



Supporting young ostomates at school: a nurse's guide

Claire Murphy, Community Specialist Stoma Nurse, Respond Healthcare, draws on her experiences caring for children with a stoma through school

Children of all ages can have a stoma formed for a variety of reasons. In paediatric stoma care, there are many challenges for children and their families to overcome. Specialist stoma care nurses can influence and assist schools to be able to provide support to children with a stoma, and this can be vital to enhance a positive school environment for the child. The psychological effect on the child with a stoma can have detrimental consequences if the adequate support is not provided to both the child and the school.

Psychological challenges

The psychological impact of stoma formation can decrease an individual's quality of life. This is an important factor to consider; not only does the child have a stoma, they also have changes to the body, social isolation, stigma, embarrassment and decreased mood (Liao and Qin, 2014). Altered body image has a psychological effect on ostomates of all ages, and children also often see stoma surgery as a physical threat to their body integrity (Black, 2004).

Paediatric patients may experience a sense of shame due to a loss of control over body elimination, as they understand elimination to be a taboo topic that they are expected to keep private and never discuss. Edelman (1995) highlighted the embarrassment caused by loss of control over body behaviours, odours and lack of privacy, while Garcia et al (2005) discussed how bodily waste is associated with disgust and the loss of control over elimination causes public humiliation and is a major threat to self-esteem. In a classroom setting,

further distress is caused by fear of the stoma making noises, producing odour or leaking. This concern can cause children to lose concentration on classroom activities due, with a negative effect on their development. Such anxieties are often reported by ostomates (Anderson et al, 2010).

These negative feelings have a huge impact on children sense of their own identity and social role, with consequences for their quality of life. The embarrassment caused by a stoma during social and physical activities can lead to children trying to hide their stoma from their peers (Teitelbaum, 2004)

Children with stomas often have to attend frequent medical appointments, which can in turn harm their psychological and academic performance.

An 11-year-old girl who I was asked to review reported feeling isolated, anxious, withdrawn, ashamed and 'dirty'. She also spoke about a lack of concentration and self-confidence and a loss of interest in social activities.

Supporting children

Specialist nurses have the skills that are required by young patients in their care. In certain aspects providing care for children is no different to providing care for adults; everyone should be treated with dignity and respect, and children should also be encouraged to contribute to their own care. As outlined in the Nursing and Midwifery Council's (NMC) Code, nurses should be treating patients as individuals and respecting their dignity. Nurses must also work with others to protect and promote

the health and wellbeing of those in they care for, as well as their families and the wider community (Nursing and Midwifery Council (NMC), 2015).

Good communication skills are vital, not only with the child but also with their family and school staff, and this will help enable the child to feel fully supported in their everyday life. Communicating with children and young people about their health to ensure their needs are met requires a high level of skill (Lambert et al, 2012). Specialist nurses have gained the vital communication skills that are required to enable them to provide teaching, guidance and support in a way that is appropriate to the child's age and development. This in turn will enhance the child's quality of life and make adjusting to nursery or school a positive experience.

It is usually a good idea to first meet with the child and their family in their safe

Box 1. Main points raised in author's discussion with children aged 4–15 years

Stoma leakages

What happens if odour occurs in class

What happens if their pouch makes a noise in class

Where they can change for physical education

Where they can dispose of their pouch

Where they can go to change their pouch

Whether spare clothes can be left at school

Whether they can be excused from class as required to check stoma

environment, where the nurse can build a rapport with the child, before meeting with the educational team. There are a number of practical issues that are likely to concern the child (Box 1), and talking these points through with patients and their families and bringing in role play for younger children can be very beneficial.

Supporting the school

Rodgers (2003) stated that 'schools are required to provide fully supportive, inclusive education for all children, including those with medical needs such as a stoma', while 'a school's lack of awareness can have a detrimental effect on the child and their wellbeing.'

