Ostomy Life Study Review 2018/19

Raising awareness and improving the standard of ostomy care by sharing evidence-based data and clinical insights

The Ostomy Life Study Review is a recurring publication developed by Coloplast in cooperation with expert ostomy nurses in the Global Coloplast Ostomy Forum.

Coloplast® Professional

It's all about providing you with the latest insights and tools – so you can deliver the best possible care to your patients.


Nurse
Manon
Horizon General Hospital
CLEANSING BALM
Living with stomas
ABSTRACT

Contents

Welcome to the Ostomy Life Study Review 2018/19

In this year's Ostomy Life Study Review, we focus on some of the challenges that healthcare professionals working within the field of ostomy care experience. By sharing new research, our latest survey results, and best practice guidelines, we hope to present solutions to some of these challenges – and give you new insights and tools that you can use in your clinical practice.

Reducing the burden of leakage

Leakage is one of the greatest challenges for people with a stoma, and the consequences are serious. Not only in terms of skin complications. The constant worry of having an accident in public has a huge impact on a patient's quality of life too.[1]

We know that a poor fit to the body is the main cause of leakage. So, the clue is to find a type of pouching system that creates a perfect fit. But since every body is different, this can be quite a challenge.[2]

In "Working together to find the right fit for the patient" (p. 8), we share the process and outcome of our Peristomal Body Profile Consensus Project. Consolidating frontline experience from almost 2,000 ostomy nurses from all over the world, the project has managed to reach a global consensus on how to accurately assess body profiles and determine the best ostomy pouching system to fit. With these best practice guidelines and recommendations at hand, you finally have the valid tools you need to ensure perfect fit, greater comfort and ultimately reduce the burden of leakage for your patients.

Reflecting the patient perspective

That so much depends on a perfect fit, is more than evident in "The importance of finding the right fit" (p. 12), Steve Cartmail shares his struggle with rashes and leakage – challenges he has had to live with for years until the right pouching system for his body profile finally put an end to his discomfort.

Steve's struggle is verified by the thousands of people with an ostomy who took part in our survey providing data for the article "Understanding stoma-related skin complications" (p. 16). The results reflect how they deal with skin complications – and what impact these complications have on their quality of life. Giving us real insight into how patients cope with their condition, this may inspire discussions on how to focus clinical practice in the future.

Mapping unexplored areas

When looking at the existing research on ostomy care, there are still a number of important areas that are less documented. One of them is pediatric ostomy care.


any bodies.
Different fits.

Seven nurses from five different countries – each with extensive experience in pediatric ostomy care – have joined forces to fill this gap. In "Defining best practice for pediatric ostomy care" (p. 20), Louise Forest-Lalande shares the progress of the group's work to develop best practice guidelines for ostomy care for babies and children.

A group of healthcare professionals from the UK, headed up by Claire Bohr, are working to cast light on another unexplored area within pediatric ostomy care. "Examinating the emotional impact of living with a stoma for children and teenagers" (p. 24) provides an overview of the key findings from the initial phase of their project, involving focus group interviews with school-age children and pediatric surgical staff.[3]

Stoma formation is a common complication in very premature infants – and the procedure itself is not without risks either. One way of reducing the associated complications is through a procedure called mucous fistula refeeding. The article, "Nutritional support and additional benefits for infants with stomas" (p. 26) explains what this practice is all about – and shares insights on the benefits of this treatment option and the current barriers to its widespread adoption.

Delivering better outcomes

As a healthcare provider, your role is to respond to the emotional disruption that ostomy surgery causes for any patient, whether child or adult, male or female. In "Crucial paths of healing" (p. 30), Rune Nørager and Mette Terp Høybye reflect on the power of recognition when it comes to restoring a wounded self and engaging the patient in self-care.

Feeling empowered to resume an active life – be it in or outside the labor market – is not only hugely important for the individual, but also for society. Ostomy patients present a high cost to the healthcare system, as the data in "Exploring the burden of illness for people with an ostomy" (p. 32) testify. Healthcare providers and product developers both have an important role to play in easing this burden.

We hope the articles in this volume will provide new inspiration and support you in your efforts to give patients the care and confidence they need to move forward with their lives.

Medical Marketing, Coloplast A/S

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1. Claessens I, Probert R, Tielemans C, Steen A, Nilsson C, Andersen BD, Storling ZM. The Ostomy Life Study: the everyday challenges faced by people living with a stoma in a snapshot, Gastrointestinal Nursing 2015. 13(5)
2. Coloplast, Market Study, Usage Pattern Study, 2015, Data-on-file (PM-04465)
3. Hein-Nielsen AL, Petersen SM, Greisen G, Unchanged incidence of necrotizing enterocolitis in a tertiary neonatal department, Dan Med J 2015; 62(7): A5091

Reducing the burden of leakage

Working together to find the right fit for the patient

Minimizing the risk of leakage is crucial when it comes to ensuring quality of life for patients with an ostomy.[1] This article presents consensus-based best practice guidelines for peristomal body assessment – based on the expert opinion of almost 2,000 ostomy nurses from all over the world.

Building a consensus on best practice

To facilitate the development of peristomal assessment guidelines, Coloplast embarked on a Peristomal Body Profiles Consensus Project. The goal was to create an international consensus among ostomy nurses on how to quickly and accurately determine what type of ostomy pouching system would provide the best fit and deliver the best comfort and security for their patients.

"The process has been conducted to reach a global consensus on a structured and validated assessment of peristomal body profiles," says Anne Steen Hansen, Senior International Medical Specialist at Coloplast. "We wanted to develop a set of guidelines that will guide nurses all over the world to determine which ostomy pouching system they should use to ensure a tight seal between the body and the barrier for each individual patient."

The methodology

To arrive at a consensus, the project team used a modified Delphi process (see Figure 1). This method drew on the frontline experience of ostomy nurses from around the world to develop peristomal assessment guidelines that can be implemented internationally.

