



This is a repository copy of *Patient decision-making and regret in pilonidal sinus surgery: a mixed-methods study*.

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/172068/>

Version: Published Version

Article:

Strong, E., Callaghan, T., Beal, E. et al. (6 more authors) (2021) Patient decision-making and regret in pilonidal sinus surgery: a mixed-methods study. *Colorectal Disease*. ISSN 1462-8910

<https://doi.org/10.1111/codi.15606>

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here:
<https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>



ORIGINAL ARTICLE

Patient decision-making and regret in pilonidal sinus surgery: a mixed-methods study

Emily Strong¹ | Tia Callaghan¹ | Erin Beal² | Christine Moffatt³ |
 Nyantara Wickramasekera⁴ | Steven Brown^{1,5} | Matthew J. Lee^{5,6} |
 Catherine Winton¹ | Daniel Hind¹ | on behalf of PITSTOP Project Management Group,
 PITSTOP Collaborators[†]

¹Clinical Trials Research Unit, University of Sheffield, Sheffield, UK

²University of Liverpool, Liverpool, UK

³School of Social Sciences, Nottingham Trent University, Nottingham, UK

⁴School of Health and Related Research, Sheffield, UK

⁵Department of General Surgery, Northern General Hospital, Sheffield, South Yorkshire, UK

⁶Department of Oncology and Metabolism, The Medical School, University of Sheffield, Sheffield, South Yorkshire, UK

Correspondence

Emily Strong, Clinical Trials Research Unit, University of Sheffield, Regent Court, 30 Regent Street, Sheffield, S1 4DA, UK.
 Email: e.b.strong@sheffield.ac.uk

Funding information

This study was funded by the National Institute for Health Research (NIHR), Health Technology Assessment (HTA) programme (project number 17/17/02). The funder was not involved in the trial design, patient recruitment, data collection, analysis, interpretation, or presentation, writing, editing of the report, or decision to submit for publication. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Abstract

Aim: Little is known about optimal management strategies for pilonidal sinus disease (PSD). We conducted a mixed-methods study to understand why patients make, and sometimes regret, treatment decisions.

Method: We conducted longitudinal semi-structured interviews at the time of surgery and 6 months later with 20 patients from 13 UK hospitals. Framework analysis was performed, and themes were mapped to (1) the coping in deliberation framework and (2) an acceptability framework. Results were triangulated with those from structured survey instruments evaluating shared decision-making (SDM, best = 9) at baseline and decision regret (DR, most regret = 100) at 6 months.

Results: Nine of 20 patients were not offered a choice of treatment, but this was not necessarily seen as negative (SDM median 4; range 2–4). Factors that influenced decision-making included previous experience and anticipated recovery time. Median (range) DR was 5 (0–50). Those with the highest DR (scores 40–50) were, paradoxically, also amongst the highest scores on SDM (scores 4). Burden of wound care and the disparity between anticipated and actual recovery time were the main reasons for decision regret.

Conclusion: To minimize regret about surgical decisions, people with PSD need better information about the burden of wound care and the risks of recurrence associated with different surgical approaches.

KEYWORDS

colorectal surgery, pilonidal sinus disease

What does this paper add to the literature?

People with pilonidal sinus disease underestimate the time needed for post-surgical wound healing, the burden of wound care and the risks of recurrence. The outcomes patients think most important may change after surgery. While many patients are not involved in choice of surgical treatment, regret may be minimized by better information.

[†]See Appendices S1 and S2 for members of the PITSTOP Project Management Group and PITSTOP Collaborators.

Clinical Trial Registration: 95551898

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. *Colorectal Disease* published by John Wiley & Sons Ltd on behalf of Association of Coloproctology of Great Britain and Ireland.

INTRODUCTION

Pilonidal sinus disease (PSD) affects 26 in 100 000 people, predominantly men of working age [1]. Obstruction and rupture of hair follicles in the natal cleft lead to abscess and sinus formation, progressing through insertion of hairs into the sinuses [2,3]. Patients present to emergency services with a painful abscess between the buttocks or electively with a chronic cycle of pain and discharge [4].

The proliferation of small, single-centre studies, using different classification systems and outcome assessments, means that there is no clear consensus on what constitutes optimal treatment—one that most general surgeons could perform, which results in rapid healing and minimal complications [5,6]. If surgical treatments are perceived as ineffective, individuals with simple sinuses may be asked to wait for their condition to deteriorate or offered medical management, before surgical intervention [7–10]. On emergency presentation, a pilonidal abscess requires hospitalization for its incision and drainage, following which one in five individuals re-present with recurrent symptoms [11]. Treatment of chronic PSD typically involves excision of affected skin and fat and management of the wound, if it is not closed using fibrin glue [12]. The most common excisional approaches leave sizeable open wounds [13,14]. The need for prolonged wound care over a period of months impacts education, work, intimacy, social life; recurrent infection, fear of wound deterioration and pain can profoundly affect quality of life [15,16]. Treatments may be advocated without evidence of clinical or cost effectiveness [17] while inadequate preparation for postoperative wound care, uncontrolled pain and delayed wound healing affect patient well-being and activities of living [18,19].

For these reasons, in 2018 the UK National Institute for Health Research commissioned the Pilonidal Sinus Treatment—Studying the Options (PITSTOP) study. The centrepiece of this work was a large observational cohort intended to understand the effectiveness of common excision and closure techniques used in UK practice [20,21]. To enhance our understanding of patient decision-making and responses to treatment we undertook a nested mixed-methods sub-study, triangulating findings from semi-structured interviews with patient-reported experience measures (PREMs). The objectives of the sub-study, reported in this paper, were an overview of patient views and experiences, including (1) how treatment decisions are made and why they might be regretted and (2) attributes of interventions they would rather avoid and which outcomes they most value.

METHODS

Design

Case study methodology is a mixed-methods research design used for in-depth examination of complex phenomena in real-world settings [22]. The study was a multiple case design: it compared more than one data type between and within more than one person [23]. The case study was nested in an observational cohort, with two

embedded units of analysis—longitudinal semi-structured interviews at baseline and 6 months, and quantitative cohort data at the same time points.

