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ORIGINAL ARTICLE

Assessment of the quality of online patient information resources for patients considering parastomal hernia treatment

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Abstract

Aim: The aim was to examine the quality of online patient information resources for patients considering parastomal hernia treatment.

Methods: A Google search was conducted using lay search terms for patient facing sources on parastomal hernia. The quality of the content was assessed using the validated DISCERN instrument. Readability of written content was established using the Flesch–Kincaid score. Sources were also assessed against the essential content and process standards from the National Institute for Health and Care Excellence (NICE) framework for shared decision making support tools. Content analysis was also undertaken to explore what the sources covered and to identify any commonalities across the content.

Results: Fourteen sources were identified and assessed using the identified tools. The mean Flesch–Kincaid reading ease score was 43.61, suggesting that the information was difficult to read. The overall quality of the identified sources was low based on the pooled analysis of the DISCERN and Flesch–Kincaid scores, and when assessed against the criteria in the NICE standards framework for shared decision making tools. Content analysis identified eight categories encompassing 59 codes, which highlighted considerable variation between sources.

Conclusions: The current information available to patients considering parastomal hernia treatment is of low quality and often does not contain enough information on treatment options for patients to be able to make an informed decision about the best treatment for them. There is a need for high-quality information, ideally co-produced with patients, to provide patients with the necessary information to allow them to make informed decisions about their treatment options when faced with a symptomatic parastomal hernia.

KEYWORDS

parastomal hernia, patient information, shared decision making

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INTRODUCTION

Patients seek treatment, both operative and non-operative, for their parastomal hernia (PSH) for many reasons. The symptom burden will vary from patient to patient [1], and this combined with their acceptance for risk and personal beliefs and circumstances will impact on whether surgery is indicated. Currently there is a lack of high-quality evidence to guide treatment decisions. Surgeons do not know the best way to repair a PSH, nor do they know whether watchful waiting is safe or whether it can result in more complications [2]. Additionally, recurrence risks from PSH repair are high [3, 4]. In order for patients to be able to make informed decisions about their treatment options, this uncertainty and the risks and benefits of different treatment options need to be conveyed to the patient so that they have a reasonable understanding in order to inform decisions [5].

Providing patients with information about their treatment options is part of the National Institute for Health and Care Excellence (NICE) guidelines on shared decision making (SDM) [6]. SDM is a process where clinicians provide patients with information on treatment options, allowing them to make decisions that take their preferences and personal circumstances into account. Evidence shows that SDM and promoting patient involvement in treatment decisions can have a positive impact on patient satisfaction and clinical outcomes [7, 8].

Patients may be given information on treatment options for a PSH by a clinical nurse specialist in stoma care, or colorectal nurse specialist, or by a colorectal or general surgeon, who may or may not have a special interest in hernia surgery. For many patients this may be the first time that they have heard of a PSH. Recent research has shown that over a third of patients first heard about PSH when their hernia was diagnosed [9]. These healthcare professionals may provide them with information produced by NHS Trusts, patient support charities or commercial stoma product manufacturers. This is to allow patients time to read and digest information away from the hospital setting so that they can consider their treatment options [10]. Additionally, patients often turn to the internet to source information on their disease and the treatment options. Previous studies have suggested that between 50% and 76% of patients use the internet as a source for healthcare information [11–13] with Google being the most popular search engine [14].

Previous studies have explored the quality and availability of online patient information in surgical treatment decision making for other surgical conditions [13, 15–17], but no assessment has yet been made of the quality and content of patient information for patients considering PSH treatment. Our aim was to examine the quality and content of current online information for patients considering PSH treatment.

What does this paper add to the literature?

This paper has assessed the quality of online patient information resources for patients considering parastomal hernia treatment and a lack of high-quality information has been identified. Clinicians should be aware of this when discussing parastomal hernia treatment with patients.

METHODS

Search strategy

Searches were performed using Google incognito mode so that personalized search responses were not offered. Google was selected as it is the most popular search engine and can work out the user's intention from a search string even when spelt incorrectly.

A predefined list of search terms was used. These were based on terms that patients commonly use on social media when discussing PSH treatment, based on an informal review of public social media posts. Searches were run separately for each term to ensure that no sources were missed.

The search terms selected were 'parastomal hernia treatment', 'surgery for parastomal hernia', 'peristomal hernia surgery', 'stoma hernia', 'hernia support wear' and 'hernia belt'. The first three pages of results for each search term were screened for relevant sources. The first three pages were selected as the cutoff as, while research shows that people tend not to go past the first page on Google [18], it was expected that some sources, such as the National Health Service (NHS) Trust websites, may not necessarily appear high up on an organic search (organic search is a listing that appears because it is relevant to someone's search, rather than a paid listing).