"The modified Delphi process is a method that can ensure that experience and evidence-based knowledge is combined into valid, practical guidelines that can guide stoma care," explains Anne.

At the end of the process, the project team had gathered input from almost 2,000 stoma care nurses from 15 countries. The nurses surveyed had a combined 16 million hours of ostomy care experience to draw upon.

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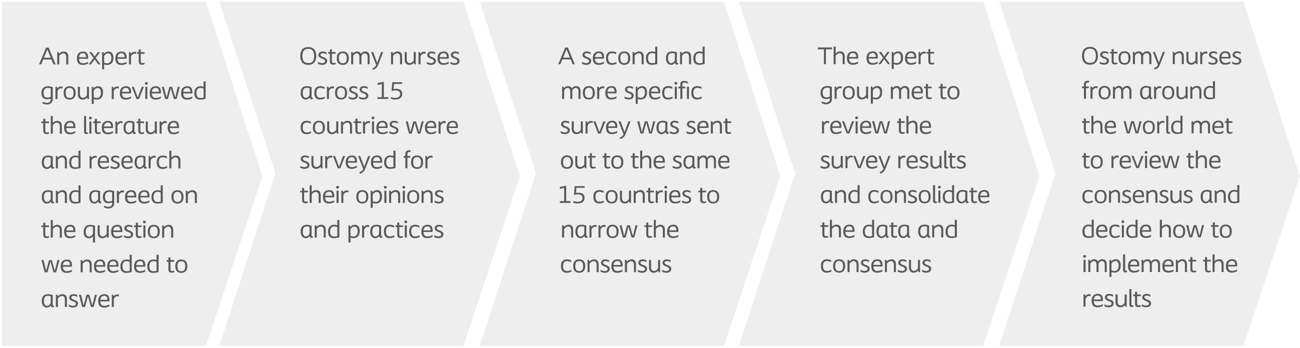
1. Coloplast, Market Study, Ostomy Life Study Review, 2016, Data-on-file (PM-03463)

MODIFIED DELPHI PROCES



An expert group reviewed the literature and research and agreed on the question we needed to answer

Ostomy nurses across 15 countries were surveyed for their opinions and practices

A second and more specific survey was sent out to the same 15 countries to narrow the consensus

The expert group met to review the survey results and consolidate the data and consensus

Ostomy nurses from around the world met to review the consensus and decide how to implement the results

Figure 1

The recommendations

The first recommendation addresses patient follow up.

The goal with these recommendations is to eliminate the burden of leakage, so patients feel secure and confident to continue engaging in their pre-stoma activities and lifestyle.

Recommendation: Contact with the patient with a newly formed stoma should be made within 2 weeks after hospital discharge or after a product change.

The follow-up session should include:

- Assessment of the peristomal body profile and peristomal skin health at every product change.
- Patients should be given tools to help them accurately assess peristomal skin health and identify when to seek help.
- Use a validated skin health and body profile assessment tool when assessing skin health and body profiles.
- Make pouching system recommendations based on the individual patient's body profile and skin assessment, preferably using validated body profile and skin assessment tools.
- Pouching system type should be based on the needs of the individual patient and not be made based on provider preference, a set order of product usage or through trial and error.
- Prescribe the appropriate ostomy pouching system based on the assessment of the patient's stoma and peristomal body profile and patient preference.

Recommendation: Engage and educate patients throughout the patient journey – during the pre-operative phase, during the acute care stay and ongoing basis.

- Coach the patient and their family to become engaged in their care by educating them in all aspects of their care and to be more proactive when it comes to their own health management.
- Provide and educate the patient and their family with tools to assess their peristomal body profile - and skin health.
- Educate the patient and their family on abnormal findings and when and how to seek help.
- Guide the patient to setting realistic goals to reach their optimal health and quality of life, throughout their ostomy journey.

Validating the recommendations

The biannual Ostomy Days conference provided the backdrop for the final phase of the process (see Figure 1).

More than 850 ostomy nurses gathered in Copenhagen in late April 2018 to review the results of the consensus project and provide their feedback to the final recommendations. The recommendations were discussed in groups, and feedback was documented. Their responses demonstrated that they were in full agreement with the recommendations, and that education and communication are key to making these recommendations an integral part of ostomy care.

Learn more

If you wish to get more information about the Peristomal Body Profiles Consensus Project, please contact your local Coloplast sales representative.

6 STEP ASSESSMENT PROCESS

Based on the input and survey responses, the guidelines recommend a 6-step process for assessing the peristomal body profile.

1. Consider the shape of the area around the stoma. Is it regular, inward or outward?
2. Is the shape around the stoma uniform or variable?
3. Is the area around the stoma soft or firm?
4. Does the skin around the stoma have superficial creases or deep folds?
5. What is the location of the stoma – above the bending line, at the bending line or below the line?
6. What is the position of the stoma opening and the height of the stoma in relation to the skin's surface?

Figure 2

Reflecting the patient perspective

The importance of finding the right fit

No two bodies are the same. That's why there's no such thing as a one-size-fits-all pouching system solution. Identifying the patient's body profile – and finding the right barrier to fit – can be an important step to ensuring quality of life for the patient.

So much depends on a perfect fit

As a healthcare professional, one of your goals is to help patients maintain a high quality of life. For ostomy patients, quality of life has a great deal to do with their pouching system solution. Finding the right pouching system with a good fit makes them feel comfortable and secure.[1] It can help them to carry on their lives in much the same way as they did before their stoma operation.

Meet Steve

Steve Cartmail's experience illustrates this. After struggling with ulcerative colitis for many years, Steve had an ileostomy created two years ago. Shortly after surgery, he developed a hernia.

After discharge, Steve tried many different ostomy pouching systems. "I tried them all, but they gave me rashes or leakage," he recalls. "Your confidence is just ruined when you're woken up by that warm feeling on your body – and you just know it's happened again."

