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Fourie, Simona, Johnstone, Lucy Jane and Ma, Sara (2026) You don't know what it's like until you live with it:' A qualitative study on experiences of sexual wellbeing after permanent ostomy formation. Journal of Sexual Medicine, 23 (11). qdag335.

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The Journal of Sexual Medicine, 2026, 23(11), qdag335
https://doi.org/10.1093/jsxmed/qdag335
Published: November 03, 2026
Original Research

"*You don't know what it's like until you live with it*:" A qualitative study on experiences of sexual wellbeing after permanent ostomy formation

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Abstract

Background: **The impact of stoma formation on sexual wellbeing (SWB) remains underexplored. While stoma surgery is often lifesaving, adjustment can involve significant physical, psychological, and relational challenges. Existing research has largely focused on sexual dysfunction, with less attention to the broader, multidimensional nature of SWB that includes psycho-emotional aspects.**

Aim: **The study aimed to explore the lived experiences of individuals with a permanent stoma in relation to their SWB and associated healthcare.**

Methods: **English-speaking adults with a permanent stoma were recruited via a prior international online survey. Semi-structured telephone interviews were conducted between September 2023 and March 2024. Interviews were audio-recorded, transcribed verbatim, and analyzed using reflexive thematic analysis.**

Results: **Twenty-five participants, $F = 17$ $M = 8$ (aged 21-59 years) from the UK, Ireland, North America, and Australia were included. Three interrelated themes were identified: (1) embodied and relational disruptions to SWB, including altered body image, stoma-related concerns, and fear of partner rejection; (2) structural silence and stigma in care, characterized by limited or absent professional discussions and unmet informational needs; and (3) the need to reframe SWB as a legitimate domain of care, with participants advocating for tailored, patient-centered support. Across accounts, participants described SWB as extending beyond sexual function to encompass emotional, relational, and identity-related dimensions. A lack of timely, relevant, and accessible information, alongside perceived discomfort among healthcare professionals, contributed to feelings of distress, stigma, and isolation.**

Clinical Implications: **Findings highlight the need to integrate SWB into routine stoma care through proactive, normalized discussions and multidisciplinary support, underpinned by patient-informed resources. This study highlights the importance of addressing psycho-emotional and relational aspects of sexuality within stoma care practice.**

Strenghts and Limitations: **The study strenghts include its international sample and rich qualitative data, offering insights into the psycho-emotional diemnsions of sexual wellbeing, while limitations include a predominantly female Western sample, missing ethnicity data and limited urostomy representation.**

Conclusion: **SWB is a neglected component of stoma care, leading to unmet needs and a negative impact on adapting to living with a stoma. Addressing SWB requires a shift beyond dysfunction-focused models toward holistic, patient-centered approaches that reflect the lived experiences of individuals living with a stoma and meet their informational needs.**

Keywords ostomy; sexual wellbeing; patient experience; holistic care; surgery

Received: 26 May 2026. **Revised:** 11 August 2026. **Accepted:** 12 October 2026
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Introduction

Stoma formation remains a treatment option for several conditions and can be a lifesaving surgical procedure. Cancer, inflammatory bowel disease (IBD), trauma, or congenital disease can lead to permanent stoma formation. A stoma can initially be associated with negative psycho-emotional and social impacts due to its stigmatizing connotations.[1] Sexual wellbeing (SWB), as described by the National Survey of Sexual Attitudes and Lifestyles (NATSAL) team,[2] refers to a positive and holistic experience of sexuality that includes physical, emotional, psychological, and social aspects. SWB encompasses autonomy, safety, and satisfaction in sexual experiences, alongside the ability to form meaningful relationships. However, these aspects may be negatively affected in individuals living with a permanent stoma due to pelvic nerve damage, reduced self-confidence, and body image concerns.[3,4] Current evidence suggests that SWB after stoma formation in cancer is shaped by an interplay of biological, psychological, and relational factors, suggesting the need for multidisciplinary interventions that extend beyond the management of sexual dysfunction alone.[5–7] Studies on cancer survivors' experiences and IBD patients have shown that despite healthcare professionals' understanding of the need to address SWB, the topic remained unaddressed, largely due to lack of training and feelings of embarrassment.[8–10] Evidence on experiences in those living with a stoma is limited, mostly looking at sexual dys/function and not explicitly paying enough attention to the broader psycho-emotional aspects. Current evidence indicates that those experiencing SWB concerns often do not receive adequate support[11–13] despite the negative impact of sexual problems on overall quality of life (QoL) of ostomates.[14–16] The limited existing evidence suggests that this group has unmet needs in relation to SWB, potentially contributing to delayed adaptation to life with a stoma and a negative effect on quality of life.[17,18]

