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Do geography and resources influence the need for colostomy in Hirschsprung's disease and anorectal malformations? A Canadian association of paediatric surgeons: Association of paediatric surgeons of Nigeria survey

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ABSTRACT

Background: This survey compared surgical management of Hirschsprung's disease (HD) and anorectal malformations (ARM) in high and low resource settings. **Materials and Methods:** An online survey was sent to 208 members of the Canadian Association of Paediatric Surgeons (CAPS) and the Association of Paediatric Surgeons of Nigeria (APSON). **Results:** The response rate was 76.8% with 127 complete surveys (APSON 34, CAPS 97). Only 29.5% of APSON surgeons had frozen section available for diagnosis of HD. They were more likely to choose full thickness rectal biopsy (APSON 70.6% vs. CAPS 9.4%, $P < 0.05$) and do an initial colostomy for HD (APSON 23.5% vs. CAPS 0%, $P < 0.05$). Experience with trans-anal pull-through for HD was similar in both groups (APSON 76.5%, CAPS 66.7%). CAPS members practising in the United States were more likely to perform a one-stage pull-through for HD during the initial hospitalization (USA 65.4% vs. Canada 28.3%, $P < 0.05$). The frequency of colostomy in females with vestibular fistula varied widely independent of geography. APSON surgeons were less likely to have enterostomal therapists and patient education resources. **Conclusions:** Local resources which vary by geographic location affect the management of HD and ARM including colostomy. Collaboration between CAPS and APSON members could address resource and educational needs to improve patient care.

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INTRODUCTION

The surgical management of children with Hirschsprung's disease (HD) and anorectal malformation (ARM) has undergone modifications to optimise safety and improve outcomes regardless of which method and how many stage(s) of intervention are chosen. Prior to the advent of single-stage transanal endorectal pull-through (TEPT) procedure and primary repair of vestibular fistula, a colostomy followed by a delayed definitive repair for these congenital colorectal conditions was commonly performed.[1,2] Neonatal diagnosis and even definitive surgery are now possible because of increased awareness of these anomalies, improved neonatal nursing and other supportive care.[1-4]

The morbidity and parental distress caused by a stoma are significant and have implications for the quality-of-life of patients and the psychosocial issues arising among the parents.[5,6] Many of the surgeons now believe colostomy can be avoided in most children with HD and many with ARM if they are diagnosed early. It is often not possible to avoid an ostomy in children who present with HD or ARM at an older age and in a deteriorated state, which is more common in developing countries.[1,2] The location and type of colostomy have strongly been debated and the stoma complications that are frequently reported may be

avoidable by careful technique, nursing and parental expertise and modern ostomy appliances.[7,8]

We conducted this survey to compare the clinical opinions and practice of colostomy for HD and ARM between the members of the Association of Paediatric Surgeons of Nigeria (APSON) and the Canadian Association of Paediatric Surgeons (CAPS). The descriptive design of the survey was used to determine how training, experience and availability of resources play a role in reducing the number of colostomies performed in children.

MATERIALS AND METHODS

In February 2012, members of CAPS and APSON were invited to participate in an online survey of their current practices for HD, ARM and colostomy. Permission to distribute the survey by E-mail was obtained by each society's respective executive council. We followed recently published guidelines for surveys of expert opinion.[9,10]

Data collected included surgeon demographics, availability of resources and opinions on surgical management of several case scenarios of infants and children with HD and ARM. We asked about the perceived rate of colostomy complications and the availability of resources for managing colostomies. Levels of the agreement were measured using a 5 point Likert scale.

The online survey was developed using Limesurvey© and piloted amongst 7 paediatric surgeons to validate and test the appropriateness of the survey length, quality of questions and mode of execution. The survey was revised based on feedback from the piloted version and estimated to take 15-20 min to complete.

APSON and CAPS members were invited to participate through a personalised E-mail with the link to the survey. Each member was given a unique token to ensure only a single completion of the survey. To improve the response rate, a modified Dillman's Method for internet surveys was adopted for distribution.[11] As an incentive, a donation was offered to the education program of the Association with the highest response rate.