Part of Steve's challenge was finding the right ostomy pouching system. Like 35% of people living with an ostomy[2], he has an outward peristomal body profile due to a hernia in the peristomal area. People with an outward body profile often have difficulties finding a barrier that fits properly because of the curved shape of the peristomal area. This shape can make it difficult to get a tight seal due to folds and wrinkles on the barrier and lack of adherence of the barrier to the skin.

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1. Coloplast, Review, Ostomy Life Study, 2015/16.
2. Coloplast, Market Study, Ostomy Life Study ECET Pre-Event, 2017, Data-on-file (PM-04559).

Steve is a SenSura® Mio Convex Flip user who has received compensation from Coloplast to provide this information.

Convex Flip pouching system

Steve has been able to test the SenSura® Mio Convex Flip barrier twice, which is specifically for people with an outward body profile. The barrier fit his hernia really well. "As soon as I put the product on, I knew I had found something that would work for me," he explains. "It was comfortable, and it gave me the confidence that it was going to stay where it was supposed to be."

Steve's experience shows what a difference a well-fitted barrier can make in a patient's life. And nurses working in ostomy care confirm this. "What's needed is a product that's flexible enough to work with someone's body contours and is able to give them the security they crave," says Tracey Virgin-Elliston, Lead Nurse Specialist, Stoma Care at West Middlesex University Hospital. "Ensuring that a product offers better security will work wonders for patients in terms of their self-confidence and quality of life."

Results from the evaluation with the Convex Flip barrier

Steve wasn't the only person to respond positively to SenSura Mio Convex Flip. The results from the product evaluation showed that others had a similar experience.

The barrier was evaluated by people with an outward body profile, who normally use a flat barrier. The participants tested the Convex Flip barrier over a period of four weeks. They responded that the barrier functioned well and felt comfortable. Moreover, the majority of the participants didn't experience unplanned changes with the Convex Flip barrier, compared to the flat barrier that they were currently using (Figure 1).

The life of ostomy patients with an outward body profile[2]

- have a lower quality of life compared to patients with a regular body profile
- use more accessories
- worry more about leakage
- are more concerned about the lack of discretion

Fewer changes

Percentage of participants who did not experience unplanned changes with the 'Convex Flip barrier' (compared to their 'usual barrier'). P=0.03[3]

Figure 1

■ *Convex Flip barrier n=103*

■ *Usual barrier n=83*

Quality of life measured with the Ostomy Q (0-92).

The combination of a better fit and fewer unplanned changes had a positive influence on the participants' confidence in the product, and the total quality of life score increased from 55 to 67 during the 4-week evaluation.[3]

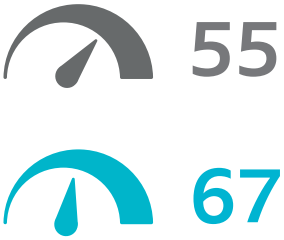
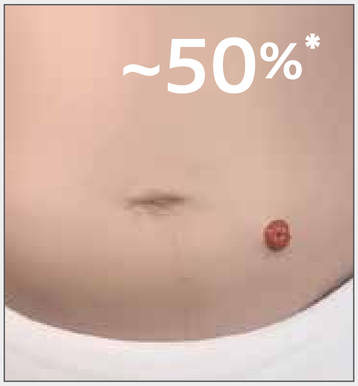


Figure 2

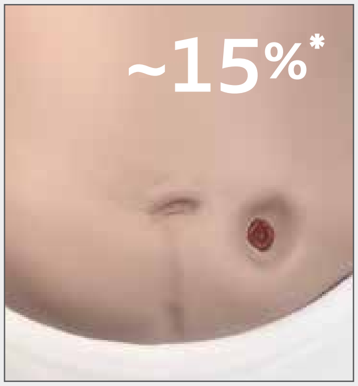
■ *Convex Flip barrier n=103*

■ *Usual barrier n=83*

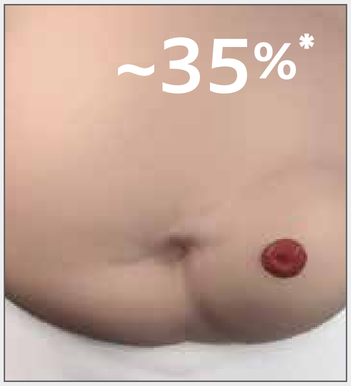
WHAT IS THE FORM OF THE AREA AROUND THE STOMA?[2]



REGULAR, where the area around the stoma is more or less even with the abdomen.



INWARD, where the area around the stoma sinks into the abdomen creating a hollow.



OUTWARD, where the area around the stoma rises from the abdomen creating a peak.

**proportion of the population with a stoma with each body profile*

> *“I’m so impressed with how well the product moves with my body. I really feel that I’ve been able to move forward and get on with my life.”*
>
> ***Steve, a SenSura® Mio Convex Flip user***

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3. Coloplast, Product Evaluation, SenSura Mio Concave, 2017, Data on-file (PM-05104).

The Ostomy-Q is a validated quality of life measurement tool, where 0 is low and 92 is the highest possible score.

Understanding stoma-related skin complications

The Ostomy Life Study 2016 was commissioned to learn more about how ostomy pouching systems affect the daily life of people living with an ostomy. The first phase gathered input from ostomy nurses on the Coloplast Ostomy Forum (COF) boards. Their input formed the basis for a questionnaire sent to over 20,000 people living with an ostomy. One of the goals of this survey was to get a better understanding of the prevalence of skin complications and how the participants are aware of and/or manage their skin complications. The following pages present highlights, concerning skin complications, from the Ostomy Life Study 2016.[1]

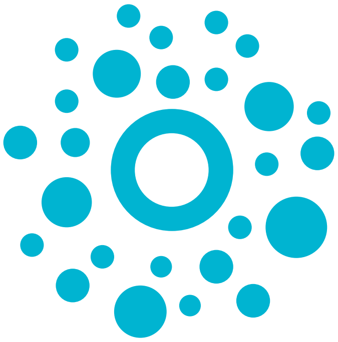
The methodology

The Ostomy Life Study 2016 includes responses from more than 4,000 people living with an ostomy in 13 countries. The respondents include both Coloplast and non-Coloplast users.

