



Best Practice Guidelines for Ostomy Care in Neonates, Children, and Adolescents

An Executive Summary

Louise Forest-Lalande

ABSTRACT

Pediatric ostomy care nursing is primarily based on best practice principles; evidence supporting care remains sparse. Although many principles of ostomy care are similar across the life span, the indications for ostomy surgery and clinical approach differ when working with neonates, children, and adolescents. An international group of pediatric ostomy care experts was brought together to offer their expertise on caring for children with an ostomy. Best practice guidelines were developed based on literature review and consensus among expert panelists. The purpose of these guidelines is to provide a resource for best practices to health care professionals caring for pediatric patients with an ostomy. This article is divided into 2 sections: the first highlights clinical aspects of pediatric ostomy care, while the second addresses psychosocial aspects of ostomy care, including effects of an ostomy on the family. These guidelines address ostomy care and need within the full spectrum of the pediatric age groups, from neonates to adolescents.

KEY WORDS: Education, Ostomy, Pediatric, Psychological impact

INTRODUCTION

Approximately 725,000 to 1 million people residing in the United States are living with an ostomy, and more than 100,000 undergo ostomy surgery annually.¹ We searched the literature but found no epidemiologic data for ostomy surgery in the pediatric population. An improved understanding of the physiologic and psychological consequences of an abdominal stoma and ostomy care has contributed to better selection of neonates, children, and adolescents requiring ostomy surgery.² Most surgeries performed in neonates and children result in temporary ostomies. Nevertheless, the length of time a patient lives with an ostomy varies from a few months to a few years, depending on the diagnosis and the surgeon's practice patterns.

Ostomy nursing comprises a framework of standards and competencies surrounding ostomy care and education, along with management of the impact on the person living with a stoma.³ Most ostomy care standards focus on the adult population. However, many aspects of ostomy care among infants, children, and adolescents differ from those of adults. These aspects include indications for ostomy surgery, the size and number of stomas, skin differences (permeability, layer number of epithelial cells, anchoring structures) in neonates and children, techniques for establishing a therapeutic relationship for both

the patient and family, and the psychosocial impact of an ostomy. Due to the relative infrequency of ostomy surgery in the pediatric population, and the paucity of research and evidence in this population, students and novice ostomy care nurses have fewer opportunities to acquire skills and knowledge specific to pediatric ostomy care. This article is an executive summary of guidelines designed to provide an overview of pediatric ostomy care. The full document, *Global Best Practice Guidelines for Neonates, Children and Teenagers*, was developed by the Global Paediatric Stoma Nurses Advisory Board (GPSNAB) (<https://www.coloplastprofessional.co.uk/stoma/clinical-evidence/best-practice-in-stoma-care-for-neonates/>). The Advisory Board that authored these guidelines is an international group of WOC nurses who completed education from a World Council of Enterostomal Therapists (WCET)-recognized program (Table 1). These guidelines for pediatric ostomy care are based on clinical evidence when available and on consensus-based best practices when evidence supporting care was not available.

METHODS

The GPSNAB met in person and virtually in 2018 and identified topics addressed in the guidelines (Table 2). From January 2018 through August 2018, all board members conducted a structured and comprehensive review of PubMed and CINAHAL electronic databases and the Google Scholar search engine for literature relevant to the keywords identified in Table 2. All elements included in this structured literature review were published in the English language. The project manager drafted the initial version of the literature synthesis for each of the 24 topics in Table 2. Board members then collaborated on crafting content for each of the topics. Content was considered final when 100% consensus was reached among board members concerning each of the guidelines. Whenever possible, related topics were grouped together, resulting

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TABLE 1.
Advisory Board Members

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Members, Advisory Board
June Amling, MSN, RN, CNS, CWON, CCRN (United States)
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in 13 final areas of guidance that comprise the best practice document summarized in this Executive Summary.

