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Hernia Active Living Trial (HALT): an exercise intervention in people with a parastomal hernia or bulge

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ABSTRACT

Background: Parastomal hernias are a common consequence of stoma surgery and can occur in up to 50% of patients. They are mangaged either conservatively, through support hosiery, or surgically. A patient feasibility study called the Hernia Active Living Trial (HALT) was designed to examine if a clinical pilates-based exercise programme offers an alternative approach to managing a parastomal hernia or bulge. Method: Adults with an ileostomy or colostomy who perceived they had a bulge around their stoma were included in the study. The intervention included up to 12 online sessions of an exercise booklet and videos with an exercise specialist. Interviews were conducted to explore participants' experiences of the intervention. The interview data were analysed systematically and thematically. Participants were also asked to complete patient diaries every week. Results: Twelve of the 13 participants who completed the intervention agreed to be interviewed. Following analysis, three main themes emerged including managing a hernia/bulge, benefits and barriers. Participants talked about the benefits of this programme including: reduction of the size of their hernia, increased abdominal control, body confidence and posture, as well as increased physical activity levels. The barriers described were generally overcome allowing participants to engage in what was perceived to be a positive and potentially life-changing experience. Conclusions: A clinical pilates-based exercise programme for people with a parastomal hernia can bring both direct and indirect improvements to a patient's hernia management, sense of wellbeing and day-to-day life. Individuals with a hernia should be informed about the need for, and value of, exercise to strengthen core muscles, as part of their non-surgical options for self-management.

Key words: Parastomal hernia ■ Bulge ■ Abdominal control ■ Exercise ■ Physical activity

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Each year, over 6000 people have a new stoma formed for a variety of reasons – most commonly rectal cancer or inflammatory bowel disease (IBD) (NHS Digital, 2021) - with an estimated 1 in 335 people in the UK currently living with a stoma (Securicare and Colostomy UK, 2023). A common consequence of such surgery is a parastomal hernia (PSH) or bulge, with prevalence estimates of 50% or higher at longer duration of follow-up (Husain and Cataldo, 2008; Shiraishi et al, 2020; Soomro et al, 2022). The European Hernia Society defines a PSH as 'an abnormal protrusion of the contents of the abdominal cavity through the abdominal wall defect' created during placement of a stoma (Antoniou et al, 2018). A parastomal bulge is similarly defined, but also includes subcutaneous prolapse (Antoniou et al, 2018). It can be difficult to differentiate between the two on clinical appearances alone.

The authors hypothesised that clinical pilates-based exercises could increase participants' core abdominal strength and control with the aim of improving quality of life (QoL) and possibly reducing the risk of parastomal hernia or bulge progression.

To the ostomate, a PSH or bulge can be very distressing and augment body image, cause discomfort and/or pain and decrease QoL (Kald et al, 2008; Reali et al, 2023). Studies indicate that QoL and body image are likely to be worse in people who have a parastomal bulge compared with people with a stoma who do not have a parastomal bulge, and this impairment can be significant and sustained (Krogsgaard et al, 2021). A large longitudinal French survey found that, on average, a PSH developed 18 months after creation of the stoma and only 24% reported being free from symptoms related to the hernia (Ripoche, 2011).

This study examined whether a clinical pilates-based exercise programme might improve the QoL in people living with a stoma who perceive that they have a bulge or PSH. The Hernia Active Living Trial (HALT) was designed to look at the feasibility, acceptability, and safety of offering this intervention, which aimed to help people manage their PSH or bulge (Munro et al, 2023). For brevity, we shall henceforth refer to any parastomal bulge as a hernia.

This article reports on the qualitative findings from both the diary records and research interviews conducted with participants after the intervention to reveal their in-depth experiences of being involved in this study and gain insights into living with a PSH or bulge.

Table 1. Sample characteristics

Variable		Total sample *n*=36
Gender	Male	19 (53%)
	Female	17 (47%)
Age (years)		Mean 58 years (Range 25–75 years)
Diagnosis	Bowel cancer	12 (33%)
	Crohn's disease	1 (3%)
	Diverticulitis	7 (19%)
	Ulcerative colitis	7 (19%)
	Other	9 (25%)
Type of stoma	Colostomy	20 (56%)
	Ileostomy	16 (44%)

Table 2. Themes and sub-themes from the interviews

Themes	Sub-themes
Managing with a hernia/bulge	Coping with pain
	Managing limitations
	Nothing to lose
Benefits	Motivation
	Physical changes
	Body knowledge
	Attitude to stoma
	Mental health
	Change in behaviour
	Avoiding/preparing for surgery
	Instructor support
Barriers	Health
	Knowledge
	Own mentality
	Time

Method

The protocol and all study documents were approved by the North of Scotland Ethics Committee on 06 February 2020 (REC reference 20/NS/0007).

