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Article:

Taylor, C, Munro, J, Goodman, W orcid.org/0000-0002-8936-0787 et al. (5 more authors) (2019) Experiences of wearing support garments by people living with a urostomy. *British Journal of Nursing*, 28 (22). S26-S33. ISSN 0142-0372

[10.12968/bjon.2019.28.22.s26](https://doi.org/10.12968/bjon.2019.28.22.s26)

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British Journal of Nursing

Experiences of wearing support garments by people living with a urostomy

--Manuscript Draft--

Manuscript Number:	bjon.2019.0220R1
Full Title:	Experiences of wearing support garments by people living with a urostomy
Short Title:	Support garments for people with a urostomy
Article Type:	Original research
Keywords:	support garments; urostomy, body image, hernia, stoma care
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Suggested Reviewers:	
Response to Reviewers:	
Additional Information:	
Question	Response
Please enter the word count of your manuscript excluding references and tables	3887

British nursing journal

Experiences of wearing support garments by people living with a urostomy

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Acknowledgements

Vanilla Blush funded the survey.

Conflict of interest

Vanilla Blush is a registered UK commercial supplier of support garments, funded the study.

Key words: Support garments; urostomy; stoma care;

Abstract

Background: Support garments are commonly worn by people with a urostomy but there has been no published data about their experiences of doing so.

Aims: To identify the views of people living with a urostomy on the role of support garments.

Methods: A cross-sectional survey of the stoma population's experiences of support garments was conducted in 2018. Recruitment was by social media within the UK. The free-text responses to this survey provided by a sub-sample of 103 people with a urostomy were analysed.

Findings: Thematic analysis of the responses **from 58 participants within this sample** indicated four themes which supported self-management; physical self-management; psychosocial self-management; lifestyle and healthcare advice and support.

There were mixed feelings about the value support garments brought, many cited a sense of reassurance and confidence to be more sociable and active, whilst others reported discomfort and uncertainty about their value.

Conclusion

These findings add new understanding of experiences of support garments and provide novel theoretical insights about life with a urostomy.

Words 165

Experiences of wearing support garments by people living with a urostomy

Background

Approximately 11,000 people are living with a urostomy in the UK and around 800 new urostomies are created each year (Urostomy association, 2019). Whilst most people who have a urostomy adapt to living with their stoma, there is a period of considerable adjustment as they adapt to this new way of looking and functioning.

A urostomy is a stoma created to divert urine to the abdominal wall after the bladder has been surgically removed. Radical cystectomy is performed to remove localized muscle-invasive and metastatic bladder cancer (Witjes et al, 2016), occasionally as part of radical surgery for a locally-advanced rectal cancer or to treat another serious condition. The stoma is created to drain the urine from the kidney by connecting the ureter to an ileal (small bowel) or colon (large bowel) conduit and then using the bowel to form a spout on the abdominal wall. A stoma appliance (bag) secured around the stoma on the abdomen is used to collect the urine, which can then be drained via a tap or bung at the bottom of the bag.

A range of complications can occur after urostomy formation including specific urinary effects such as the risk of chronic urinary tract infections and deterioration in kidney function (hydronephrosis) (Martini et al, 2017) as well as more general ostomy related problems including stoma retraction, pouch leakage, sore skin and parastomal herniation (Wound, Ostomy and Continence Nurses society, 2014; Nazarko, 2014). A decrease in health-related quality of life (HRQOL) for 6 to 12 months after urostomy formation has been reported (Furukawa and Morioka, 2017).

Many stoma accessories and products are available on prescription to help manage these stoma-related complications (Burch, 2018). One type of accessory recommended by the UK Association of Stoma Care Nurses (ASCN) is the use of a 'support belt or underwear' 'to aid prevention of hernias and offer abdominal muscle support (Association of Stoma Care Nurses UK, 2016; North and Osborne, 2017). It is suggested that a third of patients will develop a parastomal hernia (PSH) after ileal conduit diversion (Liu et al, 2013).

Although support garments are widely recommended to patients with urostomies, there has been little research on the role and value that support garments might offer people living with a stoma. This article reports on the views and experiences of support garments from those living with a urostomy.

Method

A cross-sectional survey was conducted between 26th April and 16th May 2018. The data collection method was a questionnaire which asked about the use of support garments, defined in the survey as follows: 'Support garments include support belts, and support underwear (e.g. vests, knickers, girdles, pants).' The survey questionnaire included questions to gain demographic and clinical information and

then more detailed questions about use of support garments, parastomal hernia, quality of life and physical activity. At the end of the survey a free-text comment box was used which asked respondents: 'Please tell us anything you would like to add about your stoma, and your experience with support garments and/or belts.'