This study aimed to explore the experiences of those living with a stoma regarding their SWB concerns following stoma formation, and their experiences of SWB care. The knowledge generated by this study should help bridge the gap in current evidence and practice, supporting more responsive approached to patients' SWB needs following stoma formation.

Study design

This is a qualitative study that collected data via telephone interviews between September 2023-March 2024. The study adopted a contextualist interpretivism approach, recognizing experiences as subjective and shaped by interpersonal and healthcare contexts. Participants were recruited to a prior survey and agreed to be contacted for a further optional interview. The interview guide (Table 1) was developed from preliminary survey data content analysis[19] and in collaboration with ostomates. The interviews were conducted by an experienced female qualitative researcher with clinical nursing experience. Patients and public were involved in the design stage of the study by refining the interview guide, and one of the data analysts is a representative with lived experience. Through ongoing engagement with the dataset, we judged that the interviews provided sufficient depth and diversity to address the research aim. Interviews lasted between 25 and 130 minutes and were audio-recorded and transcribed. Following interviews, the participants were allocated a pseudonym, and all identifiable information was deleted.

Data analysis was informed by Braun and Clarke's principles of thematic analysis.[20] An initial deviation was the development of a coding framework using the findings of the survey. The framework was refined iteratively during the analysis to allow for the identification of additional codes and meanings within the dataset. Themes were reviewed and discussed within the research team to ensure coherence and credibility. Consistent with reflexive thematic analysis, the researchers recognize that data interpretation was shaped by their prior theoretical knowledge and assumptions and therefore engaged in ongoing reflexive consideration throughout the analytic process. Two authors coded the data separately, then discussed the findings and named the preliminary themes. *NVivo* (version 14) was used for data management and coding. To enhance analytic rigor, a third researcher was consulted during the later stages of analysis to review and refine theme definitions, ensuring consistency and interpretive clarity. The separate coding approach was used to discuss interpretations, challenge assumptions, and mainly to refine themes as a group, which is consistent with the chosen analytical approach[21] .

Participants were not known to the interviewer prior to recruitment beyond initial survey contact. Transcripts were not returned to participants, and member checking was not undertaken, consistent with reflexive thematic analysis, which emphasizes researcher interpretation rather than participant validation. This study used the Consolidated Criteria for Reporting Qualitative Research (COREQ).[22] The study was reviewed and approved by the organizational ethics committee.

Results

A total of 25 participants were interviewed from the 63 individuals approached who gave permission to be contacted. The remaining eligible individuals either did not respond to invitations to schedule an interview, were unable to participate within the study timeframe, or withdrew before the interview. Because no further data were collected from these individuals, their reasons for non-participation and whether their experiences differed from those interviewed are unknown. Participants were recruited through purposive convenience sampling. Recruitment advertisements were disseminated through social media platforms and relevant charitable organizations. Individuals meeting the eligibility criteria self-selected into the study by responding to the advertisements. Participants to interviews were aged between 21 and 59 years old and from the United Kingdom, Ireland, the United States, Canada, and Australia. Only English-speaking participants were included to facilitate in-depth qualitative interviews. Participants had different types of stomas and a variety of health conditions leading to stoma formation, providing a broad range of participant demographics (Table 2). Two participants had both urostomy and colostomy following pelvic exenteration.

Data analysis led to three main themes: *Embodied and relational disruption of sexual wellbeing, Structural silence and stigma in sexual wellbeing care,* and *Reframing sexual wellbeing as a legitimate domain of care.*

The *Embodied and relational disruption of sexual wellbeing* theme was generated from the framework coding, while the other two themes were developed inductively. These three themes consist of nine sub-themes and are covered by the overarching theme: "*You don't know what it's like until you live it*" (Figure 1). The overarching theme depicts the lack of understanding of SWB

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Table 1 Interview guide.