Participants who had had a stoma for more than 3 months, formed for bowel disease (eg, IBD, colorectal cancer), with a colostomy or ileostomy, with a self-assessed parastomal bulge or with a clinical diagnosis of a PSH were recruited. Those in the randomised controlled trial (RCT) were randomised to intervention or control. The exercise intervention had three core components:

- An exercise booklet developed by the research team (based on the Australian Physiotherapy and Pilates Institute methods programme), which was emailed to all participants
- Exercise videos available on a private YouTube channel
- Exercise sessions delivered online by a clinical exercise instructor. Participants could arrange to meet once a week online over a period of 12 weeks (if required) for 15–45 minutes with an instructor.

Each participant was asked to complete a questionnaire, diary, and semi-structured interview. Questionnaires were sent at baseline and follow-up, and diary entries were recorded each week of the intervention to document experiences and observed changes. At the end of the intervention, participants were invited to participate in a semi-structured interview conducted by telephone or video conference with a member of the research team. Participants were asked about being involved in the trial, if they felt they had gained anything from being involved, any changes that they noticed around their hernia, any barriers they had to being physically active, and if the intervention had influenced any of their habits or behaviours in terms of activity and self-management. The diary entries were analysed concurrently using the same analytical method as the interview data. Thematic analysis was completed by three researchers independently (WG, GH, JM). Results were compared and common themes were collated and summarised.

Results

Table 1 summarises the participant characteristics of the total sample (*n*=36). There was an almost even mix of men and women, colostomates and ileostomates and a large age range of the participants with a median age of 58 years. A diagnosis of colorectal cancer, ulcerative colitis and diverticulitis were the main reasons for stoma formation.

Twelve intervention group participants agreed to be interviewed. All interviews were video calls, which were recorded with consent of the participants. The online activity diary was used successfully by 15 participants who recorded 87 comments, the remaining intervention participants completed fewer than 4 diary entries or did not complete the intervention so were removed from the analysis.

The participant interview and diary data generated a range of responses, which encompassed talking about their experiences of managing with a PSH/bulge, the benefits, barriers, and ease of the programme. The four themes that emerged from data analysis are shown in *Table 2*.

Managing with a hernia/bulge

Participants talked about the pain and discomfort of having a hernia. Several described the pain that they experienced as being either around or behind their stoma, or more widely across their abdomen. The pain appeared to be chronic in nature and was not reported to worsen during the study participation. Only one participant mentioned that the exercises caused 'a little bit of agitation around the stoma'.

For many, the hernia caused limitations in their life and for some, made work and day-to day activities difficult. These difficulties created a motivation for participating in the study as they thought that the intervention either might help them

personally or assist others similarly suffering. Furthermore, several stated there were few other management options available to them when coping with a PSH or bulge.

'So, the idea of tightening things up with a view to making things better, really, or less chance of needing any more surgery was all to the good.'

Participant 3

'I've got nothing to lose by giving it a go and seeing if, you know … I'll try it, and if it helps somebody else then brilliant.'

Participant 6

'If I can find a way of managing that hernia so it doesn't get any worse in a more proactive way than just wearing a belt that probably doesn't work anyway, just makes you feel more protected, then I'd really love to do that and be able to feel a bit more freedom.'

Participant 2

Benefits

A range of mental and physical benefits were cited by those participating in this study (*Table 3*). They reported developing new ways of thinking and feeling about themselves during the exercise programme, which included increased motivation for exercise, improved bodily knowledge, and having a more positive attitude about themselves in general. Many direct gains were cited including noticing changes in how their body looked and felt. The visual changes included seeing their hernia was now smaller, abdominal contours flatter and body posture improved.

As participants started to feel stronger abdominally, confidence in their body grew. The mental and physical benefits then became interconnected:

'I feel the best I have for 10 years. My abdominal muscles feel stronger, my posture is much better, and my hernia feels tighter. I am enjoying it immensely; this will become a way of life.'

Participant 7

The decrease in size of the hernia was reported by a few participants to reduce the associated pain:

'The reduced size is much more comfortable. Occurred overnight but has persisted so far (3 days).'

