American Journal of Qualitative Research
2026, Vol. 10 No. 3, pp. 348-371
https://doi.org/10.66815/ajqr/ 19025

AMERICAN JOURNAL OF QUALITATIVE RESEARCH
ISSN: 2576-2141

Strategies for learning to live again: A thematic inquiry into the process of ostomy adjustment

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ABSTRACT

While the formation of a fecal ostomy (colostomy or ileostomy) can be a lifesaving event, it can also be life changing as people adjust and adapt to new ways of being. Little is known about differences in adaptation, leading to adjustment between those with temporary and permanent ostomies. The current study employs reflexive thematic analysis as the primary analytical approach within a qualitative descriptive methodology to explore the circumstances influencing adjustment. It explores the perceptions and experiences of participants with either a temporary or permanent ostomy and the perspectives of interdisciplinary healthcare professionals who care for them using the Roy Adaptation Model to inform the interpretive process. Nineteen participants were recruited through purposeful sampling from a single tertiary referral healthcare facility in Australia: five participants with a temporary ostomy, six with a permanent ostomy, and eight interdisciplinary healthcare professionals. Participants completed a single, semi-structured interview. Reflexive thematic analysis was employed to interpret the data and generated five interconnected themes and 16 sub-themes. The major themes included: reconstructing a health identity, developing new ways of living with an ostomy, help seeking behaviors, the hidden layers of ostomy adaptation, and perception of care. To facilitate successful integration of the ostomy into daily life, equitable access to education, psychosocial support, and encouragement should be provided to both TO and PO patients. Given the increasing global incidence of conditions requiring ostomy formation, including colorectal cancer and inflammatory bowel disease, investigation into the processes of adaptation and adjustment to temporary or permanent ostomies represents an important research priority.

KEYWORDS: Ostomy, Colostomy, Ileostomy, Adaptation, Adjustment

Surgical creation of an ostomy results in physical and psychosocial challenges, which may hinder long-term adaptation (Jayarajah & Samarasekera, 2017; Nichols & Inglese, 2018). Adaptation is a process of transition, during which individuals grieve their pre-ostomy life, learn

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self-care and independence and move towards acceptance (Thorpe & McArthur, 2017). A new balance is ultimately achieved between their illness, mind, body, environment and ostomy, with psychosocial adaptation representing the final stage of the adjustment process (Chan, Cardoso, & Chronister, 2009; Thompson, 2011).

Understanding adaptation and adjustment to life with an ostomy is of increasing global importance, as the incidence of several underlying conditions requiring ostomy formation continues to rise, (Feng et al., 2025; Nardone, Zammarchi, Santacroce, Ghosh, & Iacucci, 2023; Wu, Zhang, Lin, & Wei, 2025) despite advances in surveillance, treatment, and health promotion efforts (Feng et al., 2025; Nardone et al., 2023). Correspondingly, the number of individuals living with an ostomy is increasing worldwide. Prevalence estimates are highest in countries such as the United States of America approximately 220 per 100 000 persons (Burgess-Stocks, Gleba, Lawrence, & Mueller, 2022), Australia 197 per 100 000 persons (Care, 2023) and the United Kingdom 260-300 per 100 000 persons (Osborne et al., 2022).

Several factors influence adaptation and psychosocial adjustment, including individual resilience (Scardillo, Dunn, & Piscotty, 2016) and ostomy preoccupation (Scardillo et al., 2016; Whiteley, Randall, Fetheny, & Stanaway, 2024). Adaptation may be compromised by financial capacity to obtain ostomy supplies (Chery et al., 2024), or by ostomy complications that reduce willingness to engage socially (Martín-Muñoz, Montesinos-Gálvez, Crespillo-Díaz, & Jódar-Sánchez, 2022; Whiteley, Randall, Fetheny, et al., 2024) and vocationally (Scardillo et al., 2016).

The quality of preoperative education, together with recurrent or persistent illness, can shape post-operative acceptance and adaptation (Haugen, Bliss, & Savik, 2006). Social interactions (J. Kittscha, Fairbrother, Bliokas, & Wilson, 2022; Martín-Muñoz et al., 2022), peer support (Julia Kittscha, Wilson, Fairbrother, & Bliokas, 2024; Whiteley, Randall, & Stanaway, 2024), and ongoing access to ostomy care nurses (OCNs) helps to facilitate adjustment (Whiteley, Randall, & Stanaway, 2024). However, existing research has not comprehensively explored the complex interactions between these factors, nor clarified why adjustment is often protracted. Furthermore, differences in adaptation between individuals with temporary ostomies (TO) and permanent ostomies (PO) remain underexplored.