Case selection

All participants with symptomatic PSD, referred for elective surgical treatment and participating in the PITSTOP cohort, were invited to take part in a semi-structured telephone interview at baseline (either before or immediately after surgery) and 6 months after surgery. We sampled for maximum variation based on the Wysocki classification (an indicator of disease severity) the method of surgical excision and closure [20]. Initial contact was made by telephone, which was followed by an email and an information sheet.

Survey instruments (PREMs)

At baseline, participants completed the CollaboRATE three-question PREM of shared decision-making (SDM), scored 0 (indicating poor SDM) to 9 (indicating good SDM) [24]. Six months after surgery, we collected pain, length of time to healing, post-surgery complications and a decision regret (DR) PREM, using a five-point scale scored 0 (low DR) to 100 (high DR), measuring healthcare decision regret [25].

Interviews

Semi-structured telephone interviews were conducted between June 2019 and September 2020 by EB and ES. A minimum of 20 interviews was considered adequate to understand common perceptions and experiences of treatment choices, thereby achieving thematic saturation [26,27]. Interviews were recorded on encrypted digital recorders and transcribed. Baseline interviews adapted key ‘choice’ (e.g., ‘did you let the surgeon choose your treatment?’) and ‘options’ (e.g., ‘did the surgeon talk you through the risks and benefits?’) questions from the coping in deliberation (CODE) framework (Table 1) [28]. At 6 months, the interview guide asked CODE questions related to decision ‘consolidation’ (e.g., ‘was this the right decision?’). Throughout, probing questions covered dimensions of Sekhon’s acceptability framework [29] as well as intervention attributes, to inform a discrete choice experiment (to be published separately).

Analysis of interviews

ES, TC, EB and DH used the National Centre for Social Research ‘Framework’ analysis approach which, unlike some other analytical approaches, allows for coding of a priori and de novo themes [30]. After familiarizing ourselves with the transcripts, we independently coded a sample of transcripts using NVivo (QSR International)

**TABLE 1** Description of constructs from the coping in deliberation (CODE) and acceptability frameworks

Framework	Stage	Construct	Description	
CODE	Pre-decisional deliberation	Health threat	The individual is presented with the identity of their health threat, i.e., a diagnosis	
		Presentation of choice	The individual is given a choice of how to proceed with the health threat	
		Presentation and interpretation of options	Treatment options are presented to the individual for them to interpret	
	Decision determination	Preference construction	The individual forms preferences from the treatment options available	
		Decision	The individual decides on their preferred treatment decision. They may decide this either independently or by transferring the decision to a healthcare professional	
	Acceptability	Consolidation	Consolidation	The decision is consolidated to ensure the individual does not regret it
			Affective attitude	How the individual feels about the treatment
Burden			How much effort that the individual recognizes is needed to engage in the treatment	
Ethicality			If the treatment is deemed a good fit for the individual	
Intervention coherence			The individual's level of understanding of the treatment available	
Opportunity costs			The extent to which the individual sacrifices other aspects of their life to fulfil the treatment requirements	
Perceived effectiveness			If the individual believes the treatment will be effective or not	
Self-efficacy	The extent to which the individual is confident that they can fulfil the required behaviours to enable the treatment to be successful			

version 11 before conferring. Integration of qualitative and quantitative data occurred during analysis and interpretation, to understand (1) how disease characteristics and surgeon preferences interacted with patient values in treatment choices and (2) how participants appraised treatments given particular outcomes. We used joint display tables to look for convergences and divergences between cohort data (disease features/treatment choices/outcomes) with experiences, views and values [31,32]. We invited a patient expert to provide feedback on a lay summary of triangulated results from interviewees.

RESULTS

Sample

Of 266 who volunteered, 20 participants (median age 28; range 20–64) from 13 centres took part in baseline interviews (median 16 [6–47] min) (Table 2). Only 13 could be reached for follow-up interviews (median 18 [11–37] min).

Health threat

Newly diagnosed participants, unfamiliar with PSD, expressed confusion about its cause and prognosis. They discussed soreness, inflammation, discharge and odour, disrupting employment, exercise habits, social life and intimacy. They reported negatively impacted

well-being and mental health. Whilst newly diagnosed participants assumed it was an acute, curable condition, those with recurrent disease understood that recurrence was common.

I was told initially, 'Oh that could be it, and then it might go away'... but once you get it once, that's it: it's coming back... If I was a bit more aware of that I would have probably started to look into the surgeries quicker.

(18: no previous pilonidal disease)

Some participants were reticent to address their condition, choosing to tolerate discomfort and delay treatment. Sometimes rapid exacerbation of symptoms would drive emergency treatment.

I said to [my girlfriend], 'Look, I can't really see it properly. Is it still getting bigger?' And she said, 'Oh bloody hell... get in the car.' So, we went straight to [hospital].

(3: one previous episode of PSD)

Participants frequently characterized general practitioners (GPs) as not taking PSD seriously and failing to escalate their case to secondary care. One presented with recurrent disease, which was disputed by the GP.

...just gave me some antibiotics... it just kept getting more painful and worse... I went back three times... then she put me on sort of the path to go back to

TABLE 2 Participant characteristics: baselines, surgery and 6-month outcomes

ID	M/F	Baseline			Surgery	6 months		FU interview?
		Number of prior operations	Severity	SDM	Excision/closure	Decision regret	Recurrence	
Complete dataset								
1	M	0	1	2.6	LE/MC	10	No	Y
3	M	1	1	4	PP/LO	10	Yes	Y
5	M	0	1	3	LE/LC	5	No	Y
6	F	3	1	4	LE/LO	40	No	Y
8	M	2	4	3	LE/LO	20	No	Y
9	M	0	1	4	LE/LC	5	No	Y
10	M	0	3	3.6	Se only	5	No	Y
11	M	1	4	3	Cu/LO	5	No	Y
14	M	0	2	2	EP/LO	15	No	Y
16	F	2	4	4	LE/LC(K)	0	No	Y
17	M	2	3	4	LE/LC (K)	0	No	Y
18	F	0	1	4	PP/LO	50	No	Y
19	M	0	4	2.66	LE/MC, M, LC	0	No	Y
Incomplete dataset								
2	F	2	4	4	LE/LC (K)	LTFU	LTFU	Refused
7	F	1	2	4	Cu, PP/FG	0	No	LTFU
12	M	0	1	4	Cu/ FG	LTFU	LTFU	LTFU
13	M	0	1	4	Cu/FG	LTFU	LTFU	LTFU
15	M	0	2	2.33	LE/Se, FI	LTFU	LTFU	Refused
20	M	0	4	4	LE/FI	LTFU	Yes	LTFU
21	F	1	2	2	LE/MC	0	No	LTFU