Eligibility criteria

The predefined eligibility criteria were any UK information sources available online designed for patients, written in English, providing information about PSH and PSH treatment that has been produced by a charity, professional association (e.g., the British Hernia Society), NHS Trust, private healthcare provider, healthcare professional or commercial stoma product manufacturer/supplier. Webpages were identified as UK based either by the .co.uk suffix in the URL or if they were a known UK-based organization. All types of information sources were included, whether these were a single webpage or a dedicated patient information resource.

Exclusion criteria were patient to patient sources sharing experiential information and sources produced outside of the UK as the information may not be suitable given the differences in healthcare systems. Any sources that appeared only as paid for Google ads were also excluded as paid for search results are temporary and may not appear if the search were replicated later.

Data extraction

Data were extracted by SB. Data were recorded on a data extraction form in Microsoft Excel 2021. The data extraction form was piloted before use by SB to ensure that all necessary data could be captured. The data extraction form captured the following domains: (1) source descriptor (URL, upload source, country of origin); (2) general disease descriptors (what is a PSH, causes, information on surgical and conservative management, conservative versus surgical management, risks and benefits of treatment options and patient preferences); these were recorded as yes or no; (3) items covered by the essential content and process standards from the NICE framework standards for SDM tools. Completeness of these was recorded as yes, no or partial. Full texts of the sources were imported into NVivo 14 to allow a content analysis to be undertaken.

DATA ANALYSIS

Data were analysed by SB. Fifty per cent of the sources were selected at random and subjected to a second analysis of the DISCERN score by SC, a patient with lived experience of hernia surgery. As the DISCERN scoring is based on the reviewer's judgement this was subjected to a second analysis to reduce reviewer bias. Conflicts were discussed and scores revised.

Identified sources were assessed using three tools to assess quality of content, readability and whether the source offered support for SDM. Content analysis was also undertaken in order to explore what the sources covered and to identify any commonalities across the content.

Discern

The validated DISCERN instrument is designed to assess the quality of written information on the treatment choices for a defined health problem [19]. The DISCERN instrument contains 15 questions (scored on a 5-point Likert scale) [20]. The rating scale allows the reviewer to determine whether the question has been fulfilled, with 1 being a definite no, 2–4 being partially and 5 being a definite yes. There is also an overall global quality score, rated 1, 3 or 5, which is considered to be an 'intuitive summary' of the responses to the first 15 questions [21]. For example, if a

source rated high and low on a similar number of questions then the global score would be a 3. A global score of 5 indicates the publication is of high quality, 3 equates to fair (moderate) and 1 is low quality.

Flesch–Kincaid

Readability was scored by the Flesch–Kincaid reading ease score [22]. It uses a formula based on the average sentence length in words and the average word length in characters which then gives a score to the text of a numerical value between 0 and 100. The higher the score, the more readable the text is considered to be. A score of 60–80 is desirable as this suggests the text is easy to read by a 12-year-old—which is just above the average reading age in the UK [23]. The Flesch–Kincaid score was calculated using the readability function in Microsoft Word.

NICE standards framework

All sources were assessed against the NICE standards framework for SDM support tools. This sets out essential and desirable content standards that SDM support tools should include [24]. These include the health condition, decision and available options; whether they provide information on where the evidence for the information came from; whether the risks and benefits are presented in a neutral and unbiased format; and whether patients have been involved in the production of the information source. Sources were assessed against the essential content and process standards. Each item was scored yes, no or partial. Partial was recorded if the source contained some but not all of the information for that domain as set out in the framework. While the sources identified were not formal SDM tools, patients will use these tools as sources of information when discussing treatment options with their clinical team, and assessment against the NICE standards was appropriate.

Content analysis

An inductive, also termed conventional, content analysis [25] was undertaken using NVivo 14. One source was selected and independently coded by SB, JM, DT. Codes were then discussed and refined, and a structure was identified for the content analysis which was then applied to the remaining sources by SB.

RESULTS

Fourteen sources were identified (Table 1). Three sources were designed as patient information resources and were available as a

TABLE 1 Characteristics of sources included in final analysis.

