

# Experiences of support garments following bowel stoma formation: analysis of free-text responses in a cross-sectional survey

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## ABSTRACT

**Aim** To explore the experiences of support garments when adjusting to bodily change following bowel stoma formation.

**Design** Thematic analyses of free-text responses in a cross-sectional survey of the stoma population in 2018.

**Methods** Free-text responses were invited so that respondents could describe their experiences in more detail. A process of induction was chosen to allow for themes to emerge directly from the data. The concept 'embodiment' was used as a theoretical framework during interpretation.

**Results** 1425 people with a bowel stoma responded to the survey, of whom 598 provided free-text responses. Four themes about experiences of support garments in the context of changed bodily experiences following stoma formation were identified: *body complications*, which is about experiences of using support garments to prevent or self-manage parastomal hernia; *body appearance*, which is about hiding the stoma and stoma appliance; *body function*, which is about managing stoma appliance complications; and *body sensation*, which is mainly about negative experiences of ill-fitting garments.

**Conclusion** Support garments can be understood as items that are used by people during an ongoing process of adjusting to bodily changes following stoma formation and as part of an ongoing process of reconstructing new embodied selves.

**Impact** This is the first study to explore people's experiences of support garments following bowel stoma formation. Support garments are used in the self-management of body complications, appearance, function and sensations. Stoma nurses may draw on the findings of this study to advise patients about the benefits of garments for adjusting to bodily change, and garment suppliers should address people's negative experiences by improving garments.

## INTRODUCTION

### Background

In Europe approximately 700 000 people are living with a stoma, and in the USA more than 1 million people have a stoma.<sup>1</sup> In the UK there are around 102 000 ostomates,

## Summary box

### What is already known about this subject?

► The psychosocial impact of stoma formation includes feelings of loss of control of body function and poor body image.

### What are the new findings?

- This is the first study to explore people's experiences of support garments following bowel stoma formation.
- The study adds new insights about the use of support garments to facilitate a sense of control over body function and appearance.
- The study highlighted that support garments may exacerbate or cause stoma appliance leaks, ballooning and pancaking; if they do not fit properly, then body function is compromised.

### How might it impact on clinical practice in the foreseeable future?

- Patients need information and support when choosing support garments.

with about 21 000 stoma formation surgeries annually, 50% of which are estimated to be permanent.<sup>2</sup> There are a number of conditions that may necessitate the formation of a bowel stoma, including colorectal cancer, diverticular disease, incontinence and inflammatory bowel disease.<sup>3</sup> A bowel stoma is an artificial opening on the surface of the abdomen that has been surgically created in order to divert the flow of enteric or faecal matter into an external bag.<sup>3</sup> The two types of bowel stomas are colostomy and ileostomy, which can be temporary or permanent.<sup>3</sup>

Anecdotal evidence suggests that common bowel stoma appliance complications include ballooning (when gas expelled through the colon collects inside the bag causing it to inflate), pancaking (when, instead of dropping to the bottom of the bag, the motion



collects around the stoma and may seep between the flange/baseplate and the skin), leakage, odours and flatulence.<sup>4</sup> Leakage is associated with unpleasant odour, soilage of clothes and skin irritation. Research shows that stomal complications may include prolapse, retraction, parastomal hernia (PSH) and stenosis.<sup>5,6</sup> The most common stomal complication is PSH,<sup>5,7</sup> which occurs when other abdominal contents protrude through the defect in the abdominal wall created for a stoma; prevalence is estimated to be over 30% by 12 months, 40% by 2 years and 50% or higher at long duration of follow-up.<sup>8</sup> The UK Association of Stoma Care Nurses recommends 'belts/underwear' 'to aid prevention of hernias and offer abdominal muscle support'.<sup>9,10</sup> Yet evidence supporting a recommendation for use of support garments to prevent or manage PSH is limited to a handful of small-scale studies using class I medical device underwear.<sup>11,12</sup> Additionally, data on PSH causation and strategies to reduce incidence remain uncertain.<sup>13,14</sup> There is also a paucity of research focusing on the effectiveness of nursing management of PSH.<sup>15</sup>