- Please describe your experience about your stoma operation and how did you get information around the time of your operation about sexual wellbeing.
- Was such information important for you? Why?
- How would you prefer to get such information? Why?
- If you had any questions and not asked them, what was the main barrier for asking these questions?
- How did your permanent stoma made you feel about intimate relationships, or new friendships?
- How do you feel about having partners involved in discussing intimacy concerns? Why?
- What do you think is important for healthcare practitioners to know if they want to meet patients' needs related to sexual wellbeing following stoma?

Table 2 Partici pants' demographics.

		Sex orientation	Marital status	Pseudonym	Age	Stoma type/Dx	Region
1	F	H	D/R	Ada	59	I/CD	UK
2	F	H	M	Anna	33	I/CD	Ireland
3	F	H	R	Bella	43	C/OI	UK
4	F	H	M	Bianca	55	I/CD	UK
5	M	H	M	Adam	34	I/UC	Canada
6	M	H	M	Alan	59	I/UC	UK
7	F	H	R	Clara	59	C/Diverticulitis	UK
8	F	H	M	Davina	34	I/UC	UK
9	M	H	S	Ben	52	C/CC	UK
10	M	H	M	Brad	50	I/UC	UK
11	F	BS	S	Daria	21	I/CD	Canada
12	F	H	D/R	Diana	48	C/Diverticulitis	UK
13	F	H	S	Elena	30	I/IBDU	UK
14	M	G	R	Dan	38	C/UC	Australia
15	M	H	S	Barry	44	C/PB	UK
16	M	H	S	Colin	26	I/CD	USA
17	F	H	M	Fiona	29	I/CD	Ireland
18	F	H	S	Fay	30	I/UC	UK
19	F	H	S	Emma	47	I/IBDU	USA
20	F	H	M	Georgina	47	C/U/Cancer	UK
21	F	H	R	Elsa	54	C/PB	Canada
22	F	H	D/S	Fiona	59	U/C/Cancer	UK
23	M	G	S	David	34	I/CD	USA
24	F	H	S	Jane	36	I/CD	UK
25	F	H	M	Gemma	32	I/CD	USA

concerns encountered during care after their stoma formation, as well as the need for information that has the patient voice at the core.

Embodied and relational disruption of sexual wellbeing after stoma

Several concerns were outlined by participants in relation to SWB following stoma surgery, these included altered body image, stoma appliance concerns, and fear of partner rejection. Collectively, these concerns negatively affected participants self-confidence and expressing uncertainty about whether they would regain normalcy in their sex lives.

" . . . because when you're sick, and you see this surgery as potentially the way you're going to feel quote unquote normal again, normal includes a healthy sex life . . . "

(Alan, M, 59, ileostomy)

"I don't feel as confident as I would have before having the surgery."

(Anna, F, 33, ileostomy)

In contrast to this, some highlighted that stoma surgery had a positive effect on their relational quality of life as they no longer had the crippling symptoms they struggled with prior to it.

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Figure 1 Themes and sub-themes.

> "I don't like having to live with it. It feels normal now, but it didn't feel normal for such a long time. However, I love it because it has given me a chance to live on. It's given me a better quality of life, actually."
>
> (Barry, M, 44, colostomy)

Altered body image

Participants described struggles with their body image following stoma surgery. They felt unattractive due to the stoma, the surgical scars, and for some participants the presence of a peristomal hernia.

> "And I've got to be honest, every time I looked at it, it made me feel like I was going to faint. It just looked so horrific. All my scarring, because, obviously, they cut me all the way down, I just felt like Frankenstein's Bride, to be honest."
>
> (Elsa, 54, colostomy)

The emotional burden associated with bodily changes following surgery was substantial, highlighting the multidimensional aspects of sexual wellbeing.

> "Having the stoma itself caused me a lot of mental health issues. It affected me mentally. I'm not a lady that has ever been a size 10, 5 ft 8 model. But I have always taken pride in my appearance. And I felt disabled, disgusting, ugly, not attractive. All those things when I'd had it [stoma]done. And once I started to get better those were the residual feelings that I was left with."
>
> (Daria, F, 21, ileostomy)
>
> "I struggle [because of low mood] some days to get up and shower. And I'm struggling some days to take the dog out for a walk. I don't think there's enough positives at the moment to even look at relationships."
>
> (Barry, M, 44, colostomy)

Stoma appliance concerns

Following surgery, a general concern described was about their stoma appliance (bag/pouch) displacing during intimate moments leading to leakage, odor, or sounds that could interfere during sex.