URL	Source	Aim of source	Country of origin	What is a parastomal hernia	Causes of parastomal hernia	Info on surgical treatment	Info on conservative management	Conservative versus surgical	Risks and benefits of treatment options	Patient preferences
https://www.colostomyuk.org/	Colostomy UK (patient support charity)	Patient information resource on parastomal hernia	UK	Yes	Yes	Yes	Yes	No	Yes	No
https://www.coloplast.co.uk/stoma/people-with-a-stoma/living-with-a-stoma/stoma-information-guides/	Coloplast (stoma product manufacturer)	Patient information resource on managing a parastomal hernia	UK	Yes	Yes	No	Yes	No	No	No
https://www.oakmed.co.uk/help-advice/stoma-hernia-surgery-what-to-expect/	Oakmed (stoma product manufacturer)	Webpage on parastomal hernia surgery	UK	Yes	No	Yes	Yes	Yes	No	No
https://www.hcahealthcare.co.uk/our-services/conditions/parastomal-hernia	HCA (private healthcare provider)	Webpage with general information on parastomal hernia	UK	Yes	No	Yes	Yes	No	Yes	No
https://www.healthandcare.co.uk/blog/living-with-a-parastomal-hernia.html	Health and Care (private company - other)	Webpage with general information on living with a parastomal hernia	UK	No	Yes	No	Yes	No	No	No
https://www.thebirninghamcolorectalclinic.com/conditions/colorectal-conditions/parastomal-hernia/	Birmingham Colorectal (private healthcare provider)	Webpage with general information on parastomal hernia	UK	Yes	No	Yes	Yes	No	No	No
https://www.securicaremedical.co.uk/blog/stoma-care-nurse-says-parastomal-hernia-and-how-to-manage-them	Securicare (dispensing appliance contractor)	Online blog about managing parastomal hernias	UK	Yes	Yes	No	Yes	Yes	No	No

TABLE 1 (Continued)

URL	Source	Aim of source	Country of origin	What is a parastomal hernia	Causes of parastomal hernia	Info on surgical treatment	Info on conservative management	Conservative versus surgical	Risks and benefits of treatment options	Patient preferences
https://www.clinimed.co.uk/stoma-care/stoma-problems/hernia	Clinimed (stoma product manufacturer)	Webpage with general information on parastomal hernia	UK	Yes	Yes	No	Yes	No	No	No
https://www.theostomystudio.co.uk/post/parastomal-hernias-how-do-we-prevent-them	The Ostomy Studio (private company – other)	Online blog about prevention of parastomal hernia	UK	No	Yes	No	Yes	No	No	Yes
https://www.dansac.com/en-gb/living-with-stoma/recoveryafterstomasurgery/preventingaperistomalhernia	Dansac (stoma product manufacturer)	Webpage about prevention of parastomal hernia	UK	Yes	Yes	No	Yes	No	No	No
https://www.vyne.co.uk/blogs/ostomy-support/parastomal-hernia-what-causes-it-and-how-can-it-be-treated	Vyne (dispensing appliance contractor)	Webpage about causes and treatment of parastomal hernia	UK	Yes	Yes	Yes	Yes	No	No	No
https://supportx.co.uk/advice/	Supportx (stoma product manufacturer)	Webpage with information on causes, prevention and treatment of a parastomal hernia	UK	Yes	Yes	No	Yes	No	Yes	No
https://www.fittleworth.com/parastomal-hernia-prevention/	Fittleworth (dispensing appliance contractor)	Online blog about parastomal hernia prevention	UK	Yes	Yes	No	No	No	No	No
https://meplus.convatec.co.uk/meplus-downloadable-booklets/	Convatec (stoma product manufacturer)	Patient information resource on exercise and parastomal hernia	UK	Yes	Yes	No	Yes	No	No	No

PDF download (or available in hard copy from the publisher) [26–28], three were blog posts hosted on websites [29–31] and eight were online resources [32–39]. One source was from a patient support charity, Colostomy UK, six were webpages belonging to stoma product manufacturers, three were webpages of dispensing appliance contractors [40], two were private healthcare providers and two were other types of private company.

Ten sources provided general information about PSH, only one of which was designed as a specific patient information resource. Four sources had a specific focus and subsequently did not contain information about surgical treatment options. These were Fittleworth and the Ostomy Studio, which were focused on the prevention of a PSH [29, 30]; Coloplast, which was focused on managing a PSH [27]; and Convatec which was focused on PSH and exercise [28].

DISCERN

Table 2 shows the DISCERN scores. The overall quality of the sources identified was low, with 11 of the 14 scoring a global DISCERN score of 1, and only three scoring a 3. Only six of the sources scored higher than a 3 in any single domain.

Four sources scored highly on question 1 'are the aims clear', two scored moderately and eight scored low, with the aims of the source being implied. Only two sources contained information on the information sources used to produce the content [27, 28]. One source scored highly for question 14 'is it clear that there may be more than one treatment choice' [26]; three scored moderately [27, 33, 39] and the other 10 sources scored poorly. All but one of the sources scored poorly for question 12 'does it describe what would happen if no treatment is used'. All sources scored poorly for question 15 'does it provide support for shared decision making'.

As previously discussed, not all sources identified were specifically about PSH treatment. Two sources were focused on PSH prevention [29, 30], one on PSH and exercise [28] and one on managing a PSH [27]. The PSH and exercise booklet from Convatec scored highly on the questions that were relevant to the content of the booklet but scored low on questions related to treatment options as this was not the focus of the source. A similar situation was seen with the Coloplast guide to managing a PSH. These sources were included in the analysis as patients are likely to download and read these when searching for information on PSH, given the paucity of information available.