Current guidelines do not refer to any psychosocial benefits of support garment use, such as adapting to changes in body function and appearance. Research about lived experiences and psychosocial health following stoma formation highlights three key themes: psychosocial impact around feeling of loss of control of body function, physical aspects that affect psychological function and quality of life, and the process of acceptance, adaptation and adjustment.<sup>16</sup> A systematic review of 11 qualitative studies about people's experiences of bodily change following stoma formation suggests that people experience profound disruptions in how their body looks, functions, sounds, smells and feels and sense of self.<sup>17</sup> A systematic review of body image in patients with inflammatory bowel disease concluded that body image dissatisfaction is associated with poor quality of life.<sup>18</sup> However, studies included in these reviews of the literature do not explore use of support garments to manage these disruptions. There is a range of stoma accessories available, including support garments which include belts, panty girdles or boxer shorts made of elastic, Lycra, cotton or microfibre materials.<sup>19</sup> An article about stoma support wear suggests that support garments may be used for physical exercise, underclothing, and for intimacy and sexual activity to provide discretion and stoma protection.<sup>20</sup> Yet very little is known about how frequently and for what purposes these garments are worn by this patient group. The study reported in this article is the first to investigate the experiences and use of support garments in people who have a bowel stoma.

## THE STUDY

### Aim

The aim of the study was to find out about people's experiences of support garments following stoma formation. The study defined support garments as follows: 'Support

garments include support belts and support underwear (eg, vests, knickers, girdles, pants)'.

### Design

The design of the study reported in this article was thematic analyses of one data set (free-text responses) from a cross-sectional survey of the stoma population completed by participants between 26 April and 16 May 2018.

### Participants

The inclusion criteria were adults 16 years old and over who currently had a bowel stoma and able to complete a questionnaire in English language. In the UK, for the purposes of research, people 16 years old and over are adults.<sup>21</sup>

### Data collection

Data on support garments were collected using a survey questionnaire hosted by Bristol Online Survey (BOS), which is an online service that allows researchers to develop, deploy and analyse an online survey. Social media (Facebook, Twitter) was used to advertise the survey, and Vanilla Blush (one of several UK-based specialist support garment suppliers with a database of customers) also invited their customers to take part via email. Potential participants were provided with a website address of the study's survey. Participants answered closed questions about support garments, PSH, quality of life and physical activity. In addition, a free-text comment box was used at the end of the survey to give participants an opportunity to add anything else about their experiences of support garments. Free-text responses provide people the opportunity to explain their experiences in more detail, providing deeper insights into their experiences. Participants were asked: 'Please tell us anything you would like to add about your stoma, and your experience with support garments and/or belts'.

### Ethical considerations

Participants completing the survey online provided implicit consent by ticking a box to show that they have read the information about the study and agree to complete the questionnaire. This way of giving consent is a standard approach for research involving online questionnaires and is recommended by BOS (<https://www.onlinesurveys.ac.uk/help-support/including-a-consent-statement/>).

The study was low risk to participants. Nonetheless, involvement in the survey may raise issues about their stoma, which is why we have included the following statements at the end of the questionnaire:

'If you have any questions about stoma support and advice please contact one of the following charities:

Colostomy UK <http://www.colostomyassociation.org.uk/>

Ileostomy association <http://www.iasupport.org/>

Urostomy Association <https://urostomyassociation.org.uk>

Data management was done in accordance with the Data Protection Act (1998). Only the research team had access to the data, which were password-protected and stored on university computer systems. The commercial partner (Vanilla Blush) did not have access to raw data. Participants were not asked their name or address when completing the online questionnaire, thereby reducing the risk of breach of confidentiality.

### Data analysis

Some researchers consider responses to general open survey questions to be qualitative data and others describe them as 'quasi-qualitative data'.<sup>22</sup> We treated these data as qualitative and analysed them accordingly. The data set was analysed using thematic analysis, which is a method for identifying, analysing and reporting patterns within data.<sup>23</sup> A realist approach to the analysis was adopted; that is, the analysis and interpretation of the data set were perceived by the researchers as a representation of participants' experiences and their realities. Data were analysed using the following three steps and are presented in online supplementary figure 1.

A process of induction was initially followed to allow for themes to emerge directly from the data and is a process that can code the data without trying to fit them into a pre-existing coding frame or theoretical framework.<sup>23</sup> To structure the data inductively, an initial set of 43 codes were set by identifying recurring words, for example, 'comfort', 'support', 'pancaking', 'bulky', 'anxiety' and 'tight'. These codes denote what appeared of interest to the researchers and what words kept reoccurring throughout the data set. Free-text comments were categorised under a code. At this stage of analysis, a rich description of participants' experiences of support garments was obtained.