> "I was worried about it [bag] coming off, or I was worried about it leaking, and that kind of thing. So, I learned very

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quickly to make sure that before I was going to engage in intimacy, that I was able to put a fresh bag on. Because there have been occasions when that's kind of ruined my night a little bit and I've ended up with a bag leak."

(Diana, F, 48, colostomy)

Fear of partner rejection

Participants with partners expressed fears of rejection, and many participants described uncertainty about when to disclose their stoma to a potential partner.

"Once I started dating, it was something that was very much on my mind because I totally feared rejection . . . "

(Alan, M, 59, ileostomy)

Structural silence and stigma in sexual wellbeing care

Participants reported that they received little to no information or support about SWB from healthcare professionals throughout their stoma care, which reinforced perceived stigma and taboo surrounding stomas and SWB. Participants identified barriers to discussing SWB and voiced concerns about the lack of holistic and person-centered approaches to their care. Several reported negative comments from healthcare professionals that negatively affected their already diminished confidence.

"I think they should stop treating people with stomas like they're lucky to have sex and intimacy in their lives. And that they need to find somebody who's a real martyr to love them and support them."

(Elena, F 30, ileostomy)

Unmet informational needs

Most participants felt there was a lack of information and support regarding sex, leaving many to think they had to manage on their own or seek information without adequate professional guidance.

" . . . there was no support for that, so I just had to muddle along. So, I didn't have any support. It was up to me to get on with it."

(Brad, M, 50, Ileostomy)

It was also reported by some participants that HCPs did not provide sufficient information about the possible adjustments to sex that might be required following stoma surgery. It was only later in their journey that some participants were informed about common issues faced by ostomates.

" . . . someone to say, "Well, actually, you know, it's okay to still want sex," or, "It's okay to be intimate," or, "It's okay to-" . . . You're not shut down just because you've got a colostomy bag . . . That's what we need, that positive attitude . . . .And if you bring it up to them, they say, "Oh, yes, that's quite normal." Well, why didn't you say so from the beginning?"

(Elsa, 54, colostomy)

There was also a reported disconnect between what information participants wanted and what information was given regarding SWB.

"The information they gave me on like sexual wellbeing and that was focused entirely on pregnancy. Would I be able to have children? Thinking that that would be, from their perspective my biggest concern as a young woman. When it completely isn't. I've never wanted children . . . and that's the only thing they spoke about."

(Daria, F, 21, ileostomy)

Shaming, stigma, and perceived judgment

Several participants felt that some HCPs held negative views about stoma surgery, reinforcing the society's perceived stigma and taboo surrounding it. One participant even noted a surgeon perceived that having a stoma would negatively impact the ability to find an intimate partner.

"A previous surgeon was like, well, you'll find it very difficult to meet anybody if you go back to a stoma. So, that sort of like stuck in your head thinking, well, if I go back to stoma, I won't meet anyone."

(Emma, F, 47, ileostomy)

Participants sensed judgment when raising concerns about SWB, which they perceived to be a low clinical priority for health professionals.

"And they just didn't talk about it at all. I think was down to an embarrassment factor if nothing else, just because no one wants to talk about the actual act of sex itself. They all prefer to talk about babies and the kind of end result of unprotected sex rather than the actual act itself, and how that can be affected [by stoma]."

(Daria, F, 21, ileostomy)

Many described feeling that if they asked for SWB support they would be judged by HCPs. When a few participants raised these issues with HCPs, some responses emphasized gratitude for survival and framed concerns about garments for body image as unnecessary, which led participants to feel a sense of shame.

"I should be lucky I was alive they said . . . she's after going through all of this and all of a sudden that's [garments] all she's thinking about . . . "

(Anna, F, 33, ileostomy)

All participants wanted HCPs to normalize talking about SWB and break the stigma surrounding the topic.

" . . . we are so afraid to talk about things that everybody's doing anyway that why not make it safe and why not make it easy and why not make sure that the people are armed with the information that they need to make sure that they can feel good about themselves?"

