



## Newsletter

# Examining the emotional impact of living with a stoma for children and teenagers

## Mapping unexplored areas

**When looking at the available research on the psychological impact of life with a stoma, there's very little out there that focuses on children and teenagers. A literature search revealed 63 results for adult stoma psychology, versus seven results for paediatric stoma psychology.**

### Uncovering paediatric psychosocial issues

Given the comparative lack of research on this subject, a group of healthcare professionals have decided to conduct more research into this area. The group, which includes Claire Bohr, paediatric stoma and bowel management nurse at University Hospitals Bristol (UK), wants to explore the psychosocial impact of paediatric stoma formation. "Our goal is to gain a better understanding of the psycho-social issues children face," explains Claire.

"We recognise that the importance of managing stress and anxiety has been well reported but poorly addressed in practice. For example, pre-operative counselling usually only focuses on potential surgical complications and not on the impact the surgery will have on these children's daily life." Claire continues. "If we understand what these children are going through, we can then provide more realistic pre-operative counselling. We can also provide families with better coping mechanisms,

once we have a clearer understanding of what children with stomas have to deal with on a daily basis."

The first phase of this project has involved a thematic qualitative analysis of school-age children and paediatric surgical staff. Using focus groups and interviews, the project team aimed to compare staff and patient perceptions of the psychological impact of stoma formation in the paediatric population.

### The children's perspective

Claire explained that the children interviewed talked freely about the positives and negatives of life with a stoma. On the positive side, they highlighted being able to meet new people; still being able to socialise with their friends; and feeling better as clear positives. They mentioned not having to go to the toilet all the time as a benefit, as well as being able to continue with everyday activities like going to the beach.

On the negative side, the children seem to struggle with feelings of anger, anxiety, discomfort, self-awareness and fear. Some felt that there were many activities they could no longer engage in such as sleepovers, going on holiday, swimming and other sports. Some struggled with leakages and bad smell. Others viewed changing the bag as an annoyance.

They also commented that the operation had a negative impact on their schooling, causing them to miss lessons and poor academic performance as a result.

#### The method

- Thematic qualitative analysis from grounded theory, through focus groups and interviews.
- Children 6-16 years of age, who had undergone stoma formation or reversal in the previous two years
- Paediatric surgical staff
- 6 boys, 3 girls (mean age: 14), 10 parents, 16 members of a paediatric surgical team.

#### The professional's perspective

The members of the paediatric surgical team commented on three distinct themes: information and in-patient training; school and social interactions; and image.

Regarding information and in-patient training, the surgical team experienced that the patients generally were well informed about life with a stoma – although the extent to which the surgery was emergent or planned would have an impact on their information level. The surgical team believed patients would be able to look after their stomas independently upon discharge, especially the teenagers.

In terms of the impact on school and social areas, the group believed using public or school toilets was an issue due to embarrassment about the smell. They expected coping at school would have a lot to do with how understanding the school was. The group was a bit divided on whether or not paediatric stoma patients would be willing to tell their friends.

There was also uncertainty about how well the stoma bag would hold up during contact sports.



#### Next steps

The next phase of the project will be to collect tangible, quantitative data that can be used to guide pre-operative counselling and expectation management of future patients. This will be done by sending questionnaires to children and their parents/carers.