Data was collected from 30 August to 3 October 2016.

[1] Coloplast, Review, Ostomy Life Study, 2016, Data on file (PM-04985).

Respondents



73%

of respondents had at least one skin issue within a 6-month period. While all types of peristomal profiles deal with skin complications, inward body profiles seem to struggle more with a wider range of issues.

Gender

Females report having more skin issues than the males surveyed.

♀ **79%**

Have skin issues

♂ **69%**

Have skin issues

Age

According to the study, people aged 18-59 have a higher tendency to experience skin issues.

86%

of 18-59 year olds have skin issues

72%

of 60+ year olds have skin issues

Type of stoma

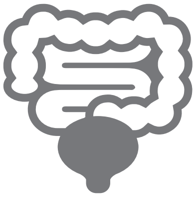
People with an ileostomy also have a higher prevalence of skin issues.

68%

of people with a colostomy have skin issues

80%

of people with an ileostomy have skin issues



69%

of people with a urostomy have skin issues

Actions taken, when experiencing skin issues

Around 25% contact their Wound Ostomy Continence (WOC) Nurse, when they experience skin issues. Around 17% don't do anything differently.

25% *contact their WOC Nurse*

50% *use a skin barrier product*

17% *do not do anything*

To what degree are skin issues linked to leakage?

Our data clearly show that the more often people experience leakage, the higher the prevalence of skin complications.

85% *of people who* ***often*** *experience leakage have skin issues*

74% *of people who* ***occasionally*** *experience leakage have skin issues*

59% *of people who* ***never*** *experience leakage have skin issues*

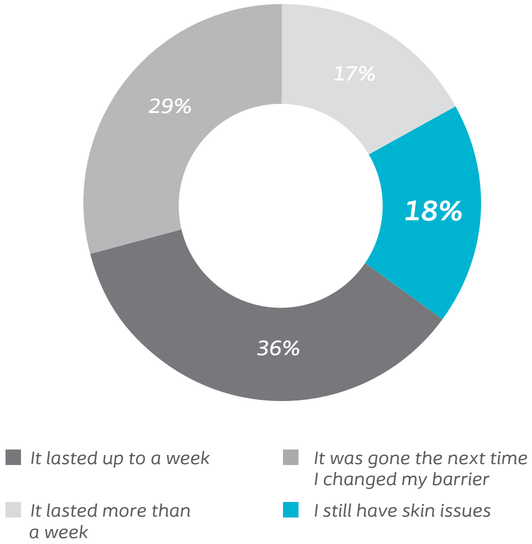
What causes skin issues

Around 6 out of 10 users believe their skin issues are caused by leakage on the skin.

answer that their skin issues are a result of leakage.

Duration of skin issues

The results also show that for some users the skin issues disappear quickly, while they are ongoing for others.



Duration of skin issues is linked to leakage!

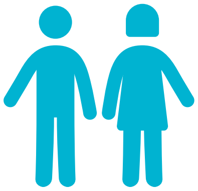
The results also show how the duration of the skin complications is linked to leakage frequency. 44% of those who often experience leakage still have skin complications as compared to only 21% of those with no leakage issues.

44% *of people who **often** experience leakage*

24% *of people who **occasionally** experience leakage*

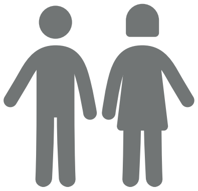
21% *of people who **never** experience leakage*

Creases/folds



84%

of people with creases/folds have skin issues

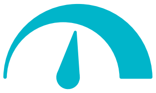


68%

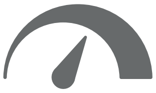
of people without creases/folds have skin issues

Quality of Life Score

The Quality of Life (QoL) score for people who experience skin issues is only 51, as opposed to 62 for those without skin issues.



51 *with skin issues*



62 *without skin issues*

QoL on a scale from 0-92

Defining best practice for pediatric ostomy care

Global best practice guidelines covering pediatric ostomy care are basically non-existent. There is no central resource that healthcare professionals across the globe can turn to for insights and recommendations when working with children living with an ostomy - and those that do exist are dated and may not fully reflect the latest practice standards and product use. The few guidelines that do exist are not readily available or accessible to everyone. Clearly, there's an acute need for well-documented guidelines for treating this particular patient group.

The purpose of the best practice guidelines in pediatric ostomy care is to:

Support better routines and outcomes by providing a central resource for pediatric best practice

Provide comprehensive information and recommendations for optimal quality of ostomy care delivery in the pediatric population

Provide credible, evidence-based **recommendations** substantiated with references

Establishing best practice

To address this need, Coloplast facilitated the development of a set of best practice guidelines by gathering an international group of seven stoma care nurses with almost 200 years of combined experience in pediatric ostomy care. The group began their work in January 2018, and held their first face-to-face meeting in March the same year.

Louise Forest-Lalande (RN, M.Ed, ET), an ostomy nurse with 26 years of experience in pediatric ostomy care, is spearheading the work. We asked her to share some thoughts about the need for best practice guidelines and give us an update on how the work is progressing.

“We are so happy that pediatric ostomy care now has a voice.”

Louise Forest-Lalande, RN, M.Ed, ET

Shining light on a lesser known area

"Ostomy care in children is not that known," comments Louise. "When I tell people that I'm working with children and babies, they are stunned to know that babies can have stomas. Their initial reaction is to say, 'I would not know how to manage that.' That's the goal of these guidelines."