(Bella, F, 43, colostomy)

Sexual wellbeing is not prioritized

Participants felt there was a clinical hierarchy of needs in which SWB was deprioritized with limited opportunity for patients to contribute to the identification of their own support needs. While participants acknowledged they would struggle to engage with

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SWB information immediately following surgery, they stated they would have liked such support later.

> "But later on, when I did go back and read the leaflet, it would have been helpful to have something [about SWB] in there . . . "
>
> (Ada, F, 59, ileostomy)

Some expressed doubts about whether healthcare professionals appreciated the lived experience of adjusting to life with a stoma, particularly in the early stages of adaptation where there was a focus on appliance and skin care. This was interpreted as a reflection of the lack of patient voice in the healthcare system.

> "And I don't really know what healthcare professionals have got access to in terms of training and support, but I think it's really important that they are made aware through discussion with ostomates about how living with a stoma affects people on a day-to-day basis, and the varied experience of that."
>
> (Elena, F 30, ileostomy)

Barriers to sexual wellbeing discussions

From the patient perspective, barriers arose both from HCP factors and patients' own reluctance to initiate and discuss SWB in a clinical setting. The reluctance of HCPs to initiate SWB discussions led to participants being hesitant to raise the topic and the feeling that this was probably not a topic that should be included in clinical settings.

> " . . . because it wasn't brought up by them I kind of felt that I couldn't really ask."
>
> (Anna, F, 33, ileostomy)

Several participants described feelings of embarrassment or shame, which prevented them from asking for SWB support. This was compounded when the HCP did not discuss it with them, reinforcing the perception that it was a shameful thing to discuss.

> "So, in my head I just thought it was like a really embarrassing thing that you just wouldn't discuss with a doctor, you know, and it's like there's this kind of shame around it."
>
> (Elena, F 30, ileostomy)

When participants had questions related to SWB, they suggested that often HCPs were not accessible due to their busy schedules, but also that some ignored conversations initiated by participants.

> "If I was particularly upset about something or worried about something I could never get through to who I needed at the time . . . So, I just give up."
>
> (Ada, F, 59, ileostomy)
>
> "I talked about that [SWB] to someone a couple of years ago and just got the same brush-off. That's a problem that lasted, as I said, for 20 years, and when I did mention it, it was just ignored."
>
> (Brad, M, 50, ileostomy)

The age and cultural values of both the HCPs and patients were noted as having an impact on the participants' willingness to discuss SWB. Younger participants felt uncomfortable discussing SWB with HCPs when there was a notable age gap between them. They felt the HCP may not relate to their current stage of life.

> " . . . the nurse that I dealt with was much, much older than I am, and it was kind of like talking to your grandmother. I just didn't feel right or comfortable doing it."
>
> (Anna, F, 33, ileostomy)

Some suggested that HCPs had limited knowledge and understanding of the impact of a stoma on their lives and were therefore unable to fully empathize, which reduced some participants willingness to approach them about SWB issues.

> " . . . maybe it's difficult to tell people exactly what it's like when they have them [stomas], if you haven't got one yourself as well."
>
> (Emma, F, 47, ileostomy)

Reframing sexual wellbeing as a legitimate domain of care

The need for ostomates to be viewed and cared for holistically by HCPs was identified as an essential factor in providing stoma care that is inclusive of SWB. It was acknowledged that patients needed access to reliable and diverse sources of information, support tailored to individualized needs and pathways to specialist support from a multi-disciplinary team of HCPs.

> "Us with stomas are not much different to how we were beforehand. And we are still sexual people. Like we're not just focused on having babies or focused on just asexual people; we're human beings. Like all disabled people, we're human beings. Deserve to have just pleasure for pleasure's sake. Not for in the pursuit of having children or anything medical that, you know, we have these organs for pleasure let's use them . . . . we deserve that kind of sexual pleasure, and we deserve to be seen as sexual people as well, and to have that information available to us."
>
> (Daria, F, 21, ileostomy)

Tailored support to individual needs

Participants recognized that not every patient or stoma surgery was the same and wanted SWB support to reflect this. They wanted to be seen as individuals and the care and support they receive to be tailored accordingly.

> "It wouldn't hurt for it to be a pre-discussed topic of what's your hopes, what's your expectations, realistically have you got any concerns at this point about any effect it may have on that side of your life, or, hopefully in the future. Because of studies like this, a little bit more confidence from the professional coming to the patient, saying some facts and figures, you know, in lots of situations people find X happens, but Y helps prevent that."
>
> (Bianca, F, 55, ileostomy)

It was advocated that there should be an option for patients to include their partner in conversations relating to SWB. Participants acknowledged that not everyone would want this, but the majority expressed that they would find it beneficial.