- Email invitations were sent to 262 CAPS and APSON members and successfully delivered to 208 surgeons (147 CAPS, 61 APSON) in active practice. Non-respondents received an E-mail reminder every week for 4 weeks and a final personalized E-mail from one of the lead investigators (LA, BC). Fisher's exact test was used to compare responses between four geographic regions of practice. $P < 0.05$ was considered to be significant. All statistical analyses were performed using SPSS® IBM® 20.0 IBM SPSS Statistics 20.0 - August 2011, IBM Corporation 2011, Illinois, Chicago.

RESULTS

There were 159 responses (response rate 76.4%) and we then excluded 31 incomplete surveys and one non-member. The remaining 127 (61.1%) complete surveys (APSON $n = 34$, CAPS $n = 93$) were included in the analysis [Figure 1]. Subanalysis of the CAPS group was performed by region of practice: Canada ($n = 53$), USA ($n = 26$) and the Arab Gulf States ($n = 14$).

The majority of surgeons from Africa and the Gulf States had trained within the previous decade and 9 APSON members were still fellows [Table 1]. Most of the respondents practiced in an institution with a paediatric surgery training program (APSON 76.5%, CAPS 62.4%). APSON surgeons performed more colostomies and treat more patients with HD, especially over 6 months of age, than CAPS surgeons. APSON surgeons were limited by lack of surgical equipment and were less likely to have reliable paediatric anaesthesia and histopathology. Cholinesterase staining and calretinin were not universally available for CAPS surgeons [Table 2].

APSON and CAPS surgeons reported experience with a range of pull-through procedures over the previous 5 years. More APSON members have experience with

Table 1: Respondent's years of surgical experience and region of practice

Qualification status	All APSON members ($N = 34$) %	All CAPS members ($N = 93$) %	CAPS members from Canada ($N = 53$) %	CAPS members from United States ($N = 26$) %	CAPS members from Arab Gulf States ($N = 14$) %
Qualified in 2001 or later	82.4	41.9	39	19.2	92.9
Qualified before 2001	17.6	58.1	60.4	80.8	7.1
Fellows in training	9*	0	0	0	0

*Fellows had completed an average of 22 months of paediatric surgery training, APSON: Association of Paediatric Surgeons of Nigeria, CAPS: Canadian Association of Paediatric Surgeons