As a second step, all codes and associated free-text comments were sorted into four main descriptive themes: reasons for wearing support garments, reasons for dissatisfaction with support garments, PSH, and lack of information and support for use of support garments. For example, under the overarching theme 'reasons for wearing support garments' were codes such as feeling safe, hide bag and prevent leak. During this second step, some free-text comments were recoded. For example, the free-text comments associated with the code 'lack of information' were reassigned to codes based on what the lack of information referred to. Lack of information about hernia prevention and lack of information about sizing were reassigned to codes 'prevent hernia' and 'size', respectively. This in effect removed the code 'lack of information' because all free-text comments were reassigned to a different code. Three other initial codes—suppliers, temporary stoma and National Health Service prescription—were removed because the associated free-text comments were reassigned to another code.

As a third step, all codes and data under the four themes were analysed in the context of the researchers' theoretical understandings of the topic of experiences of living with a stoma. Use of theory in qualitative research is contentious and researchers do not consistently articulate what theories are used or how theories have been applied.<sup>24</sup> Moreover, it is widely acknowledged that researchers cannot free themselves of their pre-existing knowledge about a phenomenon or theoretical framework.<sup>23</sup> To progress from thematic description to thematic interpretation, the researchers drew on the conceptual framework developed by Thorpe *et al*,<sup>17</sup> who interpreted experiences of a stoma as a disruption to the embodied self. Thus, all free-text comments and initial coding were reread and potential themes refined using the concept of embodiment. A final set of four interpretative themes were identified about experiences of using support garments, which were body complication, body appearance, body function and body sensation. Quotations were identified by researchers to illustrate each theme.

### Rigour

We believe that the findings from the study are trustworthy<sup>25</sup> for the following reasons: we have described study design and methods so that the study can be replicated, and a copy of the questionnaire is available in online supplementary figure 1. Two researchers (GH and CT) led the analysis, and all free-text coding and final themes were checked as a method of validation. For example, at each step of the analysis described above, CT reviewed her initial coding and themes and compared them with those by GH and referred to the original data set of free-text responses. GH and CT reached consensus on the final thematic analysis and interpretation. We have made it explicit that one of the authors (ND) is the funder and a supplier of support garments, and that to reduce risk of research bias ND did not have any access to raw data and did not assist in data analysis or interpretation. We have highlighted limitations of the research study in the Discussion section of this article.

## FINDINGS

### Participant characteristics

Any participant to the survey who provided a free-text comment was eligible for inclusion. There were 1425 people who responded to the survey, of whom 598 (42%) provided free-text responses. The average word response was 35 words (range 1–589). Participants' sex, age, stoma type, type of surgery and length of time since the first stoma formation are presented in table 1.

Four themes about experiences of support garments in the context of changed bodily experiences following bowel stoma formation were identified: *body complications* is about experiences of using support garments to prevent or self-manage PSH; *body appearance* is about hiding the stoma and appliance; *body function* is about

**Table 1** Participant characteristics

Variable	Participants, n (%)
<b>Sex</b>	
Male	121 (20.4)
Female	472 (79.6)
<b>Age (years)</b>	
16–25	21 (3.5)
26–35	73 (12.2)
36–45	118 (19.7)
46–55	158 (26.4)
56–65	119 (19.9)
66–75	91 (15.2)
76–85	16 (2.7)
85<	2 (0.3)
<b>Stoma type</b>	
Colostomy	190 (33.6)
Ileostomy	376 (66.4)
<b>Type of surgery</b>	
Open	287 (49.9)
Laparoscopic	120 (20.9)
Mixed	168 (29.2)
<b>Length of time with a stoma</b>	
0–6 months	41 (6.9)
7–12 months	50 (8.5)
13–18 months	55 (9.3)
19–24 months	63 (10.7)
25–36 months	76 (12.9)
37–48 months	49 (8.3)
More than 4 years	257 (43.5)
<b>Number of abdominal surgeries</b>	
0	3 (0.5)
1	127 (21.6)
2	130 (22.1)
3	96 (16.3)
4 or more	233 (39.6)
<b>Hernia incidence</b>	
Yes	226 (38.6)
No	359 (61.4)

managing appliance complications; and *body sensations* is primarily about negative experiences of ill-fitting support garments. Type of stoma, sex and age group and if the participant reports a bulge or having been told by a clinician that they have a PSH or incisional hernia are listed in each free-text comment.

