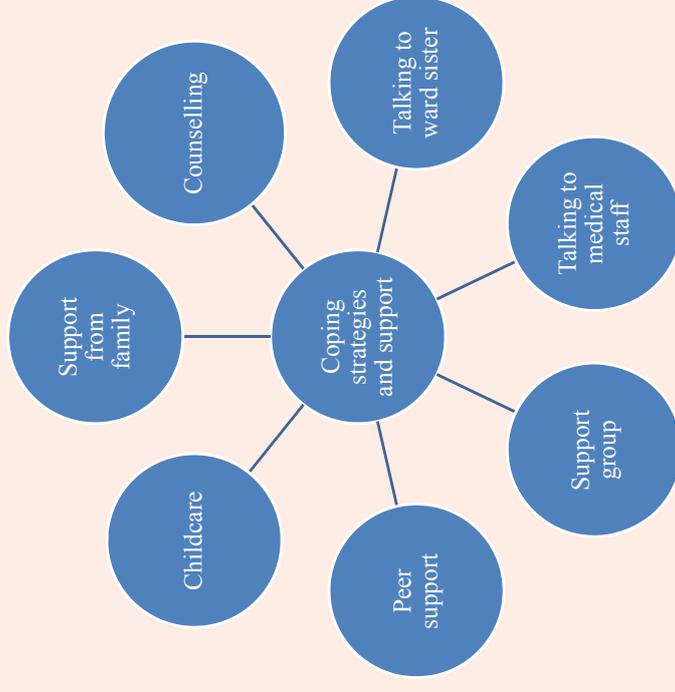
Challenges (partly related to the age of the child and severity of the condition) encountered in families of a child with SBS.

On initial diagnosis, shock, worry, anxiety, fear, loss of control and guilt. *"Feels like I have no control over my life anymore. I am not the person I used to be. Lost confidence and my identity. Want to take my baby home so much"*
Ongoing worry of living with SBS, a changeable condition. *"The problem with SBS is that as parent/carer you always have to be alert to how much eaten, how much poo has been done, how a child looks, fluid intake, signs of vitamin deficiency, signs of pain, colour of poo or vomit..."*
Difficulty maintaining relationship with partner and other family members. *"Suspect my husband and I are going to have separate lives until discharge as we need to tag team"*
"Torn between my (SBS) child and my dad. Always feel guilty that I can't be with one of them" hate this situation"

Problems socialising due to events being cancelled at short notice and disappointment of siblings *"Means you always come last even when you need help. It feels rubbish"*
Not able to do normal things easily such as siblings playing out, days out, going on holiday, swimming, eating out. *"To prepare for "day out" ...medication-needs to be refrigerated/boiled water/food (special diet of no wheat, egg, dairy, gluten, soya, milk). Nappies, three changes of clothes, conti sheets (used in car seat in case of emergencies). "His bowels make it difficult for him to swim as an explosion would leak in the pool"*
Continence issues, accessing medication, accessing medical advice (especially out of hours), financial worries. *"Spoke to dietitian at Manchester yesterday, had to pick up my child's new antibiotics for tomorrow as my local pharmacy cannot dispense them, having to travel all the way to Manchester for them is really hard work"*

Key themes: coping strategies

Coping strategies used by parents and siblings of a child with SBS.



Conclusion

Diaries kept over a 2-week period by families of a child with SBS reflect psychological, social and practical challenges that cause significant biographic disruption. Diaries also reflect how support systems/coping strategies can help ameliorate some of this disruption. This information (together with interview data) will be used to shape recommendations for measures that could be put in place to help parents and families of a child with SBS.

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