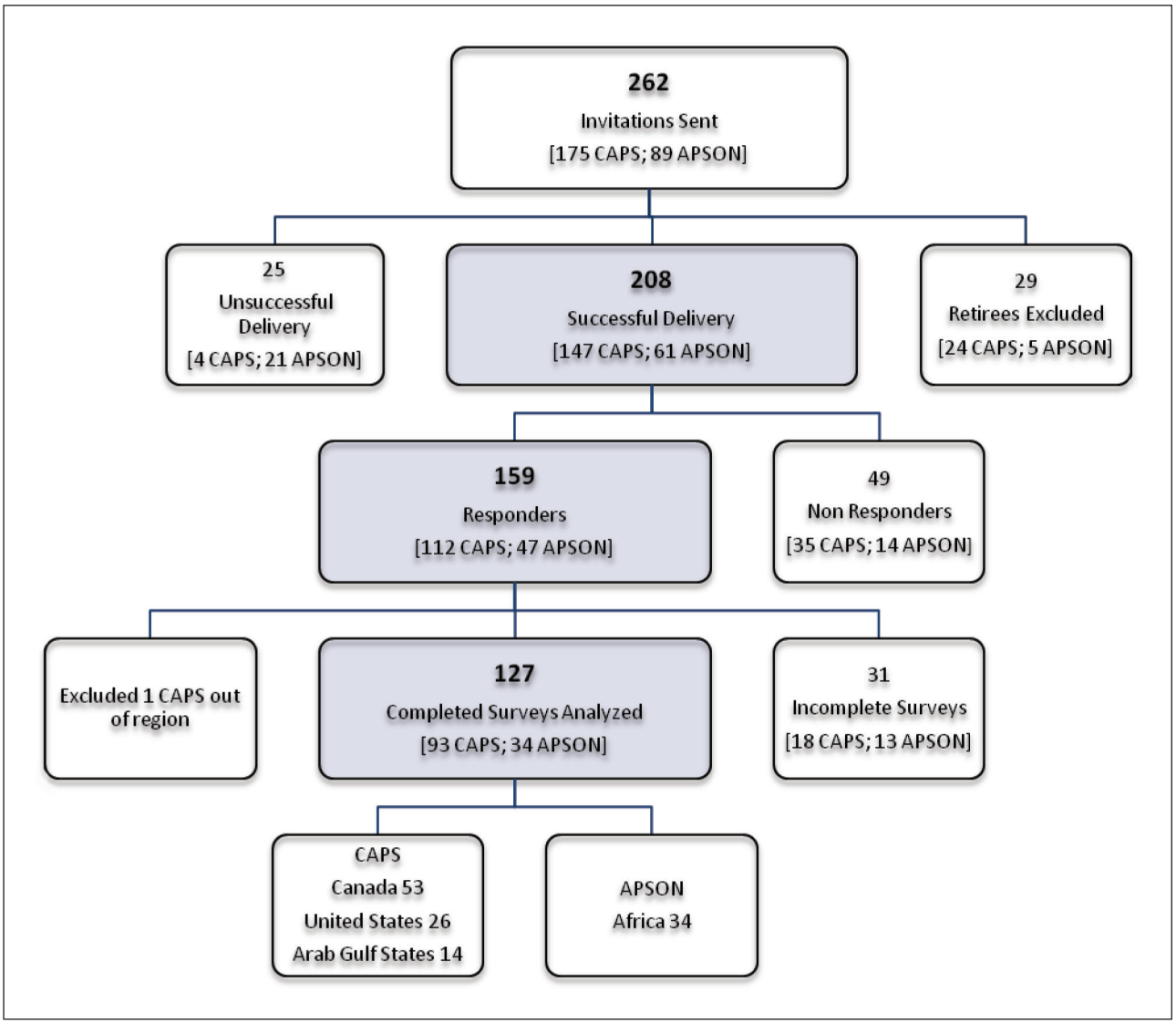


Figure 1: Survey response rate = 76% (159/208); Completion rate = 61% (127/208)

Table 2: Resources available to APSON and CAPS surgeons

Which resources are available in your personal practice?	APSON members (%)	CAPS members (%)	*P* value
Operating loupes	44.1	96.7	<0.05
Reliable laparoscopy equipment	11.8	95.7	<0.05
Reliable paediatric anaesthesia	67.6	96.8	<0.05
Reliable histopathology	73.5	92.5	<0.05
Frozen section for ganglion cells	32.4	97.8	<0.05
Permanent section for ganglion cells	91.2	97.8	NS
Cholinesterase staining	5.9	58.1	<0.05
Calretinin immunohistochemistry	0	33.3	<0.05
None	5.9	0	NS

APSON: Association of Paediatric Surgeons of Nigeria, CAPS: Canadian Association of Paediatric Surgeons

the Swenson operation and more CAPS members use laparoscopy-assisted trans-anal techniques. Both APSON and CAPS surgeons (APSON 76.5%, CAPS 66.7%, P = NS) reported experience with TEPT for HD within the previous 5 years [Table 3].

When respondents were asked how they would manage an infant with suspected HD, 90% of CAPS members would doa suction rectal biopsy whereas most APSON members did not have frozen section pathology available and would do a full thickness rectal biopsy (APSON 70.6%, CAPS 10%, $P < 0.05$) and a colostomy (divided sigmoid 42%, loop sigmoid 37%, transverse loop 21%). There was some variation between CAPS members depending on the country of practice. Those practicing in the United States were more likely to perform a one-stage pull-through procedure for infants with HD during their initial hospitalisation (USA 65.4%,

Canada 28.3%, $P < 0.05$) whereas most surgeons in Canada favoured sending the infant home with rectal irrigations and performing the one-stage pull-through electively within 3 months.

When asked how they would manage a 2-year-old child presenting with HD, there was no difference between APSON and CAPS surgeons: 71% would do a full thickness rectal biopsy and a colostomy. In addition to patient age, other reasons given for choosing a primary colostomy included advanced patient condition and lack of reliable pathology or paediatric anaesthesia.

There was general agreement on initial management of most ARM: 94% would 'frequently' or 'always' do a colostomy for a male with a rectourethral fistula, 93% would 'occasionally', 'rarely' or 'never' do a colostomy for a male with a perineal fistula and 91% would 'frequently' or 'always' do a colostomy for a female with a cloaca. However, there was a wider variation of practice whether to perform a colostomy for females with ARM and rectovestibular fistula, [Figure 2]. Most of the surgeons prefer a sigmoid rather than transverse colostomy for a high ARM, regardless of the year of qualification [Table 4].