### Body complications

Support garments were used by participants to prevent or self-manage a PSH. The threat of a PSH preoccupied

many participants, and they managed this stoma complication by wearing support garments. Many participants referred to support garments as “hernia support underwear,” “hernia support pants,” “hernia vests,” “hernia belt” and “exercise hernia belt.” Several participants wore support garments as part of preventing PSH, especially when engaging in strenuous physical activities. Some participants perceived the use of a support garment increased their confidence to be active in the belief that their use would reduce the risk of a hernia.

I strongly believe that stoma nurses and surgeons should tell people about stoma products and accessories. I love my support garments and I find them very helpful, reassuring and comfortable. They increase my confidence. Whilst I am not back exercising, yet I am confident that the garments will massively help me and reduce my risk of developing a hernia. —Ileostomy, male, 36–45, bulge

Wearing a support garment when doing anything strenuous helps prevent any adverse effect on stoma/hernia. —Ileostomy, female, 66–75, PSH

Participants who already had a PSH wore support garments to self-manage the condition. Participants felt support garments provided support, reduced associated pain and could prevent enlargement of a hernia.

I would be in pain and I think my hernia would be larger if I didn't wear my support garment. —Ileostomy, female, 56–65, PSH

I have to use them daily. I have had 5 major surgeries in the past 10 years so I need to support my 5 hernias as much as I can so that I don't have to have surgery. —Ileostomy, female, 26–35, PSH

Support garments have been essential for me as if I do have a hernia, I do not want this to get bigger or worse. —Colostomy, female, 26–35, no reported bulge or PSH

Some participants with and without a PSH felt safer while wearing a support garment, which helped them forget about the stoma. Some participants felt exposed without a support garment.

I feel unsafe/open/no support when I don't wear my support underwear. I do try every now and then to wear 'normal underwear', but always go back to my support undies. —Ileostomy, female, 26–35, no reported bulge or PSH

### Body appearance

Many free-text comments about support garments related to body appearance, illustrating how participants perceived support garments to be important objects in the management of disrupted bodily appearance following stoma formation. Support garments were worn by some participants to hide the stoma bag; these participants described how they wore support garments to look

and feel “normal.” Some participants wanted the added security that a support garment could bring.

For me I feel that I look normal. And it is just great support of the bag and the security I feel wearing them. —Colostomy, female, 46–55, no reported bulge or PSH

Some participants referred to the importance of concealing or muffling the bag when dating and during intimacy. The free-text comments highlight the significance to people with a stoma of all sensory experiences including sight and sound.

The only thing I ever wear over my bag is a bandeau when being intimate, just to hold everything in and conceal the appliance. —Ileostomy, female, 26–35, no reported bulge or PSH

My wife insists that I wear a vest during sex to stop my bag rustling. —Ileostomy, male, 36–45, PSH

I like to wear support bands when I meet new people, go on dates with my partner or when I wear tight clothing, because they hide the bulge my stoma appliance can create. —Ileostomy, female, 26–35, no reported bulge of PSH

However, most written comments about body appearance were not about intimacy but being in public. Support garments were perceived to protect and hide the bag, giving participants the confidence to socialise because the stoma appliance was less visible.

For me the support garments I use give me some protection from my clothes running/pulling around my bag but mostly they give me the confidence of another layer between the bag and the outside world! —Colostomy, female, 36–45, no reported bulge or PSH

My life and confidence changed the day I discovered support vests and underwear. They made me feel like my bag was hidden better. —Ileostomy, female, 26–35, no reported bulge or PSH

Getting the right size and fit was seen as essential for body appearance. Many participants complained about support garments being too tight, loose, short, long, small and large. Participants reported difficulties with getting a support garment that fitted their body size and the stoma site. The free-text comments highlight the significance of where the stoma is sited on the body and the use of support garments.

I have a very high stoma; it is about two inches below my boob and I find it hard to get clothing underwear and things to help cover it so I wear tops that are two sizes too big. —Ileostomy, female, 46–55, no reported bulge or PSH

I have a low level stoma, this has made it impossible to wear most of the prescription garments either because the ‘security pouch’ is too high or bands roll

up/down strangling my stoma. —Ileostomy, female, 36–45, bulge

A few participants criticised support garments that looked too clinical or lacked style.