Notes: Decision regret, highest score 100, high level of regret. SDM, self-reported quality of shared decision-making using the CollaboRATE instrument, high score (highest 5) denotes best SDM. Severity (Wysocki classification), high scores more severe.

Abbreviations: Closure types: FG, fibrin glue; FI, flap; K, Karydakis; LC, lateral closure; LO, leave open; M, marsupialization; MC, midline closure; Se, seton. Excision types: Cu, curettage; EP, endoscopic pilonidal sinus treatment; LE, local excision; PP, pit picking. FU, follow-up; LTFU, lost to follow-up; M/F, male/female.

surgery but she didn't send me [as] an urgent patient...
so I had to wait for maybe like 5 months.

(14: no previous PSD)

Another saw their GP numerous times over 25 years and was repeatedly dissuaded from surgery.

he basically sort of said to me that it's a very precarious operation... that the success rate wasn't very high... that it was something that if I could live with....

(15: no previous pilonidal disease)

Once referred to secondary care, 9/20 participants were offered a choice of treatment, although absence of choice was rarely expressed negatively. Some participants viewed healthcare professionals as best placed to make the treatment decision, given their own limited knowledge (intervention coherence), especially where emergency surgery was concerned (Table 3, participant 3; Table 4, participants 3, 17).

Choice and options

Where participants were given a choice, preferences were constructed, based on one or more factors, including previous experiences of surgery ($n = 3$), surgeon's guidance ($n = 3$), invasiveness of the treatment ($n = 3$), or anticipated recovery time ($n = 2$). One participant rejected their surgeon's advice to have a procedure in which the wound was left open, on the grounds of opportunity cost, because this would require more time off work (Table 3, participant 15). Some reported using significant others, friends, relatives or the internet to support decision-making, with some deriving a sense of control (self-efficacy; intervention coherence) from researching the condition and treatment options.

Key outcomes at the time of decision-making

Around the time of surgery, not every participant would specify a single most important outcome (Table 3). However, the following

**TABLE 3** Decision-making—cases ordered by self-reported quality of shared decision-making

Participant information			Decision-making	
ID	Number of prior procedures	Key outcome	CollaboRATE score	Sample quote (coding)
21	1	Recurrence	2	'[The surgeon] said they'd cut like a flap out, get everything out and sort of stitch it back up... that was the only option... that or managing with medication... I was like yeah do what you have to do' (Presentation of choice)
14	0	ADL	2	'I only really got a say in it this time... cos it was a new surgery coming through... They offered me to do the other one if I wanted' (Presentation of choice)
15	0	Recovery time	2.33	'If you're asking me how it felt like, it felt like I didn't have a choice' (Presentation of choice) 'At first I, [the consultant] sort of said, oh you might be back in a... couple of weeks and then when my friend said oh, 12 weeks for this open wound to heal, I thought... I can't take that long off work. I can't afford it' (Preference construction)
1	0	Recurrence	2.6	'[The surgeon] said you either don't have the surgery and hope that it maybe sorts itself out.... I took the decision that the chance of the surgery resolving the matter was worth the risk that it might still reoccur... with no other sort of major health issues that seemed like an easy enough choice' (Presentation of choice)
19	0	Recurrence	2.66	'No, [the surgeon] did not give me any option. He just said, just, just he only mentioned the surgery. As I say, I wasn't given any other options' (Presentation of choice)
5	0	Pain	3	'[The doctor] said that they'll operate and that was pretty much it... just leave it, or you could have the operation and I thought well best to try and get it sorted before it keeps getting infected, and gets worse' (Presentation and interpretation of options)
8	2	Smell	3	'[The surgeon] give me options of what I wanted and I just wanted one, like obviously cos I had it packed last time, it healed better that way, so I asked for it that way' (Preference construction)
11	1	Pain and ADL	3	'[The consultant] explained to me that you know, we could try medication first and then if that doesn't work, we could try surgery... it was a scraping out I think... that was something [the consultant] recommended' (Presentation of choice)
10	0	(Not specified)	3.6	'I didn't decide any treatment. The treatment was decided for me by the consultant... I'm not medically qualified you know... I'm told what the problem is and how it can be rectified. We go along with that' (Decision)
2	2	ADL	4	'No, there was only one procedure left.' (Presentation and interpretation of options)
3	1	Recurrence and pain	4	'It's not me fighting this battle... I'm just a battlefield. You guys are fighting it... by the time I got to A&E, they may have given me options, I can't remember... I'm quite happy to accept that I don't know what I'm talking about, so even if I'm given options I will say to the man giving me options, what would you do' (Presentation and interpretation of options)
6	3	Reducing anxiety of knocking the sinus (reduce symptoms)	4	'I saw my consultant and he said... depending on the MRI, I'll give you a few options... one is that we do the same but obviously different in theatre and then the, the other option is to have it like lasered removed' (Health threat)
7	1	ADL	4	'They gave me two options but obviously because I have to get a mastectomy in September... I wouldn't have been healed in time... my immune's so low as well, we said that the glue one'd be more beneficial for me' (Preference construction)
9	0	Recurrence	4	'The wording was this is the best thing to go for... either don't have the surgery and hope that it maybe it sorts itself out... or sort of cutting it out... I wasn't really exploring every single option available' (Preference construction)

(Continues)

TABLE 3 (Continued)