The survey was advertised using social media including Facebook and Twitter. Customers of a supplier of specialist support garments called Vanilla Blush were also emailed about the study (equivalent to a Participant Information Sheet) providing them with a web site address to access. A link directed respondents to the study's survey hosted by Bristol On-line Survey (BOS). BOS is an online service that allows researchers to develop, deploy and analyse an online survey.

1528 people with a stoma responded to the main survey (reported by Hubbard et al 2019) of whom 103 were people living with a urostomy. Of these 103 survey respondents, 58 added additional free text comments which form the focus of this article.

Qualitative Analysis

This dataset was analysed using thematic analysis, which is one of the most common forms of analysis within qualitative research. It emphasizes identifying, examining, and recording patterns of meaning (or "themes") within data (Braun and Clarke, 2006). The rationale for choosing this method, over any other qualitative analytical method is that it allows rich description across cross-sectional data and keeps the patient voice clear and perceptible.

A process of induction was chosen to allow for themes to be based directly on the data - a process that claims to code the data without trying to fit it into a pre-existing coding frame or theoretical framework (Braun and Clarke, 2006). The researchers independently familiarised themselves with the data by reading all the comments, then an initial set of codes were listed which represented recurring words. These codes were then sorted into potential themes, discussed and compared until agreement was reached. Thematic analysis was theoretically framed by the concept of self-management, considered to be central to understanding how people cope and manage chronic disease on a day-to-day basis. (Holman and Lorig 2004).

Ethical acknowledgement

The study was approved by the University of the Highlands and Islands Research and Ethics Committee (Ref: OLETHSHE903). All study procedures were performed in compliance with these institutional guidelines. Respondents indicated their consent to complete the online survey by ticking a box to show that they had read the information about the study and agreed to participate. This way of giving consent is a standard approach for research involving on-line questionnaires and recommended by BOS (<https://www.onlinesurveys.ac.uk/help-support/including-a-consent-statement/>).

Findings

103 urostomates responded to the survey and their demographic and clinical characteristics are presented in Table 1.

Table 1: Participant characteristics (N=103)

Variable	Participants N(%)
Sex	
<i>Male</i>	30 (29.1)
<i>Female</i>	72 (69.9)
<i>Missing</i>	1 (1.0)
Age (years)	
<i>16-25</i>	1 (1.0)
<i>26-35</i>	4 (3.9)
<i>36-45</i>	13 (12.6)
<i>46-55</i>	20 (19.4)
<i>56-65</i>	29 (28.2)
<i>66-75</i>	29 (28.2)
<i>76-85</i>	6 (5.8)
<i>85<</i>	1 (1.0)
<i>Missing</i>	0
Length of time with a stoma	
<i>0-6 months</i>	4 (3.9)
<i>7-12 months</i>	7 (6.8)
<i>13-18 months</i>	9 (8.7)
<i>19-24 months</i>	8 (7.8)
<i>25-36 months</i>	12 (11.7)
<i>37-48 months</i>	6 (5.8)
<i>More than 4 years</i>	56 (54.4)
<i>Missing</i>	1 (1.0)
Reason for stoma formation	
<i>Cancer</i>	63 (61.2)
<i>Physical Trauma</i>	13 (12.6)
<i>Other</i>	25 (24.3)
<i>Missing</i>	2 (1.9)

Table 1 highlights that within this sample just over **two-thirds of respondents** were female (69.9%) and just under two-thirds were aged under 55 years (63.2%). More than half the sample had lived with a stoma for 4 years or more, with only a small percentage (10.7%) having the urostomy formed within the year of responding. The majority (63%) stated that the reason for stoma formation was for cancer.

They were asked about their usage of support garments, both underwear and belts, and in particular how frequently they had worn either of them in the past month. Both of these questions were dichotomised to produce a frequent /infrequent variable for support belt and underwear use (Never or less than once a week = Infrequent; Once a week or more = Frequent). Figure 1 shows support underwear was used more frequently (56.3%) within the sample than support belts (31.1%).