Guideline 1: Common Pathologies and Indications for a Stoma in Neonates and Children

Neonates and children have stoma surgery for reasons differing from the adult population.^{4,5} Although advances in surgical management have decreased the frequency of ostomy

creation in the pediatric population, it is still essential that ostomy care nurses and bedside nurses are aware of the common pathologies and indications leading to ostomy surgery in the pediatric population. More than half of all ostomies in the pediatric population are created during the neonatal period, and another 25% occur in children younger than 1 year.⁵ Fecal ostomies in neonates are usually created to manage anorectal malformations.⁴ The anomalies occur in approximately 1 in 5000 live births and vary from imperforate anus to cloacal exstrophy. Necrotizing enterocolitis usually affects premature neonates under 1500 g, but up to 10% occur in full-term neonates.⁴ Other indications for fecal ostomies are children with Hirschsprung disease, which occurs in approximately 1 in 5000 births,⁴ and meconium ileus that does not respond to conservative treatments. Additional indications for ostomy surgery in the pediatric population are chronic intestinal obstruction, inflammatory bowel diseases, familial polyposis, intestinal atresia or malrotation, or abdominal trauma.⁶

Urinary ostomies are even less common in the pediatric population. A vesicostomy (stoma that drains urine from the bladder) is occasionally performed when neurogenic lower urinary tract function compromises the upper urinary tract and renal function.⁴ Rarely, infants may experience bladder cancer

TABLE 2.
Selected Topics and Key Words

Topics	Key Words
Common pathologies and indications for a stoma in neonates and children	Neonate, children, adolescent, pediatric, ostomy, indications, pathologies
Therapeutic relationship	Therapeutic relationship, family, children
Types of stomas	Neonate, children, adolescent, pediatric, ostomy
Premature neonates, neonates, and children's skin characteristics	Skin, premature, neonate, children, characteristics, preemie
Stoma site marking	Neonate, children, adolescent, pediatric, ostomy, site, marking
Body profile	Babies, children, body profile
Use of convexity	Stoma, convexity, babies, children
Care of mucous fistula	Stoma, mucous fistula, skin, pouching
Multiple stomas	Necrotizing enterocolitis, management
Wear time of ostomy product	Stoma, pouching, babies, wear time
Cutting of the stoma opening	Skin barrier, opening, babies, children, measurement
Peristomal skin cleansing	Peristomal skin, babies, children, premature neonate
Flatus	Stoma pouch, emptying, breastfeeding
Rectal discharge	Colostomy, stoma, rectal discharge, loop ostomies
Mucous fistula refeeding	Enterocolitis, short bowel syndrome, mucous fistula refeeding
Vesicostomies	Urinary diversion, vesicostomy
Stoma care	Stoma, stoma care, preemie, neonate, child
Pediatric stoma care products and accessories	Stoma, pouch, babies, children
Prevention and management of stoma, peristomal skin, and systemic complications	Peristomal, skin, complications, prevention, management
Prevention and management of diaper dermatitis post-stoma closure	Stoma, colostomy, closure, baby, child, complications, diaper dermatitis, fungal, infection, diaper rash
Anal dilation, incision, and scar care post-stoma closure	Anal dilation, ostomy closure, babies, children, scar care, babies, children, complications, wound, Hirschsprung disease, anorectal malformation, imperforate anus, rectal stricture
Stoma care education according to the needs of the child and family	Stoma care, education, child, parents, developmental phases
Potential psychological impact of a stoma in children and teenagers and strategies to assist them with coping	Body image, socialization, peer relations, sexual identity, emotional, stoma, baby, childhood, adolescence, developmental phases
Activities of daily living with a stoma in children	ADL, stoma, children, teenagers, school, sleepover, sports

Abbreviation: ADL, activities of daily living.

requiring radical cystectomy and construction of an ileal conduit. Later, when the child is in remission of cancer, a urinary continent reservoir can be created. However, this occurs after the child is old enough to understand and adhere to the need for intermittent catheterization of the reservoir.