Participant information			Decision-making	
ID	Number of prior procedures	Key outcome	CollaboRATE score	Sample quote (coding)
12	0	Recurrence	4	'[The surgeon] gave me two or three different options that we could take, i.e., stitching, gluing, leaving alone etc. and I thought the gluing one sounded the best and of course she agreed that she would like to do the gluing one anyway but she wanted me to make the choice really' (Presentation of choice)
13	0	Closing the wound	4	'It was either an option of having it packed, which the doctor said can take up to a month for it to be fully healed... obviously being self-employed, I need to be back in work... I just plumped for the one that sounded like the one that I thought would work the best and I think it was a newer procedure' (Presentation of choice/presentation and interpretation of options)
16	2	ADL	4	'I could leave it and just live with it, which obviously for me wasn't an option! ... My other option was to get a cosmetic surgeon in... So, I was just kind of worried that I would always kind of be left with some sort of wound' (Health threat)
17	2	Recurrence	4	'[The nurse] just told me I'd be having emergency surgery... someone looked at me that following morning and decided that I definitely had to have the incision and drainage. They didn't go through the details of why that was, I'll be honest... I didn't know the in's and out's of what I had, and I didn't know if there was any other options available' (Presentation of choice)
18	0	Solve the problem	4	'I wasn't given the choice as such of which ones to do but when [the Consultant] said that this is what she recommends, I completely took that on board from somebody with her kind of experience and knowledge of it' (Presentation of choice)
20	0	ADL and recurrence	4	'[The GP] said you've got two options, I either give you some antibiotics and pain relief now or I recommend you go to hospital... I wanted to maintain as much quality of life as possible whilst listening to the consultant's guidance' (Preference construction)

Notes: The key outcome is the primary desired outcome for each participant expressed at the baseline interview. CollaboRATE score is the mean collaboRATE score regarding shared decision-making of treatment recorded at baseline; high score, more shared decision-making, low score, less shared decision-making (0–9); the table reports collaboRATE scores low–high. The sample quotes are taken from interview at baseline.

Abbreviation: ADL, activities of daily living.

outcomes were highlighted during decision-making: avoiding recurrence ($n = 8$), return to normal activities ($n = 6$) and/or the elimination of symptoms ($n = 7$). Six participants were not aware of procedural risks; others expressed awareness of risks presented by anaesthesia ($n = 2$), infection or bleeding ($n = 4$), the wound not healing ($n = 5$) and recurrence ($n = 8$).

Consolidation

After surgery, most participants were fearful of aggravating the wound and/or delaying healing. They made physical adaptations (altered sitting and reclining positions) and behavioural adaptations (reducing duration and type of exercise), which negatively affected their well-being.

It has made me reticent to engage in some activities... exercise and things like that... through the pain and discomfort, and also the chance of sort of popping the cyst....

(1: no previous pilonidal disease)

Participants visited the GP or were visited by the district nurse for wound care, daily or weekly. Because of its location, many had difficulty attending to the wound themselves: they used mirrors or were reliant on others for daily examination and wound management (including cleaning, dressing and packing the wound), often resenting this loss of independence (self-efficacy) and expressing embarrassment. On the other hand, the emotional support provided by participants' social networks was important in alleviating emotional distress.

I think the worst part of it is that you always have to rely on someone else to do, like, a dressing for you... you can't drive cos you can't sit down... you basically you can't do anything.

(6: sinus excised and left open)

Key outcomes at the time of follow-up

Six months after surgery, people recalled hoping surgery would address pain ($n = 3$), recurrence ($n = 5$), wound healing ($n = 1$), the smell

TABLE 4 Outcomes and reflections ordered by level of decision regret (0–100, high to low).

Participant Information					Decision regret	
ID	Excision	Closure	Time to healing (days)	Pain/post-surgery complications	Score	Sample quote (coding)
16	Local excision	Lateral closure and Karydakis	62	0	0	'Everything was great from that first consultation at the doctors to all the way through my recovery. So yeah, I've not really got anything to change about it'
19	Local excision	Primary midline closure, marsupialization and lateral closure	28	0	0	'I would've done it much earlier. As I say, I waited a very long time, probably 12, 13 years, possibly more!' (CODE: Consolidation)
21	Local excision	Midline closure	78	0	0	Follow-up interview not complete
7	Curettage and pit picking	Fibrin glue	51	0	0	Follow-up interview not complete
17	Local excision	Lateral closure and Karydakis	54	0	0	'I think the first surgery was so quick that I wasn't really able to almost consider what I was getting done...I didn't have any time to think about what was happening so it meant afterwards I didn't really take it seriously enough' (Intervention coherence)
5	Local excision	Lateral closure	60	0	5	'As I say it all, all went well. You know there's, there's no reason for me to want to do anything differently' (Acceptability: Perceived effectiveness. CODE: Consolidation)
9	Local excision	Lateral closure and Karydakis	Length of time not specified	0	5	'Tried to get it [treatment] sooner' (CODE: Consolidation)
10	Seton (no excision)		38	0	5	'[So is there anything that you would have done differently?] No' (Acceptability: Perceived effectiveness/ethicality. CODE: Consolidation)
11	Curettage	No closure/leave open	112	0	5	'I think surgery was the way to go. I don't think I could have done it differently' (Acceptability: Perceived effectiveness. CODE: Consolidation)
1	Local excision	Midline closure	Not healed	2	10	'The end result has been a positive one... I think that I would've rather had been in a position in which the wound had just been left open to be packed... that would've actually caused less pain and discomfort overall as well as avoiding the need to sort of visit the hospital for a follow-up' (Acceptability: Perceived effectiveness/opportunity costs)

(Continues)





TABLE 4 (Continued)