Colostomy prolapse and skin breakdown were the most common colostomy complications reported.76% of respondents agreed that most colostomy complications are avoidable through careful technique. More APSON members than CAPS members 'agreed' or 'strongly agreed' that general surgeons should be taught how to do colostomy in infants [Figure 3], although most reported that <20% of paediatric colostomies were done by someone who is not a trained paediatric surgeon. APSON surgeons were less likely to have stoma therapists and patient education materials, but felt that these resources should be made available [Table 5].

DISCUSSION

Our survey identified several significant differences between APSON and CAPS members in the management of HD and ARM. APSON members perform more colostomies, mainly because of differences in their patient population and available resources rather than lack of training or experience in current single-stage techniques.

Table 3: Experience with types of pull-through operations

Which type of pull-through operations have you done in the past 5 years?	APSON members%	CAPS members%	*P* value
Trans-abdominal Duhamel	8.8	26.9	0.05
Trans-abdominal Soave	41.2	25.8	NS
Trans-abdominal Swenson	61.8	12.9	<0.05
Trans-anal pull-through	76.5	66.7	NS
Laparoscopy-assisted trans-anal	8.8	78.5	<0.05

APSON: Association of Paediatric Surgeons of Nigeria, CAPS: Canadian Association of Paediatric Surgeons

Table 4: Type of colostomy preferred for high anorectal malformation

What type of colostomy would you perform for a male with a rectourethral fistula?	Qualified before 2001%	Qualified 2001 or later%	*P* value
Divided	61.7	80.6	<0.05
Loop	36.7	14.9	NS

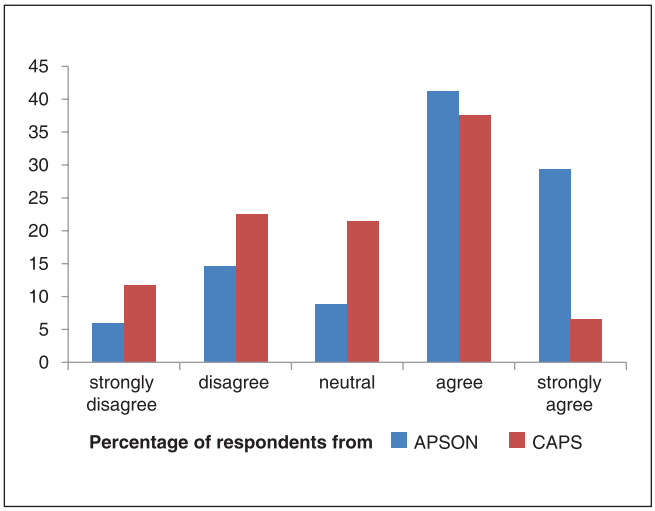


Figure 3: Should general surgeons be taught to do an infant colostomy?

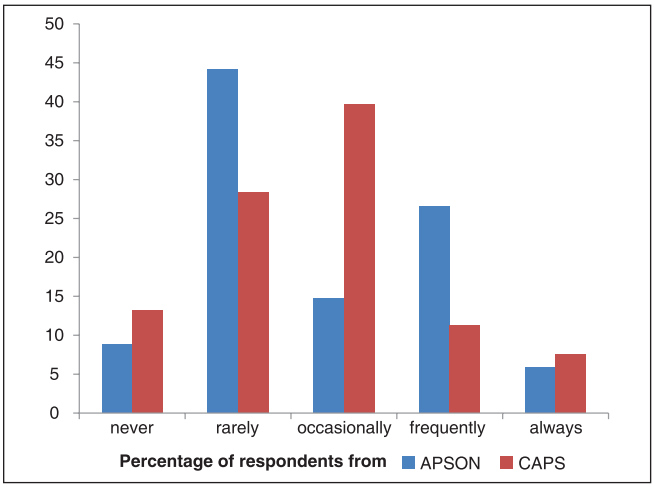


Figure 2: How often would you do a colostomy for a female with a rectovestibular fistula?

Table 5: Which resources should be available for children with colostomy?