Many ostomy surgeries performed in neonates and children are temporary.^{4,5} The length of time a child will live with an ostomy varies from a few months to a few years depending on the diagnosis, child's condition, and surgeon's practice patterns.⁶

Guideline 2: How to Develop a Therapeutic Relationship With the Child and Family According to Age and Developmental Phase

Forming a therapeutic relationship with patients and their families is fundamental to pediatric ostomy care and the nurse's approach and credibility play a large role in building this type of relationship.^{7,8} Having ostomy surgery creates distress for both pediatric patients and their family. The parents of a child with an ostomy need to be supported regardless of the age of the child because they are emotionally affected by this challenging period. Informing the parents about the stoma is important. Nevertheless, the nurse must remain aware that this news may cause the parents to feel overwhelmed and parents must also be allowed to express their feelings before addressing the stoma and its repercussions. Older children may not verbally express their feelings when informed about the need for ostomy surgery. They may interpret the ostomy as a punishment, and boys may express fears of castration associated with stoma surgery. Based on their developmental age, children may feel incompetent and anxious about a reversal of the autonomy they have gained over time. The ostomy nurses should be attentive to nonverbal messages and use different strategies, such as puppets, dolls, and drawings, to enable children to express their feelings related to ostomy care. Adolescents may perceive their ostomy as a barrier to their independence and, in some cases, they may enter a period of rebellion or depression. By remaining attentive and sensitive about responses to a stoma, the ostomy nurse is most able to adopt a patient- and family-centered approach that nurtures a therapeutic relationship with the patient and family, facilitating psychosocial adjustment to the ostomy.

Guideline 3: Types of Ostomies Observed in Pediatrics

Knowledge of the types of ostomies commonly seen in infants and children is a foundational competency for health care professionals (HCPs) caring for pediatric patients living with an ostomy.^{4,6} As with adults, children can have end or loop ileostomies and colostomies. Mucous fistulas are also sometimes created in this population, especially following necrotizing enterocolitis where several fecal ostomies may be performed. They may be placed close together or further apart. The proximal ostomy is functional and eliminates stool, while the distal stoma is a mucous fistula that only produces mucus. For this reason, it is essential to accurately identify the active ostomy and mucous fistulas to ensure that the ostomy pouching system is placed appropriately on the active ostomy. In contrast, the mucous fistula may stay uncovered or be covered with a dressing or smaller ostomy pouching system depending on the amount of mucus discharge.

A vesicostomy is formed by making an opening suprapubic to the abdominal wall; the bladder wall is incised and brought up to the abdominal wall to create a small stoma, which may have the appearance of a small hole.⁶

Guideline 4: Premature Neonates, Neonates, and Children's Skin Characteristics

Knowledge of the skin characteristics in the neonates, and especially skin of the premature neonate, is essential for the pediatric ostomy nurse because it guides the nurse when selecting an optimal ostomy care product and caring for the peristomal skin. The skin of premature neonates is highly permeable when compared to the skin of an adult; it is also characterized by a weaker cohesive bond between the epidermis and the dermis.^{9,10} These changes in the epidermal and moisture barrier of the skin also increase transepidermal water loss.

Guideline 5: Stoma Site Marking

A significant portion of ostomy surgery in the pediatric population is emergent, which precludes preoperative stoma site marking.¹¹ Nevertheless, research supports stoma site marking for school-age children and teenagers undergoing elective ostomy surgery.⁶ Although the same criteria for siting are used in children and adolescents as compared to adults, the body profile of neonates and younger children who have a smaller skin surface area differs more significantly than those seen in older children or adolescents. In addition to learning techniques of stoma site marking in infants and young children, the ostomy nurse should explain the process and rationale to prevent any unrealistic expectations, especially in adolescents.

Guideline 6: Basics of Stoma Care in Neonates and Children

These include body profile, use of convexity, care of mucous fistula, multiple stomas, wear time of stoma product, cutting for the stoma opening, peristomal skin cleansing, flatus, rectal discharge, vesicostomies, and other challenges unique to pediatrics.

While ostomy care principles used in adults apply to neonates and children, the application of these principles must be adjusted to the special needs of this population. The components include body profile and differences in skin characteristics. According to *Wound, Ostomy and Continence Nurses (WOCN) Pediatric Ostomy Care: Best Practice for Clinicians* (2011), convexity should be avoided in newly formed ostomies.⁶ However, in infants and children when the suture line has healed, flexible convexity can be created with skin barrier rings and strips that prevent leakage while preserving peristomal skin integrity.