I find that some support garments are unattractive and clinical looking. —Ileostomy, female, 36–45, no reported bulge or PSH

It would be nice to find some support garments that are stylish and look more like regular underwear and not old lady girdles. —Ileostomy, female, 36–45, no reported bulge or PSH

A handful of participants criticised a lack of choice of support garments. Some participants wanted a choice of different styles and colours.

I feel the range of styles and colours for young men are poor compared to woman. The men basically get black or white hernia support boxers compared to the choice women have. —Ileostomy, male, 26–35, no reported bulge or PSH

Would like more feminine designs & colours available on prescription. —Ileostomy, female, 66–75, bulge

However, the main criticism about support garments was that they were too bulky, rode up or down or stretched and so did not have the desired effect on body appearance.

The NHS garments were bulky and made me look a lot fatter than I am. —Colostomy, female, 26–35, no reported bulge or PSH

Support garments tend to bunch up and have always made my stoma appliance more visible because of this. —Ileostomy, female, 26–35, no reported bulge or PSH

Support belts stretch over time so don’t last long and very noticeable under clothing. Support pants very supportive but roll down constantly so noticeable under clothing. —Colostomy, female, 46–55, PSH

### Body function

Stoma formation surgery changes how people eject enteric content or faeces from their bodies. Participants discussed how support garments were worn to manage anxiety about leaks from the stoma and were perceived to help prevent leaks or to contain a leak. Some participants addressed problems with a stoma appliance through the use of a support garment. For example, support garments were worn to hold the stoma appliance in place and therefore minimise the risk of a leak.

I have not yet come to terms with having a stoma. However, the support garments make the medical appliance less obvious under clothing and I wear a support belt 24/7, which makes me a lot less anxious about having a leak. —Colostomy, female, 46–55, bulge, incisional hernia



Support belts help hold the bag and also help to contain any leaks even if these are rare. —Ileostomy, male, 36–45, no reported bulge or PSH

Nevertheless, the majority of responses about support garments in relation to body function were negative. Ill-fitting support garments were believed to have caused leaks, pancaking and ballooning. Hence, rather than assisting in managing body functions, support garments that were too tight were perceived to have compounded problems with eliminating faeces from the body.

I have found that when I wear support garments I tend to have more leaks. I have tried belts and wraps. I find they don't allow my stool to flow down into the bag and can cause pancaking which leads to leaks. —Ileostomy, female, 26–35, bulge, PSH, incisional hernia

I cannot wear support garments as they squish my stoma and cause leaking under the flange-baseplate. —Ileostomy, female, 46–55, incisional hernia

Support underwear not always high enough, especially when bag fills with air. The bag 'pops' out of the top of the garment! —Ileostomy, male, 56–65, bulge, PSH

A failure of support garments to assist in the discrete elimination of faeces led people to feel self-conscious and worry.

I found support garment (elasticated band) to be very constricting; I worried that my stoma would leak because of the extra pressure. —Colostomy, female, 26–35, bulge, PSH

### Body sensations

Participants commented on changes in how their body felt when wearing support garments. These bodily sensations were mainly negative and were primarily about the sensation touch. Some participants reported that support garments were uncomfortable.

Everything is so uncomfortable. —Ileostomy, female, 56–65, no reported bulge or PSH

Reasons for lack of comfort varied. Some participants reported that support garments were restrictive.

I find support garments uncomfortable and I feel they restrict me and my abdomen. —Colostomy, female, 66–75, bulge

I wear pants with the pocket for my bag. I find support garments restricting and uncomfortable. —Ileostomy, female, 36–45, no reported bulge or PSH

Other participants reported that support garments caused pain.

I love the hernia support underwear that I have as they keep the bag hidden. However, I can only wear

them for a few hours as my stoma becomes painful. —Ileostomy, female, 36–45; bulge

Belts are usually made with hard rigid plastic that digs into my abdominal scar, this caused constant pain so I cannot use them. They also caused eczema where they rubbed on my hip, and were too narrow so kept twisting and turning on themselves and digging in. Always obvious under my clothes as an indent around my body. I do not use them. —Colostomy, female, 36–45, no reported bulge or PSH

Another cause for discomfort was feeling hot and sweaty.