Flesch–Kincaid

The mean Flesch–Kincaid reading ease score of 43.61 (range 43.7–69.1) would be considered difficult to read [41]. Only two sources scored between 60 and 80 which is the equivalent of a reading age of 12, which is slightly above the average UK reading age [23].

NICE standards framework for shared decision making tools

Table 3 sets out the assessment of the sources against the essential content and process standard from the NICE standard framework. These were scored as yes, no or partially (if the source contained some but not all the information for that domain as set out in the framework).

All the sources analysed contained information on the health condition, decisions and options but the content and the level of detail varied considerably, with some having very basic content that did not provide enough information for a patient to make informed decisions. Only two sources contained information on the risks and benefits of treatment options, and this was only partially covered. Five sources had had patient involvement in their production: Fittleworth and the Ostomy Studio were both written by authors who have lived experience of a stoma and who were writing in a professional capacity. Three others stated that patients had been involved but did not specify what involvement this was [27, 28, 35]. Eight of the identified sources had no details of who the authors were or their qualifications. Only two sources acknowledged the evidence sources for the content.

Content analysis

An inductive content analysis identified eight categories from the 14 sources (Table 4). These were as follows:

- causes of PSH, which included coughing and sneezing, emergency surgery, stoma location, being overweight and lifting heavy weights;
- impact on quality of life which included items such as body image, psychological impact and peristomal skin problems;
- impact on stoma function which included items such as changes to the stoma, issues with irrigation and peristomal skin problems;
- PSH prevention which included exercise, avoidance of heavy lifting, weight management and the use of support wear;
- risks, which included risks of having surgery for a PSH, risk of recurrence and complications related to having a PSH;
- symptoms of a PSH which included items such as ache, bulge, pain, swelling;
- treatment options, which included conservative management, use of mesh, methods of repair and use of support wear;
- other background information on PSH which included description/definition of a PSH, prevalence and diagnosis.

There were some commonalities across the sources. Each resource described what a PSH was, and 11 included information on the causes of a PSH and suggestions for preventative measures. There were variations within the content in the categories on the presentation of causes for developing a PSH, how the surgical options were presented, and how conservative management was described.

TABLE 2 DISCERN scores by source.

	Colostomy UK			Health and Care			Birmingham Colorectal Clinic			The Ostomy Studio			Dansac			Vyne			Suportx			Fittleworth			Convatec				
	Coloplast	Oakmed	HCA	HCA	Care	Birmingham Colorectal Clinic	Securicare	Clinimed	Studio	Dansac	Vyne	Suportx	Fittleworth	Convatec	Coloplast	Oakmed	HCA	HCA	Care	Birmingham Colorectal Clinic	Securicare	Clinimed	Studio	Dansac	Vyne	Suportx	Fittleworth	Convatec	
Q1. Are the aims clear?	1	1	1	1	1	1	2	1	3	5	1	5	5	5	1	1	1	1	1	1	2	1	3	5	1	5	5	5	5
Q2. Does it achieve its aims?	1	1	1	1	1	1	2	1	4	5	1	4	5	5	1	1	1	1	1	1	2	4	4	5	1	4	5	5	5
Q3. Is it relevant?	3	4	2	1	1	1	2	1	3	2	2	3	4	4	2	2	2	2	2	2	2	3	3	2	2	3	4	4	4
Q4. Is it clear what sources of information were used to compile the publication?	1	5	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	5
Q5. Is it clear when the information used or reported in the publication was produced?	3	5	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	3	5	5
Q6. Is it balanced and unbiased?	3	3	2	2	2	2	2	2	3	2	2	2	2	2	2	2	2	2	2	2	2	2	3	2	2	3	3	5	5
Q7. Does it provide details of additional support and information?	2	2	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	3	2	3	3
Q8. Does it refer to areas of uncertainty?	2	2	1	1	1	1	2	1	2	1	1	2	1	1	1	1	1	1	1	1	2	1	2	1	1	2	1	3	3
Q9. Does it describe how each treatment works?	2	2	3	1	1	1	2	1	1	1	1	2	1	1	2	2	2	2	2	2	2	1	1	1	2	1	1	1	1
Q10. Does it describe the benefits of each treatment?	2	2	3	1	1	1	2	1	1	1	1	2	1	1	2	2	2	2	2	2	2	1	1	1	2	1	1	1	1
Q11. Does it describe the risks of each treatment?	2	2	3	1	1	1	2	1	1	1	1	2	1	1	2	2	2	2	2	2	2	1	1	1	2	1	1	1	1

(Continues)

TABLE 2 (Continued)

	Colostomy		Health and Care			Birmingham Colorectal Clinic			The Ostomy Studio			Convatec		
	UK	Coloplast	Oakmed	HCA	Health and Care	Colorectal Clinic	Securicare	Clinimed	Studio	Dansac	Vyne	Suportx	Fittleworth	Convatec
Q12. Does it describe what would happen if no treatment is used?	2	2	3	1	1	1	1	1	1	1	1	2	1	1
Q13. Does it describe how the treatment choices affect overall quality of life?	2	2	3	1	1	1	1	1	1	1	1	2	1	1
Q14. Is it clear that there is more than one treatment choice?	4	3	3	2	1	2	2	1	1	1	3	2	1	1
Q15. Does it provide support for shared decision making?	2	2	1	1	1	1	1	1	2	1	1	1	1	1
Q16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices	3	3	1	1	1	1	1	1	1	1	1	1	1	3

Note: Q1–Q15: 1 = no, 2–4 = partially, 5 = yes. Q16: 1 = low quality, 3 = fair (moderate) quality, 5 = high quality.