Stoma care specialists are well placed to provide support to schools, including to teachers and school nursing staff, with visits to the school (Box 2). It is the stoma nurse specialist's role to educate and support the teaching staff. Adequate support and guidance for staff as well as the patients will make life easier for everyone and make the school experience more positive for the child with a stoma and help them feel at ease.

A booklet for clinical nurse specialists in stoma care produced by the Royal College of Nursing (RCN) outlined the paramount importance of disseminating specialist knowledge to enhance the patient experience and the education of others (RCN, 2009).

The education, health and care (EHC) plans were launched in September 2014. EHC plans are for children and young people aged up to 25 years who need

more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support required to meet those needs. This has placed greater emphasis on professionals from different services working together to support children and young people with their special educational needs and/or disabilities as required.

It is worth providing the school with a written health-care plan that includes a step-by-step guide to emptying and changing a stoma pouch, incorporating national guidelines from the Association of Stoma Care Nurses UK (2016). This will provide the school with clear advice, instruction and recommendations.

Author's experience

In meeting with educational staff, I have experienced very positive feedback regarding outcomes for the child. This ranges from the child's own designated space for changing pouches, to provision of a stoma equipment storage system, to named teaching assistants providing help at school.

I have also witnessed the opposite end of the spectrum, where the child has had a negative experience, especially with staff not being very supportive in allowing children to be excused from class to check on their pouch, resulting in leaks. I have also heard from paediatric patients who have not had somewhere to freely change their stoma pouch without being interrupted, as well as those who have had their change of clothes at school locked in a cupboard and

not been able to locate the key, resulting in them having to wear soiled clothing for the rest of the school day, as the next of kin was also not informed about the lack of clean clothes.

In these cases, the EHC plan was not satisfactorily facilitated, and the staff gave the general impression that they were oblivious to the child's needs. When I asked staff if they would be happy to use the toilet in full view of our meeting, as this was what was being expected of the child daily, they appeared horrified.

Patient perspectives

Colostomy UK's open day in September 2017 featured an inspiring presentation by an ostomate. She had had her ileostomy for 50 years, and she confided that she had had the same school experience, with no support or private space to change pouch and anxieties about leaks, odours and soiled clothing, causing a lack of confidence and feelings of shame throughout her school years. She said that her negative experience all those years ago still affect her today. The alarming part of this conversation was the realisation that it is still a major factor today, as it was half a century ago.

The importance of support for paediatric ostomates is illustrated by the case of a 12-year-old girl I was asked to see.

The shame and stigma she associated with her stoma led to her having her colostomy reversed and an antegrade continent enema (ACE) procedure performed. An ACE procedure should allow the patient to carry out a total washout of their colon by flushing out stool, starting in the colon downwards, and thus producing a bowel movement under the patient's control. Unfortunately, the ACE failed, and she is now incontinent. If the child and her school had received more appropriate teaching, support and guidance, alongside careful implementation of the EHC Plan earlier in her schooling, she may not have found herself in her present situation. Specialist nurses are advocates for their patients and must make sure the patient's basic right to individualised, holistic care is forefront.

Box 2. Ways to support to the school

Meet with school team, including the head teacher or deputy head, class teacher, teaching assistants and school nurse (if applicable)

Teach the basics of what a stoma is and why it may be required, as many people have never heard of, never mind seen, a stoma, and so giving staff this information at this point is helpful and reassuring

Teach a basic session on sore skin and problems that can occur

Teach a basic session on changing and emptying a stoma pouch

Provide a written health-care plan that staff can refer to when required

Meet with the child, parent and school team together, involving the parent as much as possible, as they know their child better than anyone

Provide ongoing support to the school if any issues arise

Conclusion

The existent research on paediatric stoma care and the psychological effect this can have on children's quality of life is dated. More studies should be undertaken in this area, as the more support that can be provided to the child, the more of a positive effect nursing will have on not just on their psychological and academic performance but on their whole quality of life.

Ostomates of all ages require support throughout their life to help them cope with their stoma in changing environments. Providing schools with further guidance and including practice development for school staff can have a positive outcome

for the child, and care plans should always be provided for staff to refer to. **GN**

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