"It's important for healthcare professionals to have a reference or a resource they can go to when caring for children. The reference needs to cover the physical aspects of pediatric care, but also address the psychological point of view," Louise states.

Getting an experienced, international perspective

The board of seven nurses represents six different countries, which will help the guidelines have a more international perspective. "We hope to provide a more international flavor, says Louise. "It's really enriching because we all come with our personal experiences, sharing what we have learned from our daily practice. We're seasoned people, but we're still looking towards the future to see how we can improve the quality of care and life for this patient group."

A living document

Once the guidelines are completed, the team's aim is to translate them into a few main languages and present them at a regional, national and international level. They also want to host webinars; create a newsletter focused on pediatric ostomy care; and publish the guidelines in appropriate publications. "We don't want this guide to stay on the shelf," says Louise. "It needs to be a living document, which we keep nurturing. And we want everyone to know that these guidelines are available and where to find them."

The gathering of such an experienced group of pediatric stoma care nurses has also opened the door for new projects within this field.

"One of the board members has developed a Quality of Life tool for children with stomas, and she would like for the group to validate the tool. It's always difficult to do studies with children, because their number isn't big enough. But with the board members coming from different countries, we can reach more people."

Meet the Global Pediatric Stoma Nurses Advisory Board Members

Ester Sanchez, Spain
Claire Bohr, United Kingdom
Gail Creelman, Canada
Edith Ekkerman, the Netherlands
Sophie Vercleyen, France
June Amling, USA
Louise Forest-Lalande, Canada

Examining the emotional impact of living with an ostomy for children and teenagers

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 pediatric stoma psychology.

Uncovering pediatric 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, pediatric stoma and bowel management nurse at University Hospitals Bristol (UK), wants to explore the psychosocial impact of pediatric stoma formation.

"Our goal is to gain a better understanding of the psychosocial issues children face," explains Claire. "We recognize that the importance of managing stress and anxiety has been well-reported, but poorly addressed in practice. For example, preoperative counseling 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 preoperative counseling. 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 pediatric surgical staff. Using focus groups and interviews, the project team aimed to compare staff and patient perceptions of the psychological impact of ostomy formation in the pediatric population.

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
- Pediatric surgical staff
- 6 boys, 3 girls (mean age: 14), 10 parents, 16 members of a pediatric surgical team.

The children's perspective

Claire explained that the children interviewed talked freely about the positives and negatives of life with an ostomy. On the positive side, they highlighted being able to meet new people; still being able to socialize 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 vacation, swimming, and other sports. Some struggled with leakage and bad smell. Others viewed changing the pouch as an annoyance. They also commented that the surgery had a negative impact on their participation at school, causing them to miss class and poor academic performance as a result.

The professionals' perspective

The members of the pediatric 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 an ostomy – 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 manage their stomas independently upon discharge, especially teenagers.

In terms of the impact on school and social areas, the group believed using public or school bathrooms was an issue due to embarrassment about odor. 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 pediatric ostomy patients would be willing to tell their friends. There was also uncertainty about how well the ostomy pouching system 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 counseling and expectation management of future patients. This will be done by sending questionnaires to children and their parents/caregivers.

Nutritional support and additional benefits for infants with stomas

Mucous fistula refeeding has emerged as a way of addressing nutritional and developmental needs of infants with stomas. How does this practice actually work – and what do the literature and the practitioners have to say about this treatment option? This article shares insights from our recent survey.

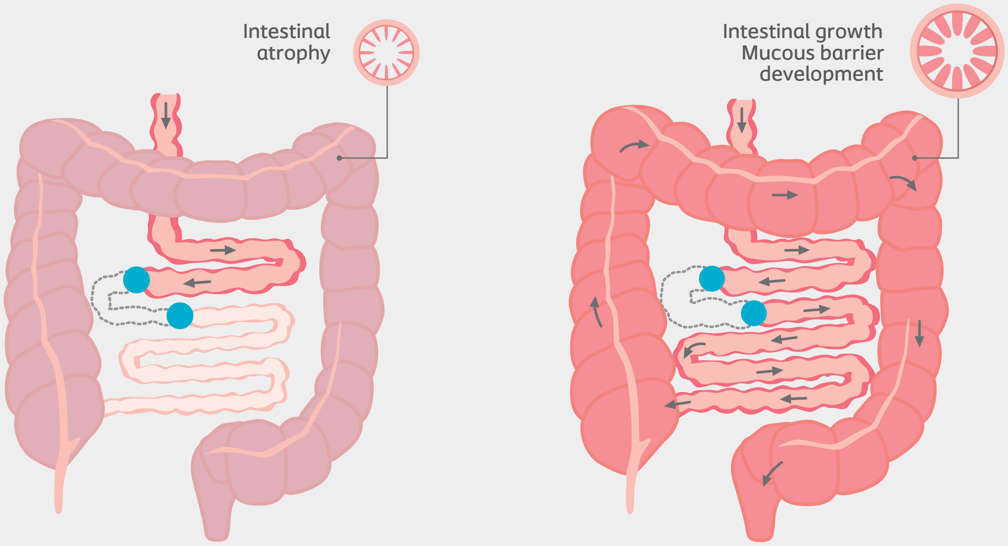
Common complications with premature infants

Stoma formation may be a necessary treatment option in premature infants. Unfortunately, ostomy surgery may lead to further complications.

According to one study, 6% of infants with birth weight below 3.3 pounds developed intestinal inflammation, known as Necrotizing Enterocolitis (NEC). And 56% of these infants needed intestinal resection and stoma formation.[1]

In most cases, stoma formation is an acute procedure performed after removing the necrotic part of the intestine. While the length of this part of the intestine varies from patient to patient, the lower part of the intestine may be unaffected. Following the surgical procedure, the infant will often have two stomas: a producing stoma (proximal) and a mucous fistula, the distal part of the bowel connected to the rectum. Since the lower part of the intestine is still functioning, the stoma can be reversed once the infant is stable.