Participant 8

Overall, the two most consistently reported benefits were a greater body awareness and sense of body control. The intense focus on the body plus mastery of the exercises and breathing techniques, brought a sense of control. These were skills that they felt they could use not only when practising their exercises, but also in their day-to-day lives.

Several participants also reported that improving their overall health empowered them to make a more lasting change in their behaviour. A few participants commented on weight loss because of the programme, which was seen as an unexpected benefit. However, for many, the benefits were due to having the confidence to be more active – to go for longer or faster walks and try new things.

This programme also offered a few participants the perceived possibility of avoiding a surgical repair of their hernia or, for a couple of participants, as a way to prepare for such surgery. The exercises gave them a focus on strengthening their core while waiting for revision of their PSH.

The final sub-theme related to the design of the programme with several comments stating that the technology had worked well, the exercises had been challenging but manageable and the instructors very friendly and supportive. Most participants were impressed with the instructor's attention to detail, receiving individualised feedback from them on their positioning, movement and breathing. While the programme was offered

Table 3. Examples of reported benefits of the programme from diary entries and interview transcripts by sub-theme

Motivation	'I'm genuinely starting now to get my CV together ready to go back to work, which before the programme, I would have been thinking twice about, because the discomfort and the pain and the tiredness were making me kind of go, "Actually, what employer is going to really want me?" To now going, "You know what, yeah, there's issues, but I know how to manage them, and I will do…"' *Participant 1*
Physical changes	'I feel, like, more stable when I'm running and that sort of thing, so, like, my core just feels stronger, like more … Over Christmas I had a cough, and… I could cough, and I just felt myself naturally doing the, like, preparing myself to cough, even, I wasn't thinking about it, just doing it.' *Participant 2*
Body knowledge	'It is definitely smaller, the hernia … I could feel everything was tightening up, and for somebody of my age, that is quite amazing, really. The actual reduction in the hernia has probably been certainly more gradual … over a few weeks.' *Participant 3*
Attitude to stoma	'The biggest thing has been my change in attitude towards my stoma. It's no longer a negative thing for me … I control it, it doesn't control me anymore.' *Participant 1*
Mental health	"'It certainly increased my mental health, I think that that was not a requirement of the study, but it certainly made me feel a lot better about myself. It was good to have goals that I set and that I met.' *Participant 4*
Change in behaviour	'I really feel in control of me and my body and what I'm doing, which I didn't before.' *Participant 1*
Avoiding/preparing for surgery	'I think that I'm … I'm more conscious of what's going on in that part of my body now … I'm more conscious of what I can do to … to strengthen it and prepare it for the surgery, and what I can do after the surgery to make things better.' *Participant 4*
	'I've got to live with this for a long time, so I want to try and manage it the best I can, so I don't need any more surgery or anything later down the line.' *Participant 2*
Instructor support	'She (the instructor) is really nice and easy to talk to. And there was no pressure either … I could do it at my own pace.' *Participant 5*

virtually this presented no issues, in fact it was reported to be an efficient and effective mode of delivery:

'So, for me, doing it this way on Zoom is much, much better, I much prefer it.'

Participant 3

Participants reported that the instructors were encouraging and enthused them with positivity, which further boosted their spirits and gave them motivation to continue exercising:

'I genuinely can't see me ever stopping completely doing the same set of exercises that the instructors got me doing.'

Participant 1

One participant captured the benefits as follows:

'I'd go so far as to say it's a life-changing experience, I'm absolutely chuffed, and it's … yeah, to think something so … so simple can be so effective.'

Participant 9

Barriers

Very few barriers were cited but there were four sub-themes relating to participants' health, knowledge, attitudes, and time required to commit to the programme. As well as coping with the hernia, many of the participants had not been active for some years and were apprehensive about how they would cope with the exercise demands of the programme. Some also shared worries about how they would cope with being more active:

'Struggled with doing more than one set so alternated doing two sets with one particular group then built up. Stoma quite painful this week'

Participant 10

Initially participants voiced concerns about whether they would be fit and flexible enough to undertake the exercises planned. However, as the exercises were personalised, they realised they could adjust and accommodate any changes in their health:

'Sometimes I'd get a bad health day, like one or two days per week, and then it would make things difficult … But say for instance, I was going to do four workouts in that week, I might find for two of them … I'm actually really unwell because … health issues.'

Participant 11

'Saturday I was very low on energy and only just completed the exercises. Monday was all good. Yesterday again a little low on energy. This is more down to an excessive workload and long hours than anything, I think.'