TABLE 3 NICE standards framework assessment by source.

Source	Health condition, decision, and available options	Details of the available options	Support for person's values, circumstances and preferences	Use of language and numbers	Formats and availability	Evidence sources	Patient involvement and co-production	Risks and benefits	Date for review, funding, COI, authors' qualifications
Colostomy UK	Partial	Partial	No	Uses language that is easy to understand. No figures given	Patient information resource. Booklet. Online, as a PDF download or in hard copy from Colostomy UK	No	No	No	Yes
Coloplast	Partial	Partial	Partial	Includes diagram to explain what a PSH is, and where muscles are and what they do	Patient information resource. Booklet. Online as a PDF to download or in a hard copy from some SCNs	Yes	Yes	Partial	Yes
Oakmed	Partial	Partial	No	Written in fairly easy to understand language; no diagrams or images included	Single page online webpage	No	No	No	No
HCA	Partial	Partial	No	Written in fairly easy to understand language; no diagrams or images included	Single page online webpage	No	No	No	No
Health and Care	Partial	Partial	No	Written in fairly easy to understand language; no diagrams or images included	Single page online webpage	No	No	No	No
Birmingham Colorectal Clinic	Partial	Partial	No	Written in fairly easy to understand language; no diagrams or images included	Single page online webpage	No	No	No	No
Securicare	Partial	Partial	Partial	Written in fairly easy to understand language; no diagrams or images included	Single page online webpage	No	No	No	No
Clinimed	Partial	Partial	No	Written in fairly easy to understand English. No diagrams included. Has a link to a YouTube video on core exercises	Single page online blog post on website	No	Yes	No	No
The Ostomy Studio	Partial	No	No	Written in fairly easy to understand English but does copy and paste some items that are not easy to understand, i.e. AAAA	Online blog post on website	Partial	Yes	No	No
Dansac	Partial	No	No	Generally easy to understand language; includes a picture and basic diagram. Uses peristomal rather than parastomal	Single page online webpage	No	No	No	No

(Continues)

TABLE 3 (Continued)

Source	Health condition, decision, and available options	Details of the available options	Support for person's values, circumstances and preferences	Use of language and numbers	Formats and availability	Evidence sources	Patient involvement and co-production	Risks and benefits	Date for review, funding, COI, authors' qualifications
Vyne	Partial	Partial	No	In generally easy to understand language. Does swap between peristomal and parastomal in some places. Has a very basic diagram	Online webpage	No	No	No	No
Suportx	Partial	Partial	No	Written in fairly easy to understand English. No diagrams or images used	Online webpage	No	No	No	No
Fittleworth	Partial	No	No	Written in easily understood English; no diagrams or images used	Online blog post on website	No	Yes	No	No
Convatec	Partial	No	No	Is generally in easy to understand language but does use some medical terms that are not explained, i.e. prone CT. Has a diagram to explain core exercises, and very basic diagram for PSH	Patient information resource booklet. Online as a PDF to download	Yes	Yes	No	Partial

Abbreviations: AAA, Abdominal Aortic Aneurysm; COI, Conflict of Interest; NICE, National Institute for Health and Care Excellence; PSH, parastomal hernia; SCNs, Stoma Care Nurses.

There was also considerable variation in the presentation of risk factors for developing a PSH. When all resources were pooled together, content analysis identified 19 risk factors for developing a PSH, with four of the identified risks only being mentioned in one source. Coughing and sneezing, increased weight and smoking were the most frequently listed risk factors. In the majority of cases, no explanation was given as to why these were a risk factor, for example the raised intra-abdominal pressure resulting from coughing and sneezing [42]. Five of the sources mentioned that a PSH may be symptomless or have very minor symptoms.

DISCUSSION

This study has identified and assessed the available online information available to patients with a PSH. It has found that the current information available is of low quality and does not meet current recommendations for ease of readability. There are currently no SDM or patient decision aids available for patients diagnosed with a PSH [43] and so it is likely that the identified sources will be utilized by patients seeking further information to be able to make decisions about treatment options.

Previously published work in colorectal cancer and inflammatory bowel disease surgery [15, 17] has also shown that written and internet-based information for patients is of low quality (assessed using the DISCERN instrument) and written to a higher educational level than recommended [41]. Both studies recommended that further online and written resources should be created to provide patients with high-quality information. This study has shown that this is the same for information relating to PSH.