Sources of information and availability of resources	Resource is available		Resource is not available but should be	
	% APSON members	% CAPS members	% APSON members	% CAPS members
Pre-operative parent/patient education materials	5.9	76.3	91.4	21.5
Pre-operative consultation with an ostomy or wound care specialist	0.0	82.8	91.2	12.9
Post-operative printed instructions for colostomy care	2.9	71.0	94.1	23.7
Post-operative access to an ostomy or wound care specialist	2.9	89.2	85.3	9.7
List of internet resources and resource groups	11.8	59.1	73.5	29.0
Ostomy appliance bags	32.4	97.8	64.7	1.1

APSON: Association of Paediatric Surgeons of Nigeria, CAPS: Canadian Association of Paediatric Surgeons

Hirschsprung's Disease

APSON surgeons were more likely to choose an initial diverting colostomy for children with HD presenting at any age due to the lack of frozen section and limited access to reliable paediatric pathology and anaesthesia. They generally perform a full thickness biopsy with a colostomy and staged pull-through for their patients with HD. Although the majority of APSON members have experience with the TEPT procedure, there is a need for caution as the practice of primary pull-through in the absence of frozen section may cause an aganglionic segment pull-through with its attendant poor outcome.[12]

Interestingly, CAPS members practicing in Canada and APSON members who do TEPT were more likely to delay the pull-through procedure in infants, discharging neonates with HD after teaching the parents to do rectal washout irrigations, whereas CAPS members practicing in the United States preferred to do a pull-through during the initial hospitalisation. This may be due to differing access to elective operating time, or differing clinical opinions about the ideal infant size for primary pull-through procedure.

The literature reports a wide variation in operative management of HD, even within the same region.[13,14] Part of the practice variation is due to differences in the extent and complications of HD in the local patient population, especially in Africa.[15-17] Colostomy is still necessary in children who have complicated HD, but it has accompanying morbidity, poor acceptance by the parents in many African settings and children may not return to medical care to receive definitive treatment.[6] These morbidities are often preventable by adequate preparation, provision of information to the parents and use of proper technique.

The introduction of the TEPT has led to a consensus that colostomy can be avoided in most children with HD who are diagnosed early in life before colonic distension occurs. In 2009, over 85% of American Paediatric Surgical Association members surveyed on their management of HD used a one-stage TEPT and over 95% were doing a trans-anal anastomosis although with a wide variety of cuff length.[14] A number of multicenter studies have demonstrated the efficacy and safety of the TEPT for HD even in newborns.[18-20] A 2010 meta-analysis of single-stage TEPT for HD concluded that there was less pain, a shorter hospital stay, fewer adhesions, less damage to pelvic structures and fewer wound infections compared to laparotomy.[21]

Anorectal Malformation

Survey respondents agreed on the necessity for colostomy in high ARM, but there was a wide variation in opinion regarding the indication for a colostomy in females with recto-vestibular fistula. To avoid problems associated with a stoma, Adeniran and Abdur-Rahman.[3,4] advocated single stage posterior sagittal anorectoplasty (PSARP) for intermediate ARM in boys and girls but have observed post-operative complications including wound dehiscence, neo-anal stricture and faecal overflow incontinence which may require a diverting colostomy.[22]

Several centres have reported success with one-stage repair for recto-vestibular fistula done to avoid colostomy complications.[23-26] One of the largest series was reported from India where 1169 children with vestibular fistula were treated over 38 years. They demonstrated a remarkably low complications rate – only 4 patients required a subsequent salvage colostomy. Single-stage PSARP has also decreased the cost of treatment, total length of stay and procedure completion default however, a primary pull-through should be avoided if there are associated issues like sacral anomalies.[22,25-27]

Colostomy complications, resources and care

Colostomy is perhaps one of the under-rated paediatric surgery procedures which is often delegated to junior

surgeons in some low-resource settings.[6] Ostomies created during emergency situations have a higher incidence of complications.[28] Major avoidable complications such as improper siting and incorrect levelling of colostomy for HD can be avoided through resident trainee education, wider availability of frozen section for HD and development of standard management protocols. Other colostomy complications are widely experienced and perhaps harder to completely avoid, although the majority of survey respondents agreed that 'most colostomy complications are avoidable through careful technique.' The literature reports a colostomy complication rate of 28-74% and indicates that up to 5.5% of patients require a colostomy revision.[8]