Participant Information				Decision regret		
ID	Excision	Closure	Time to healing (days)	Pain/post-surgery complications	Score	Sample quote (coding)
3	Pit picking	No closure/leave open	84	1	10	[Is there anything that you would've done differently?] Not really because..., it's not a condition that you have knowledge of...if you have tingling in your left hand and you have shortness of breath, you know you're having a heart attack...whereas this is not something you have any knowledge of so (mm) I suppose...you sort of do learn on the job with this sort of condition because it's not that common'
14	EPSIT	No closure/leave open	Not healed	3 / Discharge	15	'The only thing I could have done is... asked for a different doctor, or... said it was more urgent, so I could have been got in sooner... I'm pretty convinced that months of waiting around, and getting worse and splitting open my skin is the first problem with why it hasn't healed as well as...' (CODE: Consolidation)
8	Local excision	No closure/leave open	49	0	20	'...I did everything like as soon as I could like' (CODE: Consolidation)
6	Local excision	No closure/leave open	Not healed	5 / Discharge and infection	40	'I don't know what I would do differently but I think the, that is what I did differently to change going from [hospital name] to [hospital name]' (Self-efficacy)
18	Pit picking	Pit picking closed and lateral wound left open	18	0	50	'I'm glad I waited for the right person and the right procedure' (CODE: Consolidation)
2	Local excision	Lateral closure and Karydakis	LTFU	LTFU	LTFU	Follow-up interview not complete
12	Curettage	Fibrin glue	14	LTFU	LTFU	Follow-up interview not complete
13	Curettage	Fibrin glue	LTFU	LTFU	LTFU	Follow-up interview not complete
15	Local excision	Seton and flap (type: fascial)	8	LTFU	LTFU	Follow-up interview not complete
20	Local excision	Flap (type: rhomboid)	LTFU	LTFU	LTFU	Follow-up interview not complete

Notes: Pain/post-surgery complications were recorded at the 6-month follow-up. Score is the decision regret score regarding treatment decision recorded at 6-month follow-up: high score, high decision regret; low score, low decision regret (0–100); the table orders participants in low–high decision regret scores. The sample quotes were taken from the 6-month follow-up interview.

Abbreviation: LTFU, lost to follow-up.



($n = 1$), the inconvenience ($n = 1$) and impaired ability to perform activities of daily living ($n = 1$). In five cases (Table 4, participants 1, 5, 11, 14, 17), these priorities had changed since baseline. During recovery, some patients became more accepting of the recurrent nature of the condition. Patients sometimes managed their own expectations by considering any improvement as an indicator of effectiveness.

I've still got some kind of stuff going on down there that is just a recurring thing... if I've had four operations, it probably won't get rid of [it].

(6)

In a closed question—one in which the range of potential answers was limited—participants felt that the single most important outcome was the wound healing in the expected time ($n = 3$), avoidance of recurrence ($n = 4$) and return to activities of daily living ($n = 1$). Three participants who had undergone PSD surgery for the first time found their treatment to be effective and, when asked, did not think they would have done anything differently (Table 4, participants 5, 10 and 11).

Wound healing took a median of 51 (8–112) days (Table 4). One participant reported that the wound had not healed 6 months after surgery (Table 4, participant 1). Four patients experienced varying degrees of post-surgical pain, one of whom had a wound infection that required antibiotic treatment. Six months after surgery, five participants did not regret their decision (DR score 0). Eight reported low regret (DR score range 5–20), with three adopting a problem-focused coping style, expressing a wish they had undergone surgery sooner (Table 4, participants 9, 14, 19), for instance by moving hospitals (Table 4, participants 6, 14). Two participants (6, 18), both of whom had their wound left open after surgery, regretted their decision more (DR scores 40 and 50 respectively). Patient 6 had a history of PSD with multiple prior operations. One (6) stated that they would not choose the same procedure again due to the wound taking significantly longer to heal than expected, with significant pain and resultant lifestyle adaptations and psychosocial impact. Qualitative and quantitative data from the other (18) was discordant. On the decision regret PREM, the participant was ambivalent as to whether the decision was right, whether she regretted the decision and whether the choice did her harm. The transcript was more positive but demonstrated acute anxiety about possible recurrence.

DISCUSSION AND CONCLUSIONS

This study explored how patients make, and sometimes regret, PSD treatment decisions. Patients and GPs are often reluctant to address the condition—patients because of embarrassment and lack of knowledge and GPs because they perceive surgical approaches to be poorly evidenced. Once referred, patients are not always involved in the choice of surgical treatment. They are typically unconcerned about the potential burden of post-procedural wound care, the support they will need from others, or the risks of post-procedural pain

and recurrence. They are also uninformed about, and therefore unprepared for, dealing with these matters. Those receiving surgery for the first time are often overly optimistic about the chances of success. In contrast, those with recurrent disease sometimes regret poorly informed decisions and exhibit higher psychosocial burden. Irrespective of prior experience of PSD, treatment decisions are challenging; new, substantial and complex treatment information can be difficult to comprehend and may lead to distress [28]. Insufficiently informed, patients are unable to articulate what they would have done differently, but often demonstrate changing priorities after 6 months' follow-up. Patients with a history of PSD who had undergone an excise-and-leave-open procedure—associated with high levels of pain, intensive wound management and long healing times—demonstrated the highest levels of decision regret.

This study does not attempt null hypothesis significance testing using quantitative data, and is reasonably large by qualitative research standards [27], the largest yet conducted in people with pilonidal sinus [7,19]. The sample is satisfactory for the application of existing theory to empirical data [33]. While the participants' surgical treatment is representative of current UK practice, emerging minimally invasive techniques increasingly common in other health systems are not represented; their acceptability should be the subject of future research.

As post-surgical wound healing can take over 6 months and recurrence of PSD may take place over many years, our study is limited, and the attitudes of participants may be affected by its short follow-up period. Like other contemporary studies [34,35] the COVID-19 pandemic limited our ability to follow up participants. Even where remote data collection was possible, asking people to engage with research activities was difficult, given the burden placed on them by the pandemic [36]. Attrition rates are poorly reported in PSD studies but thought to be high, due to the young, mobile, mainly male population [5,37] a widely reported challenge [38,39]. Attrition may also result from reluctance to express negative thoughts [40] or loss of interest in research after wound healing [41].