There was considerable variability in the design of the sources identified. Some were single webpages designed to provide limited information about PSH treatment, whereas others were blog posts that discussed aspects of living with a PSH, and three were specific patient information resources. It was not always clear from the sources who they were aimed at, or at what stage of the patient journey they were designed for. For example, the guides from Coloplast and Convatec were clearly aimed at patients who had been diagnosed with a PSH, while the guide from Colostomy UK was broader in scope, providing limited information on treatment options. Patients' requirements for information provision will differ depending on where they are in their surgical journey, and their understanding and retention of provided information will also be impacted [9].

The identified sources contained limited information on both conservative management and surgical options for treatment of a PSH. While some covered the use of support garments, this was not always specifically presented as conservative management, which may lead patients not fully to understand the role of support garments [44]. The limited information that was included on surgical options did not make clear the risks and benefits of surgical repair. The sources that did mention recurrence of the PSH after surgical

**TABLE 4** Categories and codes derived from the content analysis across information sources.

Category	Codes ^a	Number of sources
Causes of PSH (patient level factors relating to development of PSH)	Age	4
	Alcohol	1
	Breathing problems	1
	Collagen problems	1
	Constipation	4
	Coughing and sneezing	7
	Emergency surgery	2
	Lifting	2
	Malnourished	3
	Muscle weakness	6
	Previous abdominal surgery	5
	Smoking	6
	Surgical site infection	4
	Steroids	4
	Stoma location	2
	Avoidance of straining	4
	Type of stoma	2
	Vomiting	1
	Being overweight	8
Impact on quality of life (how a PSH impacts on patient quality of life)	Body image	5
	Issues with irrigation	2
	Issues with stoma	8
	Lifestyle factors	2
	Psychological impact	5
	Obstruction	1
	Peristomal skin problems	5
Impact on stoma function (how a PSH impacts on patient stoma function)	Bowel function	3
	Changes to stoma	2
	Issues with irrigation	2
	Peristomal skin problems	5
	Stoma function	3
PSH prevention (strategies to prevent PSH formation)	Breathing techniques	2
	Holding stoma when coughing/sneezing	4
	Exercise	10
	Avoidance of lifting heavy weights	10
	Managing weight	8
	Stop smoking	4
	Avoidance of straining	3
	Use of support wear	8
Risks (risks associated with PSH treatments)	Risks relating to surgical intervention	3
	Risk of recurrence of hernia after surgical repair	5
	Medical and surgical complications related to a PSH	7

(Continues)

TABLE 4 (Continued)

Category	Codes ^a	Number of sources
Symptoms (symptoms of PSH that patients might experience)	Ache	2
	Bloating	1
	Bulge	10
	Dragging sensation	6
	Pain	9
	Swelling	1
	Symptomless PSH	5
Treatment options (surgical and conservative treatment options for PSH)	Conservative management	3
	Use of mesh in surgical repair	3
	Options for surgical repair	2
	Use of support wear	8
	Surgery	8
Other background information on PSH (epidemiology)	Definition of a PSH	12
	How a PSH is diagnosed	9
	Prevalence of PSH in patient cohort	9
	Size of PSH	5
	Timing around development of PSH	7

Abbreviation: PSH, parastomal hernia.

^aCodes can recur across categories.

repair reported this as a small risk, whereas the published literature suggests that recurrence rates are 40%–60% [3, 4].

Some of the sources touched on the impact of a PSH on quality of life, but in some cases it was reported as something that could be asymptomatic or would not cause any problems. The published literature reports that PSHs are symptomatic in up to 75% of patients [45]. Information on quality of life after PSH treatment is being captured in the currently ongoing PROPHER study [46] which will provide high-quality prospective information and an international evidence base, which could help improve the published literature.

None of the identified sources offered any information on what questions patients may want to discuss with their healthcare professionals, or highlighted areas of uncertainty, for example conservative management versus surgical treatment that patients may wish to explore further [47].

There was a wide variation in causes for development of a PSH across the sources, which combined with a lack of explanation means that patients may find it difficult to assess their personal risk factors or to make lifestyle modifications that may help with their PSH treatment. This is important as recent research has shown that patients felt unprepared for the development of a PSH, and often felt that they had done something themselves to cause the PSH [48].

There are limitations to this work. It has only included UK-based sources. There may be better quality sources available from other English-speaking countries that were not included in this analysis. It has also only considered sources written in the English language. The majority of the sources (9/14) were produced by a stoma product manufacturer or dispensing appliance contractor, who supply products for patients to manage their PSH conservatively. It was also

unclear from all but four of the sources whether there had been any clinical input into the content. There may also be a body of locally produced printed information in outpatient departments, which may form the bulk of information transfer from clinician to patient but which cannot be found via a Google search. Additionally, not all of the sources were designed as patient information resources, or to cover specific areas regarding PSH, so would not be expected to cover all aspects of PSH treatment options. However, as these sources are easily discovered by a simple Google search it was appropriate to include them in this analysis, as patients will be provided with these sources in their own searches for information.