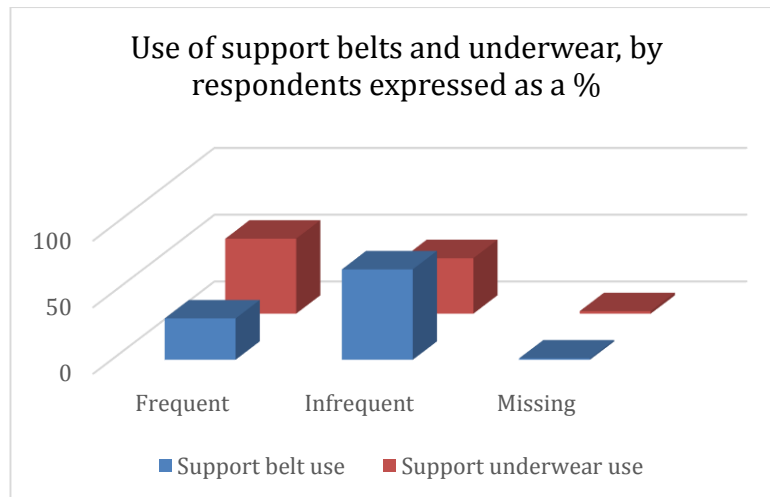


Figure 1: Use of support belts and garments

Free text comment analysis

Fifty-eight of the 103 survey respondents added free text comments about their experiences of support garments since having a urostomy formed. The four themes to arise from analysis of their responses are; physical self-management, psychosocial self-management, lifestyle and healthcare advice and support. These shall be examined in turn.

Physical self-management

This theme has two differing aspects to it, reflecting both how respondents used support garments to reduce the physical impact of having a urostomy and/or how they managed the physical irritation from the garment itself. A trade-off between these two aspects was described:

'Support garments are great and take the weight off; however, they make me sweat excessively.'

The physical symptoms reported included sore peri-stomal skin and a feeling of discomfort from the weight of the appliance when it was full of urine. There was a perception that the garment provided support and protection; a few hoped the garment would limit the likelihood and also consequence of any possible urine leakage from the appliance. Although a couple noted that these garments don't stop all the noises created by the stoma and one made a comment that the garments might increase the possibility of others hearing the *'crinkly noises'* from the appliance and *'squelching'* sounds of the urine.

Several reported wearing a support garment to reduce stoma-related discomfort associated with any abdominal weakness – particularly if they had a parastomal bulge or hernia.

'I have problems getting clothes because of the hernia. It is more of a problem than the stoma itself.'

'I have two hernia belts from X. I wear them all the time but unfortunately this hasn't prevented me from developing another parastomal hernia'.

'I have worn support garments since my stoma operation almost 10 yrs ago and firmly believe that this has contributed to the fact that I do not have a hernia'.

However, some experienced discomfort when actually wearing the support garment:

'The wrap around the girdle is hot and uncomfortable, it rolls and digs'

'The support vest is too tight so that when the bag fills, it can make it bulge out more at the bottom of the vest.'

'Tend to be made of thicker material so it sticks to clothes.'

Two stated that they wished the garments were less bulky and more comfortable and another stated they had to buy *'expensive things as the others have too much material'*. Several respondents reported trying out a range of products available to overcome such difficulties and discovering that for example *'the pants with a pouch were more comfortable'*.

Some commented on the strength of the support garment suggesting that there is an optimal level of support which each individual must decide upon to achieve the desired physical comfort.

Psychosocial self-management

Several respondents spoke about the feeling of reassurance these garments provided which enhanced their self-confidence, particularly in social situations. The three comments below highlight support garments can, for some, add a layer of emotional security and provide an invaluable addition to their daily attire:

'I gain some confidence but never total reassurance,'

'Without my (support garment) I would not have gone out.'

'I always felt self-conscious and uncomfortable before finding the support garment.'

In helping make people feel *'part human again'* they can make *'a massive difference'* to people's psychosocial adaptation to their stoma. The external compression from the garment was described to stop ballooning of the stoma, so there was the hope that by wearing the support garment, they might conceal their stoma:

'I find it difficult to find clothes that don't show my stoma'.

Belts may be worn as a base layer to improve external contouring but this didn't necessarily make choosing what clothes to wear any easier, as for some, there was dissatisfaction with the fit of the garments on offer:

'My incisional hernias are well above the waist. The majority of support garments which are described as high waisted only come an inch or two above the waist'.

Another respondent commented that they thought these garments *'needed jazzing up as they are ugly'*.

Their comments also highlight that in the back of many of their minds is the worry that they might at some stage have a pouch leak and they will have to cope with the wetness and smell of urine. There were reports of feeling scared, embarrassed and unconfident about coping with this possible scenario. Some believed their belt or supportive underwear would reduce the risk of obvious leakage.

One man's comments underlined the significant adaptation required to adjust to the urostomy - it *'has changed my life ..this is no understatement but whether I like it or not, it is one that I will live with for the rest of my life'*.