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> "I think that I would feel great about having my partner there being in an established relationship, but I think it's something that other people would have to kind of figure that out, what's right for them."
>
> (Adam, M 34, ileostomy)

Consideration of the SWB needs of sexual minorities was also identified as an area that requires particular attention.

> "So tailoring information would be great and including information about things that pertain to the LGBTQ+ community. Like, for a homosexual man would anal sex still be a thing with only part of a rectum left kind of thing, because that's a big question, I've come across online, and no one knows the answer. Literally no one! Because no one dare ask their surgeons or their stoma nurses because it just makes them embarrassed . . . "
>
> (Daria, F, 21, ileostomy)

There was a desire for access to multidisciplinary HCP support related to SWB, with everyone involved rather than it just being one person's role.

> " . . . I think it needs to be everybody involved. It should be just part of the care plan as opposed to being somebody's specific role because one person can't do everything. You can't be so stretched, you know, because nobody will get the benefit of it. If even the nurses on the ward are able to talk about it that would be good."
>
> (Bella, F, 43, colostomy)

Provide reliable information

As participants found it difficult to engage with information before or immediately following stoma surgery, they suggested access to credible resource such as a website or leaflet that would allow patients to engage with the information when they wanted to.

> "One thing that I think could be very useful, is because you're not thinking about it at the time of the surgery, or maybe even at discharge, is a dedicated leaflet on that kind of thing. Or a website with people on the internet who are health professionals, sex therapists, that kind of thing, who actually do talk about what it's like."
>
> (Daria, F, 21, ileostomy)

The risks associated with accessing unreliable information when no credible information is available was mentioned:

> "But, if you look in the wrong places it's going to make things worse for you, and then you might be less likely to want to ask because Dr Google says it's something else, so I'm going to close up even more, and never speak of it again."
>
> (Bianca, F, 55, ileostomy)

Most participants stated that due to the current lack of information from HCPs, they were most likely to search the internet to source information from other people with a stoma, recognizing their unique knowledge and ability to empathize. Therefore, many felt it was also important to include SWB support from other "ostomates" in future care plans. They wanted information and support from both HCPs and their peers.

> " . . . the world's number one expert on stomas, like whoever they are if they don't have a stoma, I think especially around sexual health, there would still be something missing. I think it's important to build in the perspective of people with stomas to that conversation in a lot of various forms . . . "
>
> (Adam, M 34, ileostomy)

Most participants described the adjustment to living with a stoma as the most challenging period, during which they experienced the greatest lack of support. Although these feelings were not always sustained over time, several participants noted that the impact of this period persisted, even decades after stoma formation. Some of the quotations presented reflect participants' experiences during that earlier stage of adjustment.

Discussion

This study extends current understandings of SWB in people living with a stoma by demonstrating that disruption is not limited to sexual function, but is embedded in embodied, relational, and socio-cultural dimensions of experience. Participants described how altered body image, stigma, and anticipated partner responses intersect to reshape sexual identity and relational confidence. The visible and externalized nature of a stoma introduces practical and sensory concerns (eg, leakage, odor, appliance displacement), which, alongside fears of partner rejection, positions SWB as central to identity, normality, and psychosocial adjustment. Several individual concerns are reported in previous research.[23] These findings suggest that the interaction between bodily change and external visibility may intensify SWB disruption in this population. Our findings reveal how these interconnected experiences shape SWB rather than representing isolated aspects of sexual function, and a SWB framework provides a more comprehensive understanding of patient experiences. The study contribution lies in three advances: multidimensional/interconnected SWB, structural silence and legitimacy, and temporality responsive rather than one-off support.

The findings also point to a structural silence within healthcare, where SWB is deprioritized and implicitly perceived as non-essential. This is not simply an absence of discussion but reflects how SWB is positioned within clinical hierarchies of need. In line with previous research, participants identified body image, intimacy, appliance-related concerns, and healthcare communication as key issues.[10,11,19,24] These findings are consistent with evidence highlighting the psycho-emotional burden associated with living with a stoma, including increased anxiety, depression, and reduced quality of life.[25–27] Practical concerns such as leakage and fear of partner rejection,[28] together with stigma and embarrassment surrounding discussions of SWB[14,29,30] may hinder adaptation, particularly in the absence of adequate support.[25,31,32] Taken together, these findings reinforce the need to conceptualize SWB as closely linked to psychological adjustment rather than as a distinct or secondary outcome.