The route of the chyme through the intestine with or without refeeding



NO REFEEDING
Just collection of output

● Stoma

WITH REFEEDING
Intestinal growth and microbial colonization

Figure 1

While intestinal resection and stoma formation are necessary, several unwanted side effects may arise.

When the lower intestine is detached from the digestive system, it doesn't receive the nutrients it needs from chyme – which can ultimately lead to atrophy of the intestine. The lower intestine also supports the infant's nutritional uptake, biliary salt turnover and fluid balance – and these functions may be compromised if the lower intestine is left unused.[2]

Mucous fistula refeeding: the benefits and the barriers

One way of preventing these side effects is through a procedure called mucous fistula refeeding. It refers to the process of taking chyme produced by the upper (proximal) stoma and transferring it to the lower, distal part of the intestine.[3,4]

To learn more about the pros and cons of this procedure, we conducted an online survey among 30 physicians (including neonatologists and gastrointestinal surgeons) in the US, UK, Canada, Italy and Germany[5] and combined this with a systematic literature search.[2-4, 6-15] Using a five-point scale ('very unimportant', 'unimportant', 'neither/nor', 'important', 'very important'), the physicians were asked to evaluate different statements on the possible benefits as well as the risks and obstacles involved when performing mucous fistula refeeding.

What is mucous fistula refeeding?
The process of taking chyme produced by the upper (proximal) stoma and transferring it to the lower (distal) part of the intestine.[3-4]

Our findings revealed that mucous fistula refeeding has a number of significant benefits[6]:

- Less fluid and nutritional complications: By providing the distal intestine with nutrition, refeeding helps to reduce the number of nutritional complications, e.g. those related to parenteral nutritional support and fluid losses.[2,3,7]
- Fewer associated complications: With less parenteral nutritional support needed, we see a reduction in cholestasis too.[2,9]
- Higher success in re-anastomosis (stoma reversal): Infants who receive refeeding have shown a higher success rate when the stoma is reversed and the intestine reconnected.[2,9]
- Increased growth rate: Infants who receive refeeding show a significantly higher growth rate.[2,3,7,8]
- ≥ 80% of the physicians surveyed stated that refeeding was 'important' or 'very important' for improving the infant's growth.[5]
- ≥ 50% of the physicians surveyed stated the practice was 'important' or 'very important' for immune system development and survival rate.[5]

Despite the reported benefits associated with refeeding, the procedure is not yet common practice. Literature on the subject and the physician survey identified three main barriers to widespread adoption:

- Complications: Some of the articles reported a few incidents of major complications (e.g. intestinal rupture or intestinal bleeding); others described concerns related to intestinal bacterial overgrowth, over the time the output stayed in the pouch,[8] and possible sepsis through the introduction of pathogenic bacteria.[10,12]
- Appliances: More than 30% of the physicians surveyed highlighted the lack of a good ostomy appliance for refeeding. If it were available, ≥70% would prefer a sterile ostomy pouch for refeeding.[5]
- Shortage of time: 20% of physicians felt the refeeding procedure was too time-consuming for nurses to perform.[5]

Future prospects?

For refeeding to become a widespread practice, healthcare professionals will have to be convinced that the benefits of the practice outweigh the risks as well as the extra time needed for nursing. According to our physician survey, this appears to be the case.

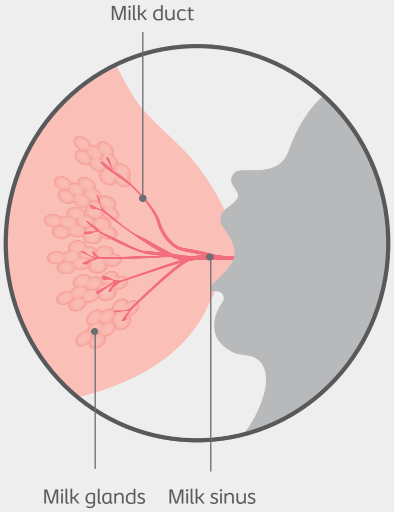
- 80% expect refeeding to be practiced more often in the future
- 53% believe the benefits of refeeding outweigh the risks, whereas 10% do not. 37% said that it depends on the situation.[5]

The physicians surveyed expected future studies to demonstrate the positive impact refeeding can have on growth, immune system development, and mortality for premature infants with stomas.

There is another fact that is hugely important for the adoption of the procedure, and that is the presence of best practice guidelines.[16,17] Hospitals will need to discuss and prepare such guidelines to help minimize any possible risks or concerns related to the procedure.

The 3 main benefits to mucuous fistula refeeding are ensuring nutritional, antibody and microbial transfer to the lower part of the intestine[18]

3 Antibody and bacteria transfer from breast milk

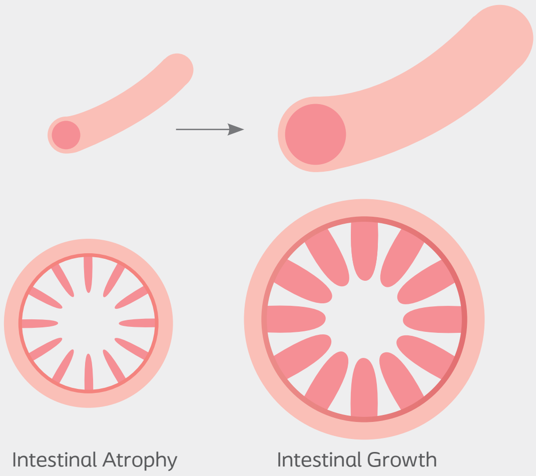


What is chyme?