Participant 8

A lack of understanding about the programme and knowing how their body might cope with it, were perceived as barriers at the outset:

'Well, my wife said it perhaps it might be a good idea to do it, and we know perhaps there would be something in it. So, I thought, well, I'll give it a go anyway to see if it does.'

Participant 12

'Actually, the first session was difficult because I didn't have that mind-muscle connection at all. It took … it took a good week to get that … that connection in the first place.'

Participant 2

Some participants had specific stoma-related concerns, such as worrying that their bag might leak or that the hernia might become more painful while exercising. These barriers evaporated over time. As did some of the attitudes people had held:

'I think the biggest barrier was I was a little bit worried about doing it … You know, sometimes you kind of think "they're going to think I can do things that I can't do".'

Participant 1

'They look easy, but when you've held it for however long suddenly it's not so easy anymore … I imagined they'd be much easier than they were at first.'

Participant 8

What might be perceived as barriers could be overcome though discussion with the instructor:

'X (instructor) videoed the exercises. Quite … quite complex, some of them. And some of them we tried, and I just wasn't succeeding, so we dropped them.'

Participant 4

One barrier that remained for a few participants was finding time to practise the exercises:

'That was the only difficulty, was trying to find a time where … where, like, in the day you're guaranteed that you have half an hour, forty-five minutes no one would call you.'

Participant 2

The patient diaries substantiated the interview findings and indicated that while commitment was required to complete the exercises prescribed, they enjoyed learning about their bodies and quickly started to see positive changes in their hernia without experiencing any serious adverse events.

Discussion

The HALT intervention was designed with the expectation that through the clinical pilates-based exercise programme, participants might gain more confidence and adapt their

behaviour, leading to improvements in body image and QoL. There was overwhelmingly positive feedback about the programme, as demonstrated by the comments presented. Those who received the exercise programme observed physical improvements, such as reduction in the size of the hernia, weight loss, core strengthening, core control, improved posture, and less need for support garments due to having better core control.

In addition to the one-to-one sessions, all the participants received an exercise booklet, which provided links to the videos the team had created offering more detailed descriptions on each exercise including cues and tips on the proper breathing and movements required. The videos could be watched at any time and proved popular with some exercises receiving up to 200 views on the site. The diary entries suggested that the participants used these resources to practise the exercises. Over time and with practice, it was evident that participants experienced a range of benefits that enhanced their body awareness and improved self-confidence, which reinforced the value of continuing with the exercises.

These positive findings are important because there is a lack of high-quality evidence to guide both the prevention and treatment of PSH. The Association of Coloproctology of Great Britain and Ireland (ACPGBI) Delphi process identified prevention and treatment of PSH as the second highest priority non-cancer related colorectal pathology (ACPGBI, 2018). Patients who are informed that they are at risk of a PSH developing understandably ask what they can do to limit this happening. The Association of Stoma Care Nurses UK (ASCN UK, 2016: 16) recommends specialist stoma belts/underwear 'to aid prevention of hernias and offer abdominal muscle support.' The use of abdominal exercises is also advised as a prevention and management strategy in these clinical guidelines (ASCN UK, 2016; North and Osborne, 2017).

If a PSH does develop and the patient is relatively asymptomatic then management should follow a conservative approach involving patient education (Thompson, 2008), weight management (Mohamed and Harries, 2023), and possibly a hernia belt to prevent further expansion of the hernia itself and exercise as per the ASCN UK (2016) guidelines. The feedback from HALT participants further reinforces the use of abdominal exercises as a self-management option. However, it is worth noting that some people who develop a parastomal hernia manage well without any problems or complications and may not see the benefit of adopting this approach (Styliński et al, 2018).

Furthermore, surgical repair must be carefully considered as recurrence rates can be quite high, reported to be between 20% and 40% (Ramirez-Giraldo et al, 2022), and there may be associated general health risks of having relatively major surgery. However, a proportion of patients will require surgical repair if they have a non-resolving obstruction or develop a strangulated or incarcerated hernia (Smith et al, 2022).

For those who consider a planned surgical repair, considering such an exercise programme as part of a prehabilitative approach may be of benefit. Although there is evidence to support a preoperative exercise programme before elective surgery (Luther et al, 2018; Chan et al, 2022), the added benefit of incorporating a clinical pilates-based exercise programme into this needs exploring. However, personalised exercise programmes have been shown to improve postoperative outcomes (Wynter-Blyth and Moorthy, 2017). Providing patients with personalised support, such as in this study can help them feel more prepared, engaged and possibly more confident in their recovery.