Our mixed-methods approach identified divergences and inconsistencies between different datasets, in terms of how people reflect on their treatment decisions later on. Even if patients feel involved with decision-making, their expectations may not be met if they are not fully informed about a care pathway [42]. Levels of self-reported decision regret in this study are in line with the 1-in-7 rate reported across 73 surgical studies, in which regret was mainly associated with type of surgery, health outcomes and absence of shared decision-making [43]. Another systematic review has flagged decisional conflict and anxiety as predictive of decision regret [44]. Surgeons [45,46] and patients [47] may have reasons for avoiding shared decision-making, and our findings complicate the common assumption that shared decision-making leads to increased decisional satisfaction [48]. Systematic reviews in other contexts suggest that unmet information needs are common and distressing [49–52]. There are growing concerns that self-report measures of shared decision-making may not capture the quality of the interaction or the multi-staged nature of the process [53,54]. PREMs may

be compromised by social desirability or acquiescence bias [55–58] and open-ended questions may reveal significant problems from patients who report high levels of satisfaction on survey instruments [59,60]. Triangulation of research methods is useful to identify such problems [61,62].

Clinical teams should ensure patients are properly informed about available surgical techniques and manage their expectations about aftercare and the uncertainties which surround clinical outcomes. Surgeons may not actively engage in wound care discussions because that is seen as the responsibility of primary care services [17]. But information gaps reduce patients' ability to self-manage and teams should ensure that patients receive verbal and written information, tailored to their needs, at the right time [63]. Surgical consultations may concentrate more on interventions than outcomes, but asking patients about their expectations gives surgical teams the opportunity to address false optimism [64–66]. In other settings, patient expectations predict satisfaction and functional outcomes following surgery [67].

Awareness-raising among primary and secondary care is needed to avoid delays in treatment where PSD is poorly recognized. Where pilonidal surgery is seen as unglamorous [68] or surgeons only specialize in one technique [69] patients with recurrent disease should be referred rapidly onward to genuine specialists. Both shared decision-making and the consent process itself are compromised if patients are poorly informed about their condition, available treatments and the probability of various outcomes [45]. This is challenging when there are many available treatments supported by variable evidence [5]. There are around 20 systematic reviews and meta-analyses on surgical techniques alone, and around 15 more on medical, wound care and other topics. An overview of these reviews should be an urgent research priority to adequately inform shared decision-making and the development of decision support tools. Until then, the review by Stauffer and colleagues remains one of the most comprehensive overviews focusing on time-to-recurrence with different surgical techniques [70]. Finally, discharge planning should begin at pre-assessment visits, involving the patient, day surgery nurses and district nurses [71–73]. Postoperative wound care is enhanced by continuity of care from a limited number of community-based health professionals [74].

In conclusion, giving people with pilonidal sinus better information about the burden of wound care and the risks of recurrence associated with different surgical approaches may improve decision-making and minimize regret. An overview of systematic reviews is needed to inform decision support tools. Surgical teams should fully communicate uncertainties about treatment effects, as well as the timescale, tasks and psychosocial issues associated with recovery.

INFORMED CONSENT

Informed consent was obtained from all individual participants included in the study. This paper is submitted as an original article.

ACKNOWLEDGEMENTS

We would like to thank all the participants who we interviewed.

CONFLICT OF INTERESTS

The authors declare no conflict of interest.

ETHICAL APPROVAL

The study received approval from East of England–Cambridge South Research Ethics Committee (REC reference 18/EE/0370).

AUTHOR CONTRIBUTIONS

Study concept and design: SB, ML, DH. Analysis and interpretation of data: EB, ES, TC, DH. Drafting of the manuscript: ES, TC, DH. Critical revision of the manuscript for important intellectual content: ALL.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Emily Strong  <https://orcid.org/0000-0002-2381-4088>

Steven Brown  <https://orcid.org/0000-0002-0980-2793>

Matthew J. Lee  <https://orcid.org/0000-0001-9971-1635>

REFERENCES

1. Søndena K, Andersen E, Nesvik I, Søreide JA. Patient characteristics and symptoms in chronic pilonidal sinus disease. *Int J Colorectal Dis.* 1995;10:39–42.
2. Hull TL, Wu J. Pilonidal disease. *Surg Clin North Am.* 2002;82:1169–85.
3. Karydakos GE. Easy and successful treatment of pilonidal sinus after explanation of its causative process. *Aust N Z J Surg.* 1992;62:385–9.
4. Ertan T, Koc M, Gocmen E, Aslar AK, Keskek M, Kilic M. Does technique alter quality of life after pilonidal sinus surgery? *Am J Surg.* 2005;190:388–92.
5. Brown SR, Lund JN. The evidence base for pilonidal sinus surgery is the pits. *Tech Coloproctol.* 2019;23(12):1173–75.
6. Burnett D, Smith SR, Young CJ. The surgical management of pilonidal disease is uncertain because of high recurrence rates. *Cureus.* 2018;14(10):e2625.
7. Bradley L. Pilonidal sinus disease: a review. Part two. *J Wound Care.* 2010;19:522–30.
8. Cevik M, Dorterler ME, Abbasoglu L. Is conservative treatment an effective option for pilonidal sinus disease in children? *Int Wound J.* 2018;15:840–4.
9. Berry DP. Pilonidal sinus disease. *J Wound Care.* 1992;2(1):29–32.
10. Rice J. How long is too long?: Patient-centred care in the case of a pilonidal sinus—a reality or not? *Wound Pract Res.* 2014;22:44.
11. Jensen SL, Harling H. Prognosis after simple incision and drainage for a first-episode acute pilonidal abscess. *Br J Surg.* 1988;75:60–1.
12. Lund J, Tou S, Doleman B, Williams JP. Fibrin glue for pilonidal sinus disease. *Cochrane Database Syst Rev.* 2017;1:CD011923.
13. Thompson MR, Senapati A, Kitchen P. Simple day-case surgery for pilonidal sinus disease. *Br J Surg.* 2011;98:198–209.
14. Enriquez-Navascues JM, Emparanza JI, Alkorta M, Placer C. Meta-analysis of randomized controlled trials comparing different