Hot, sweaty and restrictive. —Ileostomy, female, 56–65, no reported bulge or PSH

Support garments are nice but I wish they were more breathable and possibly with a drying wicking material in many areas. The garments are tight and can get very hot, so sweating is a regular occurrence. Support garments can be extremely confining, so breathability is important as well as comfort. —Ileostomy, female, 36–45, bulge, PSH, incisional hernia

A consequence of being hot and sweaty was skin irritation.

I have problems wearing the support belts as they are too warm and cause me to overheat and break out in a rash and cause huge discomforts. —Ileostomy, female, 46–55, bulge, PSH

It would be nice if available garments had the inner pouch made of cotton as the double layer gets very hot especially in the summer and makes skin prone to itchiness. —Ileostomy, female, 46–55, bulge, PSH

Support belts are great but I find when I sweat they increase the likelihood of thrush and sore skin. —Ileostomy, female, 26–35, bulge

Other body sensations associated with support garments were noise and smell.

I got measured for belts by a professional but they ride up, make me sweaty, are noisy and my bag cannot fill up very much with them on and I often find it makes my bag smell. —Ileostomy, female, 16–25, bulge

Nonetheless, despite lack of comfort, many participants continued to wear support garments, suggesting that their perceived benefits (eg, body appearance and self-managing stoma complications) outweighed discomfort. Some participants were willing to endure considerable discomfort wearing a support garment because they were important for managing a hernia.

The garment I wear gives some support but the hernia is massive so wearing the support corset can be very uncomfortable at times. It's ok that the support 'pulls you in' but it can affect the function of the stoma. —Colostomy, female, 56–65, bulge, PSH

Support belts are uncomfortable, I am under 5 feet tall and they are always too long so roll up as do the vests, but necessary evil when doing activities due to hernia. —Ileostomy, female, 46–55, bulge, PSH

## DISCUSSION

This is the first study to investigate the experiences and meanings of support garments for people living with a bowel stoma and provides new evidence and theoretical understandings about the use of support garments in adjusting to stoma formation surgery. The comments provided by participants in this study provide a rich and illuminating description of people's experiences of living with a stoma and using support garments. The study adds new insights about the use of support garments to facilitate a sense of control over body function and appearance. The study also provides an opportunity to conceptualise people's descriptions of their experiences of support garments at a more abstract level. The researchers interpreted participants' descriptions of living with a stoma as illustrating disruptions to the embodied self and support garments as a means of repairing this disruption. The study suggests that support garments are vital in people's self-management of body complications, appearance, function and sensations and the constructions of new embodied selves. Many studies suggest that people need to reconstruct new embodied selves following stoma surgery<sup>26</sup> because they experience profound disruptions in how their body looks, functions, sounds, smells and feels,<sup>17</sup> but only a few have explored how this might be achieved,<sup>27 28</sup> with the latter highlighting the importance of mastery over body function and the ability to socialise. This study produces new insights by showing how people use support garments in their attempts—successful or not—to achieve new embodied selves.

Two factors that may be influential in determining the extent of distress experienced about altered body image following stoma formation are (1) duration of the body change—whether it is permanent or temporary; (2) visibility of that part of the body—real or perceived.<sup>29</sup> In our study, we did not ask about permanency of their stoma, although we know nearly three-quarters (74.5%) had been living with their stoma over 2 years. Previous studies have shown that people can feel humiliated if the appliance is visible,<sup>30</sup> ugly,<sup>31</sup> self-conscious,<sup>32</sup> have poor body image,<sup>33</sup> find it difficult adjusting to changed appearance,<sup>34</sup> feel vulnerable, embarrassed and unattractive, and work hard to attain an appearance of ordinariness by hiding the stoma appliance.<sup>16 34</sup> Moreover, looking 'normal' is a strong ideal for people with a stoma,<sup>30</sup> and poor body image has been found to predict distress in the stoma population.<sup>35</sup> Our study shows that support garments were used to limit the visibility of the stoma and appliance in two ways; the first was a desire to conceal that they had a stoma appliance when in public, and the second function was to cover the stoma appliance during intimacy. In both respects, the support garment

may help reduce the feeling of disrupted embodiment. These support garments serve to disguise the stoma, draw in the bulges, smooth contours and minimise the noises, thereby promoting a balanced unity between body and self. When working well, the support garment can facilitate a person's desired body image, offering the armour needed to feel confident and in control of their body again. Support garments can help create a desirable external appearance that enables a closer fit between body reality and body ideal.