Despite evidence that information needs are a priority and support self-management in long-term conditions,[26,33] participants consistently reported a lack of SWB information. However, the findings from this study suggest that this gap extends beyond availability to issues of timing, relevance, and delivery. Participants described limited readiness to engage with SWB information

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Table 3 Recommendations for practice.

Topic	Recommendation	Rationale (from findings)
Timing of SWB discussions	Introduce SWB pre-operatively (briefly), reinforce at early post-operative stage, and revisit during follow-up/adaptation phase.	Participants reported limited readiness immediately post-surgery but a clear need for information later; SWB support should be timely and iterative rather than one-off.
Who should deliver SWB support	Shared responsibility across the multidisciplinary team (MDT) including stoma nurses, surgeons, and where appropriate, sexual health specialists.	Participants emphasized that SWB should not be confined to a single role; normalization requires collective responsibility and consistent messaging.
Initiation of discussions	Healthcare professionals should proactively initiate SWB conversations rather than waiting for patients to ask.	Lack of initiation reinforced stigma and patient reluctance, contributing to unmet needs.
Format of information delivery	Provide layered resources: verbal discussion, written leaflets and digital/online resources.	Participants preferred flexible access, allowing engagement when emotionally ready.
Content of SWB information	Include practical (eg, stoma management during intimacy) and psycho-emotional (eg, body image, confidence, relationships) aspects.	SWB concerns extended beyond function to embodied and relational dimensions.
Personalization of care	Tailor discussions to individual needs, life stage, and relationship context.	Participants highlighted variability in priorities and dissatisfaction with generic or fertility-focused information.
Inclusion of partners	Offer the option to involve partners in SWB discussions.	Many participants viewed partner involvement as beneficial but emphasized choice and flexibility.
Peer and experiential support	Integrate peer-led or patient-informed resources alongside clinical input.	Participants valued experiential knowledge and identified gaps in clinician understanding.
Addressing stigma	Normalize SWB as a routine aspect of care through language, training, and repeated exposure.	Silence and discomfort from HCPs reinforced stigma and patient shame.
Training for healthcare professionals	Provide training focused on communication skills and psycho-emotional aspects of SWB, not only sexual function.	Participants perceived HCPs as underprepared, particularly regarding non-functional aspects of SWB.

immediately postoperatively, but a clear need for accessible, credible resources during later stages of adaptation. This indicates that SWB support should be understood as an ongoing, responsive process rather than a single point of intervention. Inadequate or poorly timed information may contribute not only to unmet needs but also to emotional distress and uncertainty, reinforcing previous findings that ostomates remain an underserved group in this area[17,34].

In line with previous research in IBD and colorectal cancer populations, participants expressed a desire for SWB to be routinely integrated into holistic care, with greater recognition of psychological and relational dimensions alongside sexual function.[35–37] Importantly, the findings also suggest that the absence of proactive discussion contributes to the internalization of SWB as a low-priority or inappropriate topic, reinforcing stigma and reluctance to seek support during clinical interactions. While embarrassment and stigma are recognized barriers,[9,10] uncertainty among healthcare professionals regarding when and how to initiate these discussions may further contribute to their omission. This emphasizes the need for a shift from reactive to proactive approaches, where SWB is normalized within routine care and supported by consistent, multidisciplinary engagement.

Participants stressed the importance of integrating both clinical and experiential knowledge in SWB support. Existing evidence supports the role of multidisciplinary and group-based interventions, as well as digital resources, in promoting self-management and wellbeing,[38–40] with a preference for accessible written or online information.[41] Within this study, patient voice functions analytically as a means of identifying gaps between clinical priorities and lived experience. It highlights how SWB is marginalized within care interactions and how the absence of discussion shapes patient perceptions of legitimacy. At the same time, experiential knowledge emerges as a critical resource, supporting the development of co-produced, patient-informed approaches that better reflect the realities of living with a stoma.