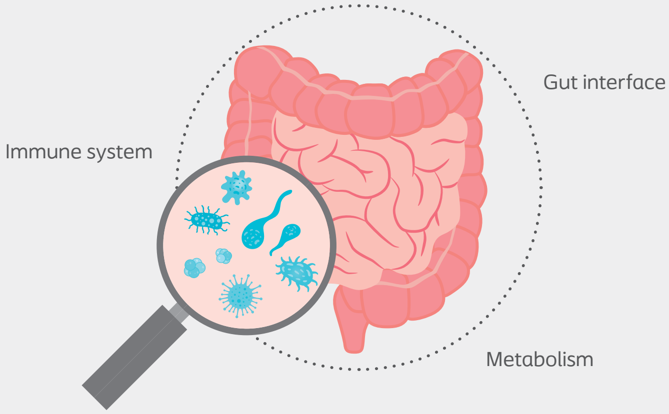
Chyme is partly digested food which, in the case of infants, consists of breast milk. Chyme helps the lower intestine by:

- stimulating intestinal growth;
- transferring antibody IgA and bacteria to the lower intestine, which may help immune system development; and
- colonizing it with bacteria from the mother and from the upper intestine

1 Stimulates intestinal growth



2 Colonizes lower intestine with bacteria from upper/ascending stoma



BREAST MILK

Extracellular vesicles

Prebiotics

Probiotics

Cytokines

Antigens

Cells

Antibodies

Intestinal immunity of the child

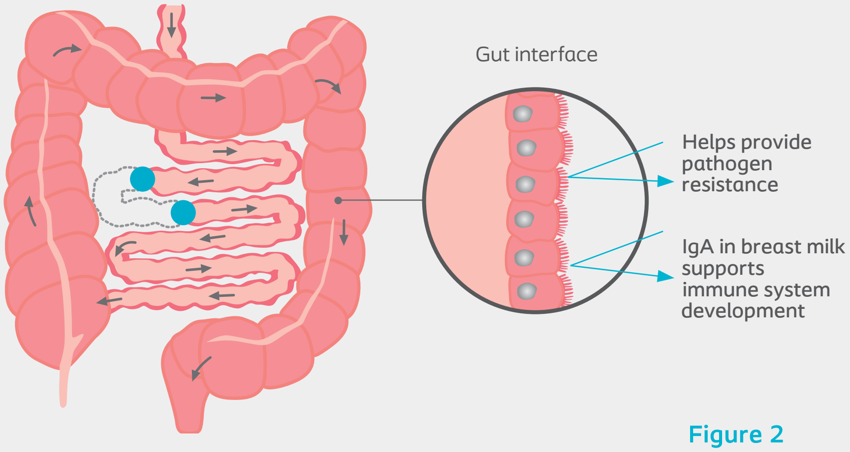


Figure 2

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Crucial paths to healing

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Going beyond the clinical practice of ostomy care is vital when it comes to helping patients feel more confident about moving forward. Research now confirms what many of you have known and practiced for a long time: that recognition and care pave the way to healing.

Trauma – such as chronic illness – can disrupt the patient's sense of self. People in this situation often describe themselves as being 'lost in the dark' – feeling a loss of self, a loss of energy, and a loss of purpose in life.[1]

Healing the wounded self

It's not surprising, then, that when ostomy patients are encouraged to engage in self-care, they might say, "What's the point? I can't even interact with people, let alone carry out a daily task like this." What the patient is really saying is that she cannot imagine her future self. She is unable to face the new normal and therefore cannot start caring for the self again.

So how do you respond to a disrupted self – to a patient who has lost a sense of self-being?

From research on how people experience and live with illness, we know that social encounters during treatment are crucial in helping to restore the patient's sense of self and ease her transition to self-management.[1]

Moments of opportunity

Words of comfort are far from enough. Saying, "Don't worry, it'll be alright" is not really listening to the patient or recognizing their suffering. As a professional caregiver, it's important to relate to the patient's suffering during treatment. By making the patient feel seen and heard, you create a space where the self can be restored.[2]

Recent findings tell us that the patients who were most confident about moving forward in life were the ones who had had meaningful social encounters in the clinic with healthcare professionals.[1] A caring touch, for example, assuring the patient that they don't have to be 'good' or 'brave', or an honest response acknowledging that their new life is not going to be the same as before.

Imagining a new normal

Open and honest interactions move the patient away from being treated as 'a patient' to being seen as a human being.

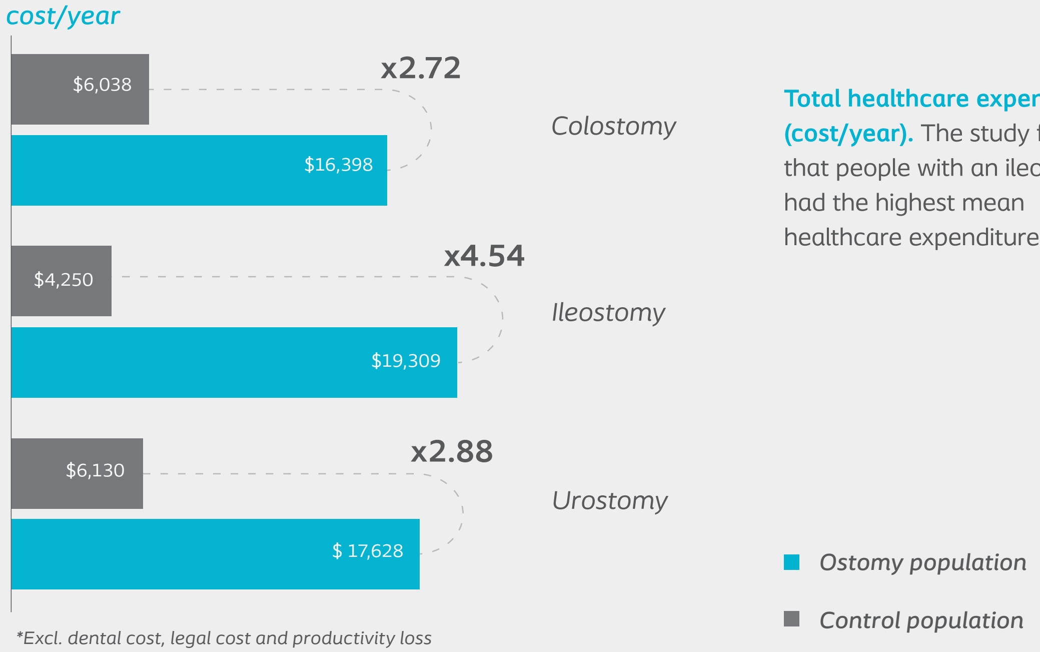
By helping them imagine life beyond the hospital setting, you help the patient into the space between the actual (a weakened physical state) and the potential (the competent body adjusting to life with a chronic condition).[3] It is in this space that the gradual restoring of self can take place.