CONCLUSION

Using validated tools to assess quality and readability, this work has shown that the current information available to patients considering PSH treatment is generally of low quality. Often it does not contain enough information, including risks and benefits of treatment options, both conservative and surgical, for patients to be able to make an informed decision about the best treatment for them. There is a need for high-quality information, ideally co-produced with patients, to provide patients with the necessary information to allow them to make informed decisions about their treatment options when faced with a symptomatic PSH.

AUTHOR CONTRIBUTIONS

Sue Blackwell: Conceptualization; methodology; formal analysis; data curation; investigation; funding acquisition; writing – original

draft; writing – review and editing. **Scott Clifford:** Data curation; writing – review and editing. **Thomas Pinkney:** Supervision; writing – review and editing. **Dean Thompson:** Supervision; methodology; writing – review and editing. **Jonathan Mathers:** Writing – review and editing; methodology; supervision.

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CONFLICT OF INTEREST STATEMENT

None to declare.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

ETHICAL APPROVAL

N/A.

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REFERENCES

- Krogsgaard M, Watt T, Danielsen AK, Klausen TW, Vinther A, Gøgenur I, et al. Impact of a parastomal bulge on quality of life—a cross-sectional study of patients from the Danish stoma database. *Ann Surg.* 2021;274(6):e1085–e1092.
- Group APH. Prevention and treatment of parastomal hernia: a position statement on behalf of the Association of Coloproctology of Great Britain and Ireland. *Colorectal Dis.* 2018;20(S2):5–19.
- Howard R, Rob F, Thumma J, Ehlers A, O'Neill S, Dimick JB, et al. Contemporary outcomes of elective parastomal hernia repair in older adults. *JAMA. Surgery.* 2023;158:394.
- Harries RL, Daniels IR, Smart NJ. Outcomes of surgically managed recurrent parastomal hernia: the Sisyphian challenge of the hernia world. *Hernia.* 2021;25(1):133–40.
- Kushner B, Holden T, Politi M, Blatnik J, Holden S. A practical guideline for the implementation of shared decision-making in complex ventral incisional hernia repair. *J Surg Res.* 2021;259:387–92.
- [NG197] Ng. Shared decision making 17 June 2021. Available from: <https://www.nice.org.uk/guidance/ng197>
- Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2017;4:CD001431.
- Kinmonth AL, Woodcock A, Griffin S, Spiegel N, Campbell MJ. Randomised controlled trial of patient centred care of diabetes in general practice: impact on current wellbeing and future disease risk. *BMJ.* 1998;317(7167):1202–8.
- Vernon E, Wright S, White P. Parastomal hernias and information retention: how and when to educate ostomates on risk minimisation. *Gastrointestinal Nursing.* 2022;20(1):26–33.
- Royal College of Surgeons. Consent: supported decision-making a GUIDE TO GOOD PRACTICE. 2016. <https://www.rcseng.ac.uk/standards-and-research/standards-and-guidance/good-practice-guides/consent/>
- He W, Cao L, Liu R, Wu Y, Zhang W. Factors associated with internet use and health information technology use among older people with multi-morbidity in the United States: findings from the National Health Interview Survey 2018. *BMC Geriatr.* 2022;22(1):733.
- Bujnowska-Fedak MM, Waligóra J, Mastalerz-Migas A. The internet as a source of health information and services. *Adv Exp Med Biol.* 2019;1211:1–16.
- Sacchi M, Yeung TM, Spinelli A, Mortensen NJ. Assessment of the quality of patient-orientated internet information on surgery for ulcerative colitis. *Colorectal Dis.* 2015;17(6):511–4.
- Stat Counter. Search engine market share. Available from: <https://gs.statcounter.com/search-engine-market-share>
- Baker DM, Marshall JH, Lee MJ, Jones GL, Brown SR, Lobo AJ. A systematic review of internet decision-making resources for patients considering surgery for ulcerative colitis. *Inflamm Bowel Dis.* 2017;23(8):1293–300.
- Musbahi A, Rao CB, Immanuel A, Hayes N. Online patient literature related to oesophageal surgery: the need for greater readability, accreditation and higher quality. *Ann R Coll Surg Engl.* 2023;105(2):107–12.
- Williams A, Cunningham A, Hutchings H, Harris DA, Evans MD, Harji D. Quality of internet information to aid patient decision making in locally advanced and recurrent rectal cancer. *Surgeon.* 2022;20(6):e382–e391.
- van Deursen AJAM, van Dijk JAGM. Using the internet: skill related problems in users' online behavior. *Interact Comput.* 2009;21(5–6):393–402.
- Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health.* 1999;53(2):105–11.
- 5-Point Likert Scale. In: Preedy VR, Watson RR, editors. *Handbook of disease burdens and quality of life measures.* New York, NY: Springer; 2010. p. 4288.
- DISCERN. DISCERN Guidelines General Instructions. Available from: http://www.discrim.org.uk/general_instructions.php
- Flesch R. A new readability yardstick. *J Appl Psychol.* 1948;32:221–33.
- NHS England. Available from: <https://www.hee.nhs.uk/our-work/knowledge-library-services/improving-health-literacy>
- [ECD8] NCD. Standards framework for shared decision-making support tools, including patient decision aids 17 June 2021. Available from: <https://www.nice.org.uk/corporate/ecd8>
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005;15(9):1277–88.
- Colostomy UK. Parastomal Hernias. Available from: <https://www.colostomyuk.org/wp-content/uploads/2023/05/CUK017-06v02r00-Parastomal-Hernias.pdf>
- Coloplast. Managing a Parastomal Hernia. Available from: <https://www.coloplast.co.uk/stoma/people-with-a-stoma/living-with-a-stoma/stoma-information-guides/>
- Convatec. Parastomal hernia and physical activity. Available from: <https://meplus.convatec.co.uk/meplus-downloadable-booklets/>
- Fittleworth. Parastomal hernia prevention. Available from: <https://www.fittleworth.com/parastomal-hernia-prevention/>
- Studio TO. Parastomal hernias – how do we prevent them. Available from: <https://www.theostomystudio.co.uk/post/parastomal-hernias-how-do-we-prevent-them>
- Ltd SM. Parastomal hernia and how to manage them. Available from: <https://www.securicaremedical.co.uk/blog/stoma-care-nurse-says-parastomal-hernias-and-how-to-manage-them>
- Suportx. Advice – Parastomal hernia. Available from: <https://suportx.co.uk/advice/>