Our survey identified prolapse as one of the most common colostomy complications, in agreement with the literature which reported colostomy prolapse in 16-20% of cases, with the majority occurring in patients with a loop transverse colostomy.[7,8] Making a colostomy in a fixed portion of bowel or fixation to the abdominal wall can decrease this complication and many routinely perform a divided stoma to decrease prolapse.[8,29] Pena *et al*. reviewed 1470 colostomies, most done for ARM and concluded that most colostomy complications are preventable using separate stomas in the descending colon. A poorly sited colostomy can lead to problems with appliance application, interference with the pull-through, mega-sigmoid, distal faecal impaction and urinary tract infections.[29]

Skin excoriation was another common colostomy complication reported in our survey. One published report cited incidence of 46.5% skin breakdown, with 8.2% severe enough to warrant admission.[7,8] Peristomal excoriation is common in developing countries secondary to use of gauze or napkin dressings instead of bags, non-availability or poorly fitting colostomy bags, or simply lack of stoma care education.[7,8] These skin problems can be avoided by minimizing the contact between the effluent from the ostomy and the peristomal skin.[28] Other post-operative colostomy complications identified in this survey and reported in the literature include seroma, wound infection, obstruction secondary to adhesions, with later complications including stenosis, retraction and parastomal hernia.[30] Dehydration and malnutrition can also result due to fluid loss from a transverse loop colostomy.[7]

Even colostomy closure is not a benign operation – some sources cited anastomotic dehiscence rates of 0-12.5%, wound infection rates up to 45%, bleeding, strictures at the anastomosis and death.[7,30,31] Better outcomes are associated with early closure.[7,8]

Survey respondents report a need for modern colostomy bags for children in Africa due to the relative advantages over improvised appliances. The challenge of the lack of stoma therapists and adequate stoma care education in Nigeria is confirmed by our survey.[31] Surgeons and trainees are often the ones teaching both parents and nurses how to care for the stomas. Ameh *et al*. in Zaria, Nigeria have stimulated nursing interest in stoma care by developing a home groomed stoma therapist at their hospital, which has helped to minimise complications.[6]

Perioperative provision of information to parents on what to expect and how to care for the stoma is an integral part of the consent process in most CAPS centres and many resources are also available on the internet. In contrast, Nigerian parents have minimal access to the library or internet services. Hence, the majority do not have adequate information before and even after stoma creation. Nigerian parents are often not involved in stoma education on the ward, leaving them with incomplete information and poor comprehension of the process. Many do not return for definitive surgery to allow reversal of the stoma or may present with complications that may jeopardize the survival of their children. Some parents get frustrated and abuse or neglect their wards due to the challenges they face in caring for these children with anomalies whereas balancing the care of other siblings.[32]

Study strengths and limitations

The response rate to our online survey was excellent and lends validity to the results.[10] There were many supportive comments confirming that colostomy indications and management are important topics. However there were more failed deliveries to the APSON membership E-mail list than to the CAPS membership. Tertiary centres are more likely to have reliable internet access and the majority of respondents were from paediatric surgery training centre, so the survey may underestimate resource limitations in smaller centres. Incomplete surveys (19%) were not included in the analysis and suggest that the survey may have been too long.

CONCLUSIONS

Our survey began as a joint effort to compare the management of congenital colorectal conditions

between members of two paediatric surgery societies, APSON and CAPS. We were interested in how the decision to perform a colostomy for ARM and HD might differ and concluded that the main reasons for practice variations are the differences in patient population and available resources rather than lack of training. APSON surgeons are experienced doing TEPT, but need to perform more colostomies because of the lack of frozen section pathology and more frequent older or sicker patients. There is a range of opinion in APSON and CAPS about the necessity for colostomy in females with vestibular fistula, but large series have now been reported supporting a one-stage repair. Colostomy complications are frequent, especially prolapse and could be partly avoided by preferring sigmoid divided colostomies.

Training of prospective stoma surgeons and therapists and provision of information to the childrens' caretakers would go a long way towards assisting in the selection of the right patient, right technique and right monitoring measures which would translate to a reduction in the morbidity and mortality of the colostomy. Despite until date training of APSON surgeons, there is a need for increased support and resources to help them provide this care. Stoma appliances and education, both pre- and post-operative, are needed. Increasing consistency and availability of pathologists and anaesthetics is needed to reduce the frequency of un-necessary stomas and associated morbidities and mortalities. There is potential for a collaborative educational effort between CAPS and APSON to help bridge these gaps.

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