These findings have direct implications for sexual medicine. They highlight a gap between dysfunction-focused models of care and the multidimensional nature of SWB as experienced and reported by patients. This is consistent with previous research on patient perspectives following colorectal cancer, which demonstrates that the consequences extend beyond sexual dysfunction to encompass broader dimensions of SWB, including psychological and social well-being.[5–7] Similarly, interventions such as comprehensive stoma education, psychosocial support, early discussions of sexual health, and involving partners in rehabilitation may facilitate adaptation and improve SWB.[5–7] Integrating SWB into routine stoma care requires a shift toward proactive, normalized discussions delivered across the multidisciplinary team, supported by flexible, patient-informed resources. Addressing the psycho-emotional and relational dimensions of SWB has the potential to improve not only sexual outcomes but also broader quality of life and adjustment to life with a stoma.

While these findings focus on challenges during adaptation and early care experiences, these difficulties are well recognized, and many individuals adapt well to life with a stoma over time.[32] Nevertheless, the persistence of unmet SWB needs during this period highlights an important opportunity for intervention. Future research should further examine partner experiences and couple-centered approaches to sexual rehabilitation.

Based on the findings of this study, we suggest some actionable and transferable measures that could be included in practice, as shown in Table 3.

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Strengths and Limitations

This study is strengthened by its international sample and rich qualitative data, capturing diverse experiences across different healthcare systems. While not generalizable, the findings may be transferable to similar contexts, particularly in highlighting the psycho-emotional dimensions of SWB often overlooked in function-focused approaches prevalent in sexual medicine.

Limitations include a predominantly female Western sample, lack of ethnicity data, and potential overrepresentation of individuals with IBD and those who experienced greater SWB difficulties, due to recruitment methods. The small number of urostomy participants reflects their broader underrepresentation but provides preliminary insight and indicates the need for further research. Limiting participation to English-speaking only is another limitation. We also acknowledge that participants self-selected into the study, and that individuals who declined participation may have had different experiences or perspectives. As information was not collected from non-participants, these potential differences cannot be assessed.

Conclusions

This study identifies a persistent gap in SWB support for individuals living with a stoma, extending beyond information deficits to issues of timing, relevance, and clinical prioritization. Participants reported limited or absent discussions with healthcare professionals, reflecting structural barriers and the marginalization of SWB within care. HCPs were perceived as underprepared to address the psycho-emotional and relational dimensions of living with a stoma, leaving key concerns unmet.

These findings demonstrate that SWB disruption extends beyond sexual function to embodied, emotional, and relational aspects central to quality of life. Neglecting these dimensions may hinder adaptation and reinforce isolation and low self-confidence, and a function-only approach to assessment does not fully reflect the patient experience. Participants highlighted actionable strategies, including patient-informed resources and normalized clinical discussions.

Future work should prioritize co-produced, accessible SWB resources and integrate SWB into routine care pathways, supported by targeted HCP training and recognition of SWB as a core component of holistic stoma care.

Acknowledgments

We thank all participants who generously volunteered their time to participate in this study.

Author contributions

Simona Fourie (Conceptualization [lead], Data curation [lead], Formal analysis [lead], Funding acquisition [lead], Investigation [lead], Methodology [lead], Project administration [lead], Validation [equal], Visualization [equal], Writing - original draft [lead], Writing - review & editing [equal]), Lucy Jane Johnstone (Formal analysis [equal], Methodology [equal], Validation [equal], Visualization [equal], Writing - original draft [equal], Writing - review & editing [equal]), Sara Ma (Formal analysis [supporting], Methodology [equal], Validation [equal], Visualization [equal], Writing - original draft [equal], Writing - review & editing [equal]).

Supplementary material

Supplementary material is available at *The Journal of Sexual Medicine* online.

Funding

This study was funded by an Investigator led Convatec award.

Conflicts of interest

S.F. had received speaker fees from AbbVie, Alfasigma, Convatec, Eakin Healthcare, Janssen, and Takeda.

AI use

An AI-assisted image was generated with ChatGPT 5.0 from the table of themes and subthemes to enhance visual presentation and support interpretation of the findings, in accordance with Wiley's guidance on the transparent disclosure of generative AI use.

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The Journal of Sexual Medicine, 2026, 23, qdag335
https://doi.org/10.1093/jsxmed/qdag335
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