Lifestyle

Some of the respondents were regular support garment users and were very reliant on their belt or vest for maintaining their lifestyle.

'I find it useful using a support belt for a lot of things and use support underwear daily'.

This lady gained confidence in her day-to-day life when she wore the supportive pants, but she did not feel secure enough to do more active things without fear of urine leakage.

'I'm more confident in everyday life by wearing the pants which support my stoma. I used to do yoga and swim. I'm not able to do either of these as don't feel my stoma would not leak'.

Others reported only wearing their garment when undertaking more physically active pursuits such as swimming, skiing, gardening and also when travelling:

'I use a XX support vest whenever I participate in sporting activities. I believe I can still do everything I did before surgery, but maybe the intensity level is not as high as I am careful not to cause injury to myself'.

'I have been wearing the prettier underwear I purchased from XX. I do wear them if I do a physical job such as gardening or painting. I did wear them all the time post op'.

The respondent who was proud to report that he cycled and scuba-dived without needing any support for his stoma was perhaps an exception. In general, there was a desire to regain and /or maintain a normal lifestyle despite the urostomy and support garments offered a way to do this even if their value wasn't always clear: *'They are easy to use but not sure how effective they are'.*

Healthcare advice and support

Some respondents stated that they had been informed and directed to select the right support garment by their health care team - generally by their stoma care nurse.

'My stoma nurse suggested them to me as a means of hernia prevention and I am so very grateful to her'.

'Not only are the prescription support garments provided stronger and offer better support, but the waistbands come above the level of the stoma which is so important'.

However, many indicated that they had found out about support garments through making their own enquiries:

'Over the years my wife and I have done a lot of research to find out the best way to deal with my stoma and we made our own bag covers'.

'It has never been discussed with me as an option to help with my hernia. I was given a thin belt from my stoma nurse AFTER I got a hernia'.

One lady stated that she felt she probably needed a support garment but seemed to be lacking information on their role as she was *'not sure how it will work when the bag fills up'.*

It appeared from the free-text comments that support garments were not always routinely being offered to this patient group. Indeed a few did complain that they had not received sufficient stoma nursing support to help guide their decision-making on which support garment to choose. Consequently, respondents described undertaking their own research to find the right support garment:

'I'm trying different pants, but the jury is still out.'

There is nevertheless a need to become self-managing with one's stoma and choosing which belt or underwear works best does in the end come down to personal preference; as an experienced ostomist said *'Over the years I have learnt many things about my stoma.'*

Discussion

This is the first study to investigate the experiences and meaning of support garments for people living with a urostomy and adds to recently reported evidence about use of support garments in adjusting to stoma-formation surgery (Hubbard et al 2019). These findings **add further insights to the main survey** of ostomists' use and views of support garments which reveal how support garments enable people to cope with the disruptions that stomas impose in their day-to-day lives (Hubbard et al, 2019).

People living with a urostomy have to cope with a number of challenges which impact on their quality of life: physical problems, psychology functioning, social concerns and lifestyle issues (Ayaz-Alkay, 2019; Pazar et al, 2015; Porter et al, 2005). By wearing a support garment, many respondents indicated they could overcome some of these difficulties. It appeared that a common motivator for wearing a support garment was to protect their body image, conceal their urostomy and minimise perceived social embarrassment. Existing literature reports that this patient group worry about the stoma showing, the pouch making noises and the urine smelling are common (Persson et al, 2002; Sprangers et al, 2002). This survey didn't reveal how support garments might be used to help overcome any associated sexual concerns, which have been reported (Villa et al, 2017; Kandemir and Oskay, 2017).

The findings did however draw particular attention to the specific physical issues which can be experienced by people living with a urostomy. Several wore a support garment to minimise the perceived risk of urinary leakage or at least reduce the chance of it being detected should this occur. Despite urine leakage being a real possibility for this patient group, it has only been the focus of two studies: Furukawa and Morioka's (2017) findings; 67% of their sample of (n= 89 people with urostomies) experienced urinary leakage, which had particular significance at night with over half recording clinically relevant reductions in their sleep quality. An earlier study by this Japanese research group also reported the worry urinary leakage generated (Furukawa and Morioka, 2013).