Non-surgical management of PSH remains a high research priority for this patient population and the findings from the non-operative treatment arm of the PROPHER (Patient-Reported Outcomes after Parastomal HErnia tReatment) study are awaited (Blackwell and Pinkney, 2020). The HALT study, aimed to examine whether a non-surgical approach might bring benefit to these patients. It was found that the physical benefits achieved by the participants in this study met with the hypothesised benefits of the exercise programme, ie, improved core control and strength. As highlighted, participants also shared how they had changed both their attitudes to exercise as well as their behaviour. The intervention encouraged them to think about their physical activity levels and undertake activities they may have previously avoided. However, a greater understanding of whether variables such as ethnicity, level of education, and employment, as well as internet use modifies the effectiveness of this intervention (Munro et al, 2023).

Having a stoma can impact physical activity levels (Beeken et al, 2019); a Danish review noted that only half of survivors with a stoma were meeting World Health Organization guideline recommendations for physical activity each week (Krogsgaard et al, 2022). This is likely to be further impacted by having a PSH as indicated by a large UK survey (2631 respondents), which found that 32% of those with a medically diagnosed hernia reported being 'much less active' than they were prior to their surgery (compared with 19% without a hernia) (Russell, 2017).

Although having a PSH may restrict ostomates from carrying out certain activities, it should still be possible to live a 'normal life' and take part in exercise provided they follow the published guidance and a personal exercise prescription. As the participant feedback indicates, one of the benefits of this programme was that it gave patients the self-confidence to become more active even with a bulge or PSH. By performing the exercises outlined in this programme, participants were not only strengthening their 'internal support belt', but they also became more confident to be more active. Participants welcomed techniques that helped them reconnect with their body and focus on body control. For those with a PSH, skilled instruction that is personalised to individual needs is advocated.

This study allowed for variation in the number and duration of sessions delivered to participants to accommodate the different need for support from the exercise instructors. Participants stated that the exercises were manageable, but that they had initially found them challenging to perform. For this reason, having one-to-one sessions is considered particularly helpful for accuracy of technique and visual feedback along with advice from the exercise specialist were highlighted as a key enabling factor. Over time and with the support of the clinical exercise specialist, their ability to perform the exercises improved, which built their body confidence.

KEY POINTS

- People living with a hernia/bulge can feel disconnected from their bodies and experience barriers – real or perceived – to being physically active
- A clinical pilates-based exercise programme can bring both physical and psychological health benefits to those living with a parastomal bulge
- Participants in this study described how these techniques enabled them to reconnect with their body and focus on improving body control
- Further research into the non-surgical management of parastomal hernia is needed

CPD reflective questions

- How can you enhance the support you offer to people who develop a parastomal hernia?
- Which patients would you refer for a surgical assessment ?
- What precautions do you need to consider for those who wish to be more physically active with a parastomal hernia?
- What education will you provide to patients who wish to be more physically active with a stoma?

Implications for practice

The ASCN UK (2016) guidelines state that everyone living with a stoma should be informed of exercises to strengthen their core muscles, as part of hernia prevention. Yet many ostomates report receiving conflicting advice from professionals on whether it is safe to undertake physical activity. Providing clear information on what exercises can be safely undertaken and the benefits of doing so, is seen as essential for both the psychological and physical wellbeing of those living with a PSH (Beaubrun et al, 2018). The findings of this study reinforced the need for such information to be available in a variety of mediums (written, video and face-to-face) and to offer ostomates choice in how they receive this. Checking receipt and assessing understanding of this information should be integral to every annual stoma care review.

Stoma care nurses provide invaluable advice and training to those with a new stomas, maintaining continuity of care following surgical intervention and offering product support and review. They also act as a conduit for referrals to surgeons when patients have deteriorating symptoms and quality of life from parastomal complications and hernia (ACPGBI, 2018). This research prompts us to look at how, as specialist gastrointestinal nurses, we can work more proactively to offer patients both a primary and secondary preventive approach to PSHs that will support self-management.

Conclusion

This feasibility study suggests that a pilates-based exercise programme for people with a stoma and parastomal bulging is safe, acceptable and feasible to conduct. The qualitative feedback from both the interviews and the diary entries highlighted and range of benefits that can be realised from such a programme. It is proposed that people with a PSH can continue to live an active life provided they receive appropriate support and advice. Further research is needed to examine both the longer-term benefits as well as the safety and efficacy of adopting such conservative approaches in this patient group. It is essential that people with PSHs participate in designing future non-invasive interventions and that is why our next research will be asking in more detail how we can help people to self-manage a PSH. **BJN**

Declaration of interest: none

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