

Colostomy in children – an evaluation of acceptance among mothers and caregivers in a developing country

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Summary

Background. Colostomy is a common procedure performed in children, mostly for anorectal malformation and Hirschsprung's disease. However, acceptance by parents in developing countries is thought to be poor.

Methods. A prospective evaluation was done to determine the acceptability of colostomy among parents and caregivers, and their attitude towards colostomy in their children.

Results. During the period January 1999 - January 2004 a structured questionnaire was administered to 57 parents and caregivers of children with colostomies (41 boys and 16 girls). The indication for colostomy was anorectal malformation in 28 children and Hirschsprung's disease in 29. The length of time the children had the colostomy ranged from 3 weeks to 8 years. Forty-four respondents (77%) found the colostomy and its management acceptable. Thirteen (23%) found the colostomy unacceptable, mainly because of a feeling of social isolation. Problems the respondents complained of included disturbing smell (17, 30%), frequent change of the cloth napkin used as colostomy appliance (15, 26%) and intermittent bleeding from the stoma (4, 7%).

Conclusions. Colostomy in children is acceptable to most parents in our environment. Although some parents found it unacceptable, adequate explanation and counselling may modify their view.

and caregivers towards colostomy in their children in this environment.

Material and methods

A structured questionnaire, framed in simple, understandable English, was administered to the mothers (or caregivers) of children who had a colostomy. Administration was done in the outpatient clinic during follow-up visits. Questions were asked specifically on the literacy level of the mother (or caregiver), attitude towards the stoma (shameful or not, and if shameful, why), difficulties encountered with stoma care, who taught the mother stoma care, whether the mother found odour problematic, discussion of stoma care with the mother of another child with a stoma, and number of times the cloth napkin used as stoma appliance was changed.

Literate mothers (or caregivers) completed the questionnaire themselves, while an interpreter helped those needing assistance. The questionnaires were administered between January 1999 and January 2004.

Before a colostomy was performed, parents and caregivers were educated on the need for the colostomy and the after-care. Team doctors usually gave this explanation. The temporary nature of the stoma was always emphasised. Following the colostomy, the parents or caregiver were educated on the care of the stoma by a paediatric-trained nurse with experience in stoma care. Opportunity was usually created for the parents or caregiver to discuss freely with parents of other children with colostomies, and to talk with those whose children had had their stoma closed following completion of treatment.

Because of cost and availability of colostomy bags, we improvise, using a strip of cloth napkin to cover the stoma, after lubrication with a bland ointment. The bland ointment (petroleum jelly or zinc oxide) is also applied on the pericostomy skin. A strap of cloth tied at the back supports the napkin. Normal clothing is then worn. The napkin is changed as soon as it is soiled.

Colostomy is a common procedure performed in children,¹ mostly for anorectal malformation and Hirschsprung's disease. Although the life-saving benefit of this procedure is well known medically, the impact on parents and caregivers has not been fully evaluated in most developing countries. However, it is frequently assumed that acceptance of colostomy in these countries is poor. This study aimed to determine prospectively the acceptance and attitude of parents

Results

There were 41 boys (72%) and 16 girls (28%). The indication for colostomy was anorectal malformation in 28 children and Hirschsprung's disease in 29. The duration for which the children had the colostomy was 3 weeks - 8 years (median 2 years). The 8-year duration was due to financial difficulty on the part of parents unable to pay for definitive surgery.

Forty-four respondents (77%) found the colostomy and its management acceptable, while 13 (23%) found it unacceptable. The main reason for unacceptability (given in all 13 cases) was a feeling of social isolation due to the altered external appearance of the child and the fact that the child passed stool from an abnormal site.

Problems encountered by all the respondents while managing the stoma included disturbing smell (17, 30%), frequent change of the cloth napkin used as colostomy appliance (more than 5 times during the day) (15, 26%), and intermittent bleeding from the stoma edge (4, 7%) (however, this ceased following re-education on colostomy care). The mother of one of the patients was blind and had little support and assistance at home.

The 44 respondents who found the stoma acceptable felt particularly encouraged by the fact that the stoma was only temporary.

Discussion

The acceptance of colostomy by parents and medical personnel alike has long been considered controversial. The attitude of the family may influence adjustment to surgery,² and the psychological impact on the patient and family may be far reaching.³ Conclusive evidence that parents are not accepting of colostomy is lacking. This study therefore set out to determine prospectively the attitude of parents and caregivers in our environment towards colostomy in their children.

In our institution, the managing team routinely undertakes detailed preoperative counselling and education on colostomy care. Other mothers whose children have had colostomies are also involved in the counselling process. Of the 57 respondents, 77% found the stoma and its management acceptable. This is encouraging because unacceptability was thought to be a major hindrance to colostomy, especially in developing countries.¹

The stigmatisation and social isolation of children with a colostomy is due to their altered appearance, especially in a culture where parents wish to show off their babies to visiting friends and relations. This was the main reason for non-acceptance given in this study. However, with correct application of the cloth napkin used as appliance and use of normal clothing, this embarrassment should be minimised. The smell from the stoma is well known and can be disturbing.⁴ This is due to the nature of the effluent from the colon, but in the present report only 17 of the respondents (29%) complained of this, the majority finding it bearable. This smell was usually controlled by changing the cloth napkin used as appliance soon after soilage.

Another aspect of colostomy management is the need to change the cloth napkin used as appliance frequently and the attendant cost implication to parents. Fifteen respondents in this report (26%) considered changing more than 5 times during the day cumbersome. One of the parents was blind, which understandably made stoma care more demanding. Gastroenteritis, a common childhood problem in most developing countries, is a frequent cause of increased frequency of effluent from the stoma; prompt control of the gastroenteritis should minimise this problem. In order to reduce the high cost of using commercial appliances and also because of limited availability, we improvise, using strips of soft cloth as a napkin. All our patients use this method.

Four respondents (7%) encountered intermittent bleeding at the stoma edge, a known complication of colostomy,⁵ which usually stopped after re-education on appropriate means of cleaning the stoma.

During the counselling many parents felt encouraged to accept the colostomy when they realised it was a temporary measure and would be closed after corrective surgery. One patient with Hirschsprung's disease had his colostomy for 8 years while waiting for definitive surgery because of financial difficulties.

Although some parents found colostomy unacceptable, this study showed that with adequate explanation and counselling, most parents and caregivers in our setting find colostomy in their children acceptable. However, efforts must continue to minimise the length of time a child lives with a colostomy and also to avoid use of colostomies as far as possible. Many children with Hirschsprung's disease and some with anorectal malformations can now be managed using one-stage procedures.^{6,7}

Individuals trained in stoma care are helpful in providing support and addressing parental concerns.⁸ However, in our setting stoma care specialists and other support personnel are not available⁹ and the paediatric surgeon needs to make time during clinic follow-up visits to address parental concerns and other relevant issues related to the stoma.

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