



## Newsletter

# Living with a parastomal buldge - the patients perspective

This article is based on a presentation given by Marianne Krogsgaard, PhD student (Denmark) at the Coloplast Ostomy Days 2018

Marianne has worked as a colorectal nurse for more than 20 years. Her PhD research focuses on colorectal surgery from a patient perspective, with specific reference to parastomal hernia as a late complication after stoma formation. Marianne is currently employed at the Abdominal Centre, Rigshospitalet, Denmark, and since 2015, she has also been the daily manager of the Danish Stoma Database Capital Region.

Very little is known about the impact a parastomal bulge has on a person's life. In this article, we share the results of a qualitative study that sheds light on life with a parastomal bulge – from the patient's point of view. We also identify the need for more research into nursing interventions that can reduce symptoms and improve quality of life for this particular group of patients.

### Patient profile and incidence rates

The typical profile of someone with a parastomal bulge is a male, over 60 years of age, with a colostomy<sup>1-4</sup>. There are also a number of other predisposing factors – for example patient factors, (e.g. malnutrition and smoking); disease factors (e.g. diabetes and hypertension); and technical factors related to stoma creation (e.g. laparoscopic surgery and aperture size). However, none of these factors are well-established<sup>1-5-9</sup>. It is still unknown which ones matter the most – and whether or not it has any effect if they are modified prior to surgery.

There are several factors that make it difficult to identify the overall incidence rate with any certainty. Incidence rates depend on definitions – that is, if it's a bulge or a hernia.

They also depend on how the incident is reported – whether it is self-reported; identified during a clinical examination; or diagnosed with a CT scan.

What is well known, however, is that the incidence of parastomal bulge increases over time<sup>4</sup>. A study using data from the Danish Stoma Database Capital Region, with more than 5,000 stoma patients, showed a cumulative incidence of parastomal bulging after just a year of 36 per cent<sup>1</sup>. The study also found that patients with a colostomy had a 40 per cent higher risk of a parastomal hernia when compared with patients with an ileostomy.

### Types of parastomal bulges<sup>20</sup>

- Type 1: Weakness of the abdominal wall, intact fascial ring.
- Type 2: Subcutaneous prolapse, intact fascial ring
- Type 3: True parastomal hernia, enlarged fascial opening.

### Impact on quality of life

When it comes to symptoms in relation to a parastomal bulge, descriptions vary significantly. Some studies report that patients are mainly asymptomatic, and others state that patients are primarily symptomatic<sup>10-15</sup>. It all depends on which patients are included and what questions are asked.



The importance of asking the right questions was revealed by a study conducted at Bispebjerg Hospital, where nurses systematically interviewed patients about their symptoms the day before a parastomal hernia repair<sup>16</sup>. They found that patients reported a number of different symptoms, and they also detected a high symptom load – i.e. each patient had a number of different symptoms. Three of the symptoms captured in the study – erratic action of the stoma, bearing-down sensation and activity limitation – are not frequently reported in studies. So if a patient has these symptoms, and isn't asked about them, he may mistakenly be categorised as 'asymptomatic'.

"Unless we have a very systematic approach, it may not be quite sufficient to only rely on clinician-reported outcomes," explains Marianne. "If we want to get insight into the patient's perspective, we need reports coming directly from the patients."

#### Symptoms experienced by patients living with a parastomal bulge

- Leakage
- Skin problems
- Cosmetic complaints
- Difficulty finding properly fitting clothes
- Pain
- Social restriction
- Erratic action of the stoma
- Bearing down sensation
- Difficulty with stoma appliance
- Activity limitation
- Difficulty with irrigation
- Intermittent bowel obstruction
- 'Falling out sensation'
- Fluctuating gas
- Incarceration or strangulation of hernia content

#### Getting the patient perspective

To gain more insight into how living with a parastomal bulge impacts patients' quality of life, Marianne conducted a qualitative study where patients were asked about their symptoms<sup>17</sup>. The study revealed a wide range of physical and emotional effects of living with a parastomal bulge.

#### The physical impact

Patients living with a bulge experience unfamiliar and unpleasant bodily sensations. These included altered bowel habits and fluctuating noisy gas that impacted their daily lives. The patients described unpleasant sensations, such as bearing down, where they feel fine in the morning, but heaviness at the end of the day. Some felt like their organs were falling out of their abdomen when they lifted their arms above their head or when they lay on their side. They classified pain into different categories: pain when lifting, pain because of stretching skin and when passing stool.

#### The psychological impact

Patients felt that the ever-changing bulge required their constant attention. They worried about whether or not it would stop growing. Patients also described the impact the bulge had on their body self-image. Some stated that they felt deformed, deviant and asymmetric. They described the bulge

as 'a woman's breast', 'a melon' or 'a cone'. The more the patients perceived that the bulge altered their body image, the harder it was for the patients to adjust to the bulge.

#### How they coped

Patients took practical measures to deal with their bulge. They would modify their clothing, and they would try to use coping mechanisms like humour and creativity to take charge of their condition. Every time the bulge grew, patients would have to change products, procedures and garments. To deal with this, they needed access to stoma care nurses. Being able to quickly and easily engage with professional staff was a way for patients to regain control over their bulge and remaster the art of self-care.

#### Need for research into best-practice nursing interventions

Now that Marianne's study, along with several others<sup>18-19</sup>, have shown that a parastomal bulge impacts patients' lives, the next step is to identify the kinds of nursing interventions that can relieve the situation and help patients manage their parastomal bulging.

This is where we run short on evidence-based know-how. There is an absence in the literature when it comes to documented, best-practice nursing interventions that can improve patients' quality of life. We find descriptions of interventions, but they are all based on expert opinion and clinical experience.

"If we want an evidence-based nursing culture, we really need research into interventions that can reduce patients' symptoms, improve their quality of life, and impact their daily lives," says Marianne. "The focus needs to be on the patient's perspective. We need to publish and share to get closer to solutions to this problem."

#### Suggested areas for additional research

Nursing interventions	Unanswered questions
Modify pouching systems	Are some systems better than others when it comes to bulging skin and leakage?
Patient education	What should the content and timing be for education around parastomal bulging?
Stool regulation	Which type of laxative should they choose, and which works best?
Pain	Which type of laxative should they choose, and which works best?
Bearing-down sensation	Which type of laxative should they choose, and which works best?
Body image changes	Do we have a uniform way of assessing body image? Could we find one and make it possible to have a dialogue from one study to another?
Easy and swift access to help	Could we use telemedicine or social media to make help more accessible to patients?

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