Studies about sex and sexuality after stoma surgery suggest that the individual with a stoma and their partner may view the body with disgust.<sup>34</sup> Indeed, most of the literature about experiences of stoma focuses on people feeling disgusted, alienated and estranged from their bodies,<sup>30 32 36</sup> and concerns over sexual activity, fear of accidents, odour and embarrassment about the stoma have been reported in the literature at least since the early 1970s.<sup>37</sup> Our study adds to this literature by illustrating the ways in which support garments help people manage these embodied disruptions. Many of the participants eulogised about how life-changing these garments had been, giving them the freedom and self-assurance to socialise again, including being intimate. Cultural aversions to faeces require individuals living with a bowel stoma to reconcile these feelings when attempting to be sexually intimate. Hence maintaining bodily aesthetics during sexual encounters becomes much more of a priority.<sup>38</sup> Furthermore, the support garment may be serving a supportive function at a more subconscious level in making the stoma appliance closer to self and thus more a part of their body by having it in pulled up to their skin, although encased within the support garment. It possibly made them feel that it was all now an integral part of the body and hence self. Nonetheless, our study has highlighted that support garments may exacerbate or cause leaks, ballooning and pancaking; if they do not fit properly, then body function is compromised. Correct sizing for support garments is perceived to be important, and some people may struggle to find a support garment for their height, weight, waist and hip circumference and the siting of the stoma.<sup>19</sup>

For some participants in our study, the support garment provided them with some control over their stoma management. Previous studies suggest that losing the ability to control body function and being fearful of leaks, smell and noise lead some people to become apprehensive about being in public and therefore avoid social events altogether.<sup>16 34 39</sup> Research about people's experiences of living with a stoma has highlighted the importance of people learning to use appliances to avoid leakage,<sup>31 34</sup> and several studies about stoma formation stretching as far back as 1952 have highlighted a feeling of loss of control of bodily functions.<sup>30 34 40</sup> Moreover, the desire to be and feel in control of the stoma has been associated with positive psychological adjustment and improved quality of life.<sup>16 28</sup> In our study, support garments were worn to reduce risk of stoma leakage or



at least minimise the consequences of leakage should it occur. A few also talked about their belief that having the garment made the appliance not only more secure but less likely to catch or rub another part of them. The final point is that many stated they wore their garment as body protection both directly as a first line of defence for their abdomen when contemplating sports or accidents but also for reducing the likelihood of parastomal herniation. Support garments therefore seemed to bring reassurance that their use would reduce further complication. By wearing the garment, many stated they believed they would have less chance of developing a hernia, thus protecting their body image concerns and future health.

### Limitations

This study relied on brief free-text comments provided by participants to a survey. While poignant, these comments are no substitute for in-depth accounts of people's experiences of living with a stoma and support garments. Moreover, participants may be cautious about offering very personal accounts of their experiences due to general concerns about information security.<sup>41</sup> The use of a cross-sectional design prevented exploring uses of support garments prospectively. It should be acknowledged that participants were identified from a customer database from a commercial company. It therefore stands to reason that these patients had previous experience of stoma support garments. It could be argued that this group does not represent the typical stoma population; for example, one conjecture is that people who wear support garments may be those with body image problems. Participants were predominantly women, and men's experiences of support garments were relatively mute. Data on ethnicity were not collected, and it was therefore not possible to examine differences in attitudes to support garments or stoma experiences by ethnic origin. Finally, while the free-texts comments suggest that support garments are associated with psychosocial adjustment, randomised controlled trial or prospective study designs are needed to provide more robust evidence of the potential benefits of support garments, such as their impact on quality of life, body image and hernia formation.

### CONCLUSIONS

These findings indicate how individuals cope with the disruptions that stomas impose as they resume daily activities and intimacy in their lives. After stoma formation a new relationship with the body is in progress, and support garments may facilitate a person becoming someone who happens to have a stoma rather than being defined by it. Using the concept of embodiment, support garments can be understood as items that are used by people during an ongoing process of adjusting to bodily changes following stoma formation, and as part of an ongoing process of reconstructing new embodied selves.

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