33. Vyne. Parastomal hernia – what causes it and how can it be treated. Available from: <https://www.vyne.co.uk/blogs/ostomy-support/parastomal-hernia-what-causes-it-and-how-can-it-be-treated>
34. Dansac. Preventing a parastomal hernia. Available from: <https://www.dansac.com/en-gb/livingwithastoma/recoveryafterstomasurgery/preventingaperistomalhernia>
35. Clinimed. Stoma problems – hernia. Available from: <https://www.clinimed.co.uk/stoma-care/stoma-problems/hernia>
36. Clinic BC. Parastomal Hernia. Available from: <https://www.thebirminghamcolorectalclinic.com/conditions/colorectal-conditions/parastomal-hernia/>
37. Care Ha. Living with a parastomal hernia. Available from: <https://www.healthandcare.co.uk/blog/living-with-a-parastomal-hernia.html>
38. HCA. Parastomal hernia. Available from: <https://www.hcahealthcare.co.uk/our-services/conditions/parastomal-hernia>
39. Oakmed. Stoma hernia surgery – what to expect. Available from: <https://www.oakmed.co.uk/help-advice/advice-articles/stoma-hernia-surgery-what-to-expect/>
40. BHTA. Dispensing Appliance Contractors. Available from: <https://www.bhta.com/sections/dispensing-appliance-contractors/>
41. Flesch R. How to write plain English. Available from: <https://pages.stern.nyu.edu/~wstarbuc/Writing/Flesch.htm>
42. Cobb WS, Burns JM, Kercher KW, Matthews BD, James Norton H, Todd HB. Normal intraabdominal pressure in healthy adults. *J Surg Res.* 2005;129(2):231–5.
43. NHS England. Decision support tools. Available from: <https://www.england.nhs.uk/personalisedcare/shared-decision-making/decision-support-tools/>
44. Borglitt T, Krogsgaard M, Theisen SZ, Juel RM. Assessment of a support garment in parastomal bulging from a patient perspective: a qualitative study. *Int J Qual Stud Health Well Being.* 2022;17(1):2039428.
45. Ripoché J, Basurko C, Fabbro-Perray P, Prudhomme M. Parastomal hernia. A study of the French Federation of Ostomy Patients. *J Visc Surg.* 2011;148(6):e435–e441.
46. Blackwell S, Pinkney T. Quality of life and parastomal hernia repair: the PROPHER study. *Hernia.* 2020;24(2):429–30.
47. Kroese LF, Lambrichts DPV, Jeekel J, Kleinrensink GJ, Menon AG, de Graaf EJR, et al. Non-operative treatment as a strategy for patients with parastomal hernia: a multicentre, retrospective cohort study. *Colorectal Dis.* 2018;20(6):545–51.
48. Krogsgaard M, Dreyer P, Thomsen T. Understanding patients' perspectives when unprepared for the emergence of a parastomal bulge—a qualitative study. *Colorectal Dis.* 2023;25(11):2198–205.

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