- techniques with primary closure for chronic pilonidal sinus. *Tech Coloproctol.* 2014;18:863–72.
15. Vermeulen H, Ubbink D, Goossens A, de Vos R, Legemate D. Dressings and topical agents for surgical wounds healing by secondary intention. *Cochrane Database Syst Rev.* 2004;2:CD003554.
 16. Price PE, Butterworth RJ, Bale S, Harding KG. Measuring quality of life in patients with granulating wounds. *J Wound Care.* 1994;2(3):49–50.
 17. McCaughan D, Sheard L, Cullum N, Dumville J, Chetter I. Nurses' and surgeons' views and experiences of surgical wounds healing by secondary intention: a qualitative study. *J Clin Nurs.* 2020. 29(13-14):2557–71.
 18. Bradley L. The lived experience of young adults with chronic pilonidal sinus disease: a phenomenological approach. Poster presentation at the World Union of Wound Healing Societies Conference. Paris, France; 2004.
 19. Stewart AM, Baker JD, Elliott D. The effects of a sacrococcygeal pilonidal sinus wound on activities of living: thematic analysis of participant interviews. *J Clin Nurs.* 2011;20:3174–82.
 20. Brown SR. Pilonidal sinus treatment: studying the options (ISRCTN95551898) [Internet]. ISRCTN Registry, 2019. [Cited 2020 Aug 26]. Available from: <https://doi.org/10.1186/ISRCTN95551898>
 21. Beal E, Hind D, Bradburn M, Lee E, Howard A, Shackley P, et al. Design and rationale of the Pilonidal sinus Treatment—STudying the OPtions (PITSTOP) study: a multicentre cohort, nested mixed-methods case study and discrete choice experiment (poster presentation) [Internet]. *Int J Surg.* 2018;59:S6. <https://doi.org/10.1016/j.ijso.2018.10.021>
 22. Yin RK. *Case Study Research.* California, CA: SAGE Publications; 2014.
 23. Yin RK. Designing case studies: identifying your case(s) and establishing the logic of your case study. *Case Study Research: Design and Methods.* London: Sage; 2014: 27–70.
 24. Elwyn G, James P, Grande SW, Thompson R, Walsh T, Ozanne EM. Developing CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical encounters. *Patient Educ Couns.* Elsevier Ireland Ltd. 2013;93:102–7.
 25. Brehaut JC, O'Connor AM, Wood TJ, Hack TF, Siminoff L, Gordon E, et al. Validation of a decision regret scale. *Med Decis Making.* 2003;23:281–92.
 26. Guest G. How many interviews are enough? An experiment with data saturation and variability. *Field Methods.* 2006;18(1):59–82.
 27. Morse JM. Data were saturated *Qual Health Res.* 2015;25:587–8.
 28. Witt J, Elwyn G, Wood F, Brain K. Decision making and coping in healthcare: the Coping in Deliberation (CODE) framework. *Patient Educ Couns.* Elsevier Ireland Ltd. 2012;88:256–61.
 29. Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Serv Res.* 2017;17:88.
 30. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. *Analysing Qualitative Data.* England: Routledge; 1994: 173–94.
 31. Yin RK. Mixed methods research: are the methods genuinely integrated or merely parallel? *Res Sch.* 2006;13:41–8.
 32. Guetterman TC, Feters MD, Creswell JW. Integrating quantitative and qualitative results in health science mixed methods research through joint displays. *Ann Fam Med.* 2015;13:554–61.
 33. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res.* 2016;26(13):1753–60. <https://doi.org/10.1177/1049732315617444>
 34. Upadhaya S, Yu JX, Oliva C, Hooton M, Hodge J, Hubbard-Lucey VM. Impact of COVID-19 on oncology clinical trials. *Nat Rev Drug Discov.* 2020;19:376–7.
 35. Patel SS, Webster RK, Greenberg N, Weston D, Brooks SK. Research fatigue in COVID-19 pandemic and post-disaster research: causes, consequences and recommendations. *Disast Prev Manag.* 2020;29(4):445–455.
 36. Bradt J. Impact of COVID-19 on clinical research. *Nordic J Music Ther.* 2020;7(29):297–9.
 37. AL-Khamis A, McCallum I, King Peter M, Bruce J. Healing by primary versus secondary intention after surgical treatment for pilonidal sinus. *Cochrane Database Syst Rev.* 2010;1:CD006213.
 38. Slauson-Blevins K, Johnson KM. Doing gender, doing surveys? Women's gatekeeping and men's non-participation in multi-actor reproductive surveys. *Social Inq.* 2016;17(86):427–49.
 39. Rourke DO, Lakner E. Gender bias: analysis of factors causing male underrepresentation in surveys. *Int J Public Opin Res.* 1989;1:164–76.
 40. Graham J, Grewal I, Lewis J. *Ethics in Social Research: The Views of Research Participants.* London, UK: HM Stationary Office; 2007.
 41. Carson P, Hong CJ, Otero-Vinas M, Arsenauf EF, Falanga V. Liver enzymes and lipid levels in patients with lipodermatosclerosis and venous ulcers treated with a prototypic anabolic steroid (stanozolol): a prospective, randomized, double-blinded, placebo-controlled trial. *Int J Low Extrem Wounds.* 2015;14:11–8.
 42. Yamauchi K, Nakao M, Nakashima M. Correlates of regret with treatment decision-making among Japanese women with breast cancer: results of an internet-based cross-sectional survey. *BMC Womens Health.* 2019;2(19):86.
 43. Wilson A, Ronnekleiv-Kelly SM, Pawlik TM. Regret in surgical decision making: a systematic review of patient and physician perspectives. *World J Surg* [Internet]. Springer International Publishing; 2017;41(6):1454–65. <http://link.springer.com/10.1007/s00268-017-3895-9>
 44. Becerra Pérez MM, Menear M, Brehaut JC, Légaré F. Extent and predictors of decision regret about health care decisions: a systematic review. *Med Decis Making.* 2016;36:777–90.
 45. Kannan S, Seo J, Riggs KR, Geller G, Boss EF, Berger ZD. Surgeons' views on shared decision-making. *J Patient Cent Res Rev.* Aurora. Health Care. 2020;7:8.
 46. Shelton RC, Brotzman LE, Crookes DM, Robles P, Neugut AI. Decision-making under clinical uncertainty: an in-depth examination of provider perspectives on adjuvant chemotherapy for Stage II colon cancer. *Patient Educ Couns.* NIH Public. Access. 2019;102:284.
 47. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Soc Sci Med.* 2005;61:2252–64.
 48. Niburski K, Guadagno E, Abbasgholizadeh-Rahimi S, Poenaru D. Shared decision making in surgery: a meta-analysis of existing literature. *Patient.* 2020;13(6):667–81. <https://doi.org/10.1007/s40271-020-00443-6>
 49. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer.* 2009;17:1117–28.
 50. Raybould G, Babatunde O, Evans AL, Jordan JL, Paskins Z. Expressed information needs of patients with osteoporosis and/or fragility fractures: a systematic review. *Arch Osteoporos.* 2018;8(13):55.
 51. Adams E, Boulton M, Watson E. The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Educ Couns.* 2009;77:179–86.
 52. Wang T, Molassiotis A, Chung BPM, Tan J-Y. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat Care.* 2018;23(17):96.
 53. Williams D, Edwards A, Wood F, Lloyd A, Brain K, Thomas N, et al. Ability of observer and self-report measures to capture shared decision-making in clinical practice in the UK: a mixed-methods

