

Short bowel syndrome and the impact on patients and their families: a qualitative study

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Short bowel syndrome (SBS) is a malabsorptive condition that can result in intestinal failure (SBS-IF). Many patients with SBS-IF require home parenteral nutrition (PN) for survival. However, PN has profound effects on patients and their family members. The study aimed to understand the lived experience of SBS-IF for patients and their families. This study used semi-structured qualitative interviews with 15 patients with SBS-IF and five adult family members living with someone with SBS-IF.

The study showed that patients' lives were dominated by having SBS-IF. They described physical impacts that included patient-reported signs and symptoms and physical restrictions comprising of restrictions on daily life, activities of daily living and physical functioning. In addition, they encountered emotional impacts with a plethora of negative feelings and social impacts, such as difficulties socialising and maintaining relationships. Patients coped by adapting their life around SBS-IF, having support, and adopting an attitude of gratitude and acceptance. Family members were also affected and, along with patients appreciated the respite of a night off from infusions.

The patients and families faced many difficulties with SBS-IF. Healthcare professionals can support patients by facilitating them explore what others have found beneficial, adapting their life around PN, viewing PN with acceptance and trying to cultivate gratitude.

Reading this article has made me reflect on the effects of many different areas of stoma and colorectal care on both the individual and their family and has helped reinforce the importance of asking and learning from experts by experience. Is there a part of your service that could benefit from learning from experts by experience?