As noted earlier, neonates may have multiple stomas requiring modification of the stoma skin barrier to compensate for their limited abdominal skin surface area; in contrast, several fecal ostomies may be pouched within the ostomy pouching system, ultimately reducing the risk of peristomal skin damage.⁶ Ostomy pouching system wear time also varies in different age groups. For example, the anticipated pouching system wear time in a premature infant is a minimum of 24 hours to prevent disrupting skin integrity due to poor anchoring structures, although with some poorly constructed stomas even this comparatively short wear time may create a challenge.¹²

Several factors contribute to the comparatively short pouching system wear time used in neonates. Unlike adults, neonates should not wear ostomy products for more than few days because pediatric ostomy skin barriers, designed for greater flexibility, are thinner and therefore less resistant to corrosive stool. In addition, neonates spend most of their time in the supine position, resulting in more continuous exposure of the skin barrier to effluents from the ostomy, leading to quicker erosion. Based on these considerations, the pediatric ostomy nurse should assess the skin barrier daily to make sure that it

still provides adequate peristomal skin protection. As the baby gets older, if the skin barrier still provides good protection, the wear time may be increased. An ostomy pouching system in an older infant is expected to remain intact for at least 24 hours and as long as 4 days; the average observed wear time in older infants is 2 to 3 days.^{6,12} Adolescents sometimes achieve longer pouching system wear time, but the pouch should be changed at least every 7 days and the stoma and peristomal skin inspected with every pouching system change.

Another difference is variability in ostomy size in adults versus infants and children. In adults, the size of the ostomy typically stabilizes around postoperative week 6; afterward, it remains relatively constant. In contrast, the size of the ostomy continues to evolve over time as the infant or child grows, requiring routine measurements.

Guideline 7: Pediatric Stoma Care Products and Accessories

While the variety of ostomy pouching and stoma accessory products has grown over time, the pediatric ostomy nurse must use creativity and handcrafting when caring for this population. For example, topical products, such as liquid skin barriers, adhesive remover, skin cement, and benzoin, should be avoided in infants and children because of the risk of systemic toxicity.¹⁰ Similarly, ostomy pastes containing alcohol are avoided in premature neonates. Products increasing the bond with the skin should not be used as they may cause skin tearing upon removal of the skin barrier.

The premature neonate's gestational age, corrected age, and skin maturity should be considered when selecting stoma care products.⁶ In infants less than 37 weeks' gestational age, transcutaneous absorption is a particular concern,¹³ and ostomy pastes that contain isopropyl alcohol should be avoided. Research suggests that infants who are 37 weeks' gestational age show no drug transcutaneous absorption and have a good skin barrier function, but repeated use of isopropyl alcohol carries a risk of systemic toxicity and should be used sparingly.⁹ Other factors to consider are the location and type of ostomy. A protruding or retracted ostomy, its proximity to other stomas, its function as an active ostomy or mucous fistula, and the consistency and volume of daily output influence ostomy care including the selection of a pouching system. Additional factors that influence ostomy care include the patient's body profile, mobility, and activity level.

Guideline 8: Prevention and Management of Stoma, Peristomal Skin, and Systemic Complications

Complications of the stoma and peristomal skin are prevalent in neonates and children as they are in adults. Therefore, the ostomy nurse must know how to prevent and manage complications, always bearing in mind the particular vulnerability of the skin of premature and full-term infants.^{6,14,15} Numerous additional risk factors other than skin affect pouching in infants and children; these include developing and relatively weak abdominal musculature, along with poor siting often seen in an ostomy created during emergent surgery.

Guideline 9: Prevention and Management of Diaper Dermatitis Post-Stoma Closure

Following stoma closure, the child may experience frequent loose stools. Though usually only temporary, this change in bowel elimination patterns may impact the quality of life of

the child and family. Diaper dermatitis is one of the most common results of frequent loose stools. Etiologic factors include a change in the pH of the skin. Healthy skin has a pH range from 4 to 6, which enhances cohesion within the stratum corneum, keeps normal skin flora healthy, and impedes colonization of potentially pathogenic microorganisms.¹⁶ Both urinary and fecal matter contains ammonia, which has a pH of 11.6. Prolonged exposure to ammonia increases cutaneous pH, rendering the skin more susceptible to pathogenic microorganisms.¹⁶ Fecal matter also contains digestive enzymes such as lipases and proteases that are activated at more alkaline pH ranges, causing further damage to the stratum corneum,¹⁷ which also results in a reduction of the normal skin flora and of the skin barrier function leading to diaper dermatitis.¹⁸

All efforts should be made to reduce perianal skin breakdown. Parents are taught to change diapers frequently, day and night, and to manage promptly any skin erosion.^{6,19} Close follow-up is also indicated during this period to prevent diaper dermatitis and provide support to children and families as they move through this particularly stressful period.