- study. *BMJ Open*. British Medical Journal Publishing Group. 2019;9:e029485.
54. Heen AF, Vandvik PO, Brandt L, Montori VM, Lytvyn L, Guyatt G, et al. A framework for practical issues was developed to inform shared decision-making tools and clinical guidelines. *J Clin Epidemiol*. 2020;10(129):104–13.
 55. Lagha E, Noble A, Smith A, Denvir MA, Leslie SJ. Patient reported experience measures (PREMs) in chronic heart failure. *J R Coll Physicians Edinb*. 2012;42:301–5.
 56. Saunders CL, Elliott MN, Lyraztopoulos G, Abel GA. Do differential response rates to patient surveys between organizations lead to unfair performance comparisons? *Med Care*. 2016;54:45–54. <https://doi.org/10.1097/mlr.0000000000000457>
 57. Ahmed F, Burt J, Roland M. Measuring patient experience: concepts and methods. *Patient*. 2014;7:235–41.
 58. Cabitza F, Dui LG, Banfi G. PROs in the wild: assessing the validity of patient reported outcomes in an electronic registry. *Comput Methods Program Biomed*. 2019;181:104837.
 59. Jenkinson C. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *Int J Qual Health Care*. 2002;14:353–8. <https://doi.org/10.1093/intqhc/14.5.353>
 60. Trujols J, Iraurgi I, Oviedo-Joekes E, Guàrdia-Olmos J. A critical analysis of user satisfaction surveys in addiction services: opioid maintenance treatment as a representative case study. *Patient Prefer Adherence*. 2014;8:107–17.
 61. Moffatt S, White M, Mackintosh J, Howel D. Using quantitative and qualitative data in health services research—what happens when mixed method findings conflict? [ISRCTN61522618]. *BMC Health Serv Res*. 2006;8(6):28.
 62. Munafò MR, Davey SG. Robust research needs many lines of evidence. *Nature*. 2018;25(553):399–401.
 63. Bekker CL, Mohsenian Naghani S, Natsch S, Wartenberg NS, van den Bemt BJJ. Information needs and patient perceptions of the quality of medication information available in hospitals: a mixed method study. *Int J Clin Pharm*. 2020;42:1396–404.
 64. McHugh GA, Luker KA. Individuals' expectations and challenges following total hip replacement: a qualitative study. *Disabil Rehabil*. 2012;11(34):1351–7.
 65. Gal R, Oostinga D, Wessels H, Verlaan JJ, Charest-Morin R, Fisher CG, et al. Pre-treatment expectations of patients with spinal metastases: what do we know and what can we learn from other disciplines? A systematic review of qualitative studies. *BMC Cancer*. 2020;20(1):1212. <https://doi.org/10.1186/s12885-020-07683-7>
 66. Baumeister RF, Vohs KD, Oettingen G. Pragmatic prospection: how and why people think about the future. *Rev Gen Psychol*. 2016;20:3–16.
 67. Mahomed NN, Liang MH, Cook EF, Daltroy LH, Fortin PR, Fossel AH, et al. The importance of patient expectations in predicting functional outcomes after total joint arthroplasty. *J Rheumatol*. 2002;1(29):1273–9.
 68. Purkiss SF. Decision making in surgery: a pilonidal sinus. *Br J Hosp Med*. 1993;50:554–6.
 69. Devereaux PJ, Bhandari M, Clarke M, Montori VM, Cook DJ, Yusuf S, et al. Need for expertise based randomised controlled trials. *BMJ*. 2005;8(330):88.
 70. Stauffer VK, Luedi MM, Kauf P, Schmid M, Diekmann M, Wieferich K, et al. Common surgical procedures in pilonidal sinus disease: a meta-analysis, merged data analysis, and comprehensive study on recurrence. *Sci Rep*. 2018;15(8):3058.
 71. Mottram A. 'They are marvellous with you whilst you are in but the aftercare is rubbish': a grounded theory study of patients' and their carers' experiences after discharge following day surgery. *J Clin Nurs*. 2011;20:3143–51.
 72. Aune E, Struksnes S. Home care nurses' experience of providing health-care to patients with hard-to-heal wounds. *J Wound Care*. 2019;3(28):178–87.
 73. Friman A, Klang B, Ebbeskog B. Wound care by district nurses at primary healthcare centres: a challenging task without authority or resources. *Scand J Caring Sci*. 2011;25:426–34.
 74. Maybin J, Charles A, Honeyman M. *Understanding Quality in District Nursing Services: Learning from Patients, Carers and Staff*; England: The Kings Fund; 2016.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Strong E, Callaghan T, Beal E, et al. Patient decision-making and regret in pilonidal sinus surgery: a mixed-methods study. *Colorectal Dis*. 2021;00:1–12. <https://doi.org/10.1111/codi.15606>