The patient's ability to visualize a new normal and to start caring for the self again eases their transition. It is important for them to see that self-management of the chronic condition is an empowering practice. Bringing the patient to this stage is exactly what you can help to do. And by doing so, pave the way to a healing of the self and better treatment outcomes.

Exploring the burden of illness for people with an ostomy

This article explores the economic and societal impact of living with an ostomy – and how you as a healthcare professional can assist patients in coming to terms with their condition and continuing to be active members of society.

Total healthcare expenditure divided by type of stoma*



Total healthcare expenditure (cost/year). The study found that people with an ileostomy had the highest mean healthcare expenditure.

**Excl. dental cost, legal cost and productivity loss*

Figure 1

Living with an ostomy

The reactions to living with an ostomy are varied and complex. People may feel overwhelmed, despondent, angry or embarrassed. They may have a hard time understanding and accepting how an ostomy impacts their daily life.

This can be a contributing factor to extended sick leave, permanent reduction in work hours or, in worse cases, permanent unemployment. These outcomes all have a significant impact on the economy of the society.[1-3]

Exploring the economic and societal impact

A recent burden of illness study investigated real-world claims data from 2.5 million German beneficiaries. The study looked at three ostomy groups; people with a colostomy, ileostomy or urostomy. The control populations consisted of a random sample of beneficiaries. For every person included in the ostomy population, 50 people with the same age and gender were included in the control populations. It examined the prevalence of medical conditions, healthcare costs related to treatments, and the economic costs resulting from productivity losses in the ostomy population throughout 2015.[4]

The study found that people with an ostomy as a group posed a significantly higher cost for the healthcare system compared to the control population (Figure 1). They are also less likely to be part of the 'active population' – that is, the proportion of the population who is employed, seeking employment, or active in volunteer work (Figure 3). And those who are a part of the 'active population' have significantly more sick days compared to the control population (Figure 4). The number of sick days taken by people with an ostomy led to an average productivity loss for society of $12,598 per year, per ostomate.[4]

The role of the healthcare professional

As healthcare professionals, you play a vital role in helping people with an ostomy accept the implications of their condition. Of course, there are many aspects of the burden of illness that are out of your hands. Yet some of the driving forces behind sick leave and unemployment are psychological. People with an ostomy who struggle with embarrassment, fear of leakage, lack of discretion and unplanned pouching system changes can be more likely to withdraw from life.

By working with users in the initial stages – helping them to uncover and address their fears – you can get them on the road to acceptance and back to being productive members of society.

Defining 'burden of illness'

'Burden of illness' is a term that refers to an illness' impact on a country, specific region, community or an individual. It can be calculated by examining the condition's prevalence and its impact on lifespans and mortality rates in a specific area. It includes the economic impact on society, including the direct and indirect costs of premature death, disability and related illnesses. The burden also includes the impact on individuals' quality of life and health status.[4]

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Distribution of total healthcare expenditure* for people with an ostomy

cost/year

Distribution of total healthcare expenditures for the ostomy population. The highest cost was inpatient costs, followed by medication costs.

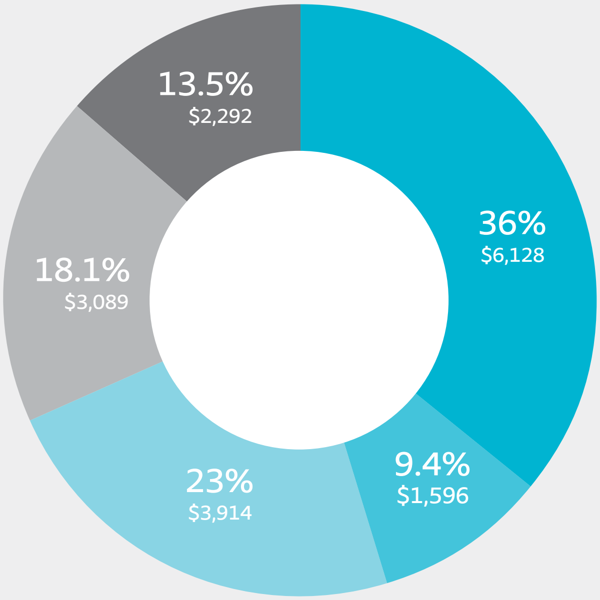

Figure 2

*Excl. dental cost, legal cost and productivity loss

Active population* divided by type of ostomy

	Colostomy	Ileostomy	Urostomy
Ostomy population	12%	31%	12%
Control population	25%	43%	19%

Active population. The number of people with an ostomy who are part of the active population. Those who are either employed, seeking employment or doing voluntary work, is lower compared to in the control population.

*Employed, seeking employment or active in volunteer work

Figure 3

Sick days for the active population*

days/year

Colostomy	Ileostomy	Urostomy
60 days	69 days	47 days
12 days	19 days	17 days

Ostomy population

Control population

**Employed, seeking employment or active in volunteer work*

Sick days for the active population. The people with an ostomy who are a part of the active population have a higher number of sick days than the control population.

Figure 4

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