Guideline 10: Anal Dilation, Incision, and Scar Care Post-Stoma Closure

The pediatric ostomy nurse should have knowledge of anal dilation. Dilation is often initiated 2 to 4 weeks following repair of an anorectal malformation or a pull-through procedure for Hirschsprung disease. Preventive anal dilation is performed to prevent anastomotic stricture, which is one of the most prevalent complications following these procedures.^{20,21} Prophylactic dilation is completed using a metal or plastic dilator or finger. Dilation is usually performed once to twice a day. Families must be educated about the goal and technique of anal dilation. Pediatric ostomy nurses must also teach parents to perform dilation correctly to reduce the risk of disruption or perforation of the anastomosis.²² We therefore recommend teaching with return demonstration. Families also must be taught how to care for the surgical incision and recognize any clinical signs of wound infection. Once the incision is healed, parents are instructed on how to care for the scar.

Guideline 11: Ostomy Care Education According to the Needs of the Child and Family

One of the challenges when working with children is adjusting our educational approach not only to patients but also to their family. This also applies to ostomy care education.⁶ The education principles used with children are based on pedagogy, while those used for adults are based on andragogy (adult education).²³ Before starting any care or education session, it is essential to be familiar with the child's condition and overall treatment plan. When planning an education session, it is equally important to take into consideration the circumstances in which the child and family find themselves. When people are in shock or denial, they are not ready to take in new knowledge and develop new skills. As much as possible, we must be sensitive to the readiness to learn on the part of the child and family. It is also important to take into account the age and developmental stage of the child as well as the presence of any cognitive, physical, or psychological barriers to learning.²⁴ The content of educational sessions can be supported by a variety of teaching aids such as puppets, dolls, coloring books, magazines, or appropriate online resources.

Guideline 12: Potential Psychological Impact of a Stoma in Children and Teenagers and Strategies to Assist Them With Coping

Creation of an ostomy impacts both children and their family. The entire family will experience changes in their activities of daily living, and the magnitude of these changes should not be underestimated. Various factors influence the impact of a stoma, and they vary based on the child's age and family composition.^{6,25-27} The guidelines discuss the respective characteristics of each stage, from birth to adolescence; they include information about the child and family's reactions and the nursing approach to adopt.

Guideline 13: Activities of Daily Living for Children With a Stoma

Resuming daily activities has a positive impact not only on children but also on the entire family. However, some precautions must be taken according to age and activities.⁶ For example, the panel recommends emptying the ostomy pouching system before placing infants in a prone position, when hugging them, or using child transport devices, such as a car seat or carrier. When going to school or for sleepovers, teach the child and family to take sufficient ostomy products and a change of clothes in case of leakage. In addition, a responsible person should be informed of the child's situation in case of need.

CONCLUSION

A best practice guideline document was developed through a collaboration of international WCET-certified ostomy nurses. This document provides a focused, evidence-based, and consensus-based resource to inform best practices in pediatric ostomy care. The GPSNAB recommend additional research focusing on ostomy care in the pediatric population. We also recommend incorporating guidelines into current management and educational programs for ostomy and WOC nurses.

The entire guideline is available as Supplemental Digital Content: https://www.coloplastprofessional.com/Global/CPOC_Paediatric_stoma_care_guidelines

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KEY POINTS

- ▶ Although similar to adult stoma care, caring for infants, children, and adolescent with an ostomy presents unique challenges.
- ▶ Knowledge of the management of potential pediatric stomal and peristomal skin complications allows the ostomy nurse to deliver optimal care.
- ▶ Pediatric ostomy nursing care must include physiological, physical, educational, and psychosocial aspects unique to this population.

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