In addition, feelings of discomfort from, or around, the stoma, particularly for those already with a parastomal bulge or hernia were described. Support garments were perceived to offer a way to reduce the risk of parastomal hernia development (PSH) even if there was doubt over their effectiveness. More attention is now being given to prevention of PSH with a national study (The CIPHER Study) underway (HRA, 2019). The likelihood of developing a PSH after stoma formation may well be lowest in those with a urostomy (Temple et al 2016). However, Donahue et al (2014) found radiographic evidence of parastomal hernia in 50% patients who have had radical cystectomy and urostomy formation at 2 years. Interestingly only just over a third were symptomatic from their hernia (37 of 93 patients). Reported risk factors to date are prior laparotomy, female and higher body mass index (Lui et al, 2014).

Nonetheless, wearing a support garment can add further discomfort for some and may be a reason why only a half described themselves as 'frequent' users of support underwear and just under a third as 'frequent' users of belts. Frequent users may have either never experienced any discomfort from their garment, or they may have overcome any reported problems such as tightness, rolling up or bulging. Certainly, those who found a garment that worked for them – offering them both comfort and protection - described how they gained confidence and a sense of mastery in their stoma management.

Half of the respondents had lived with their urostomy for over 4 years and might therefore be considered an expert in their stoma care and have had sufficient opportunities to try out a full range of support garments. Nevertheless, some

respondents suggested that they needed further guidance and signposting to find products to suit them.

Striking the right balance of healthcare support may be key. We wish for the person living with a urostomy to be sufficiently empowered and informed to take responsibility for their stoma needs but equally to know when, and be able, to call upon their health care team, and more specifically stoma care team, for professional advice and support. This is central to the concept of chronic disease management (Holman and Lorig, 2004). Regular contact with a stoma specialist nurse has been shown to improve health-related quality of life (Royal College of Nursing, 2009) but is it realistic to expect this continuity of care in today's NHS? How well resourced and orientated are stoma care teams to provide this on-going and specialist support enabling review of an individual's physical and psychosocial needs in the first five years following their urostomy formation? Studies like this, suggest there is a need for **additional specialist intervention; by providing personalised** advice and support, so that those with urostomies may feel encouraged to try new challenges including physical activity rather than living in fear of having a leak or developing a hernia (Russell, 2017).

Implications for practice

Arguably, many of the problems encountered by patients that they address by wearing support garments should be prevented thereby reducing the need for support garments. Better appliances could potentially eliminate urinary leaks, which is one of the main reasons for wearing a garment. Nevertheless, support garments appear to also play an important psychosocial role for some patients, for example through improving concealment of a stoma. Hence, all stoma patients should be advised that support underwear and belts are available on prescription from specialist ostomy manufacturers, although local policy should be considered when providing advice. It is also necessary to assess and measure the patient for the required support garment. The ASCN clinical guidelines recommend that 3 belts or girdles a year and 6 briefs or boxers a year are offered (ASCN, 2016). Funding arrangements do appear to vary across the country and so justification for the prescription and details of the support garment selected will need to be approved by the patient's GP (North and Osborne, 2017). Information on how to apply and wear support garments should be offered with a review appointment scheduled to check suitability.

Further research

Whilst this study has shown the important role that support garments can play in helping people with a urostomy feel more secure, comfortable and confident, further research to understand why these garments may not suit all and what the role they may in fact play in preventing parastomal hernias developing is needed.

There is also need for additional research on the experiences of people with a urostomy - who have to-date been an under-researched patient population; Brown's (2017) literature review elicited a scarcity of papers addressing psychosocial needs and quality of life with only a **tenth of all** papers identified citing urostomy compared

to colostomy (21 compared to 222). An intervention study aimed at reducing any physical discomfort from the urostomy and associated impact on health-related quality of life being just one suggestion.

Limitations

This study relied on free-text comments provided by respondents retrospectively. These comments are no substitute for in-depth prospective accounts of people's experiences of living with a stoma and their use of support garments. Additionally, the majority of those responding were women, over 50 years of age which will also influence their rationale for, and reported usage of, support garments.

Conclusions

The study reported in this article is the first to investigate experiences and use of support garments in people who have a urostomy. Their comments illustrate the benefits, difficulties and role that support garments have in their lives over time. For some, support garments promoted self-management offering physical support and protection, greater self-confidence and lifestyle choices. These findings advocate the value of stoma care nursing support in selecting suitable support garments and also suggest where further research is needed in this field.

Key points

- In this sample of 103 people with urostomies, support underwear was used more frequently (56.3%) within the sample than support belts (31.1%).
- Garments offered some respondents an invaluable support which became either part of their daily wear or worn as additional protection when being more physically-active.
- A particular fear was risk of urine leakage and a support garment was seen as a way to minimise this.
- Not all respondents found them comfortable to wear. This highlights that proper choice and specialist support when fitting may be key.

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