This study aimed to explore the personal experiences of adaptation and adjustment among individuals with either a TO or PO. Specifically, it examined participants' cognitive and emotional responses, namely their outlook, feelings, and beliefs during the adaptation period. Perspectives of interdisciplinary healthcare professionals (HCPs) were also included to provide broader insight into the adjustment process and to clarify how clinicians perceive their role in supporting ostomy care. The authors believe that this is the first study to explore insights from both ostomates and clinicians.

Study Design / Materials and Methods

A qualitative descriptive (QD) methodology was employed to explore the phenomenon of ostomy adaptation and adjustment. An inductive approach supported exploration of the health-illness continuum in relation to recovery, and facilitated data collection from both patients and HCPs, enabling a comprehensive understanding of adjustment experiences (Kim, Sefcik, & Bradway, 2017).

The Roy Adaptation Model (RAM) was selected as the theoretical framework for this study to facilitate a deeper understanding of patient adjustment to either a TO or PO. The RAM postulates that individuals possess fundamental needs encompassing physiological, psychological, and social

integrity. These needs are continuously shaped by dynamic interactions with the environment, where individuals respond to stimuli to produce a response. This framework presupposes that individuals possess the capacity to respond competently to the challenges imposed by illness or disease, engaging in behaviors that influence coping and adjustment (Roy & Andrews, 1999). The RAM informed the interpretive process with the shared and divergent experiences across the groups being linked to the four adaptive modes, to identify both adaptive and ineffective responses.

Study Population / Recruitment / Consent

A total of 19 participants were recruited through purposive sampling from a single Tertiary Referral Healthcare Facility in Sydney, NSW, Australia. Each received an invitation letter, study information sheet, and consent form via email or post. Participants completed a single, digitally recorded interview online via Microsoft Teams. No compensation was provided, and all provided written consent.

Inclusion Criteria

Ostomy participants were required have a TO or PO for a minimum of 2 months and be aged over 18 years. The HCPs required a minimum of 5 years' experience and routine interactions with ostomy patients.

Rigour / Trustworthiness

The lead investigator had pre-existing professional relationships with all participants. While such relationships may introduce assumptions, power differentials, or emotional challenges (Aburn, Gott, & Hoare, 2021), they also facilitate rapport, trust, and richer, candid data collection. The investigators engaged in ongoing reflexivity throughout the research process, systematically examining how their own emotions, assumptions, and prior experiences might shape the interpretation of the data. The involvement of a second investigator facilitated peer debriefing and sustained reflexive dialogue, helping to minimize bias and guard against premature or overly subjective interpretations. Role clarification ensured participants understood the research purpose and that interviews were not therapeutic (McConnell-Henry, James, Chapman, & Francis, 2009). If participants raised concerns requiring therapeutic interventions, they were referred to an independent ostomy care nurse or psychologist. This was also highlighted in the participant information sheet. Field notes were not taken during interviews to avoid distraction but were recorded afterward to capture reflections, contextual details, and preliminary coding insights, supporting auditability and trustworthiness (Phillippi & Lauderdale, 2018). Recruitment continued until conceptual depth, sufficiency, and information power was achieved (Malterud, Siersma, & Guassora, 2016). An audit trail was maintained to track revisions, modifications and accountability (Halpin, 2024).

Data Collection

A single semi-structured interview was undertaken. The interview guides, questions and prompts were different for patients and HCPs and were approved by the Ethics Review Committee. The interview guide was developed within the research team using findings of a previous

systematic review (Whiteley, Randall, & Stanaway, 2024) and a longitudinal study evaluating ostomy adjustment (Whiteley, Randall, Fetheny, et al., 2024).

Data Analysis

Interviews were transcribed in Microsoft Teams (V.7.9.0), checked for accuracy, and uploaded into NVivo (V.1.6) ("NVIVO qualitative data analysis software," 2023) for data storage, coding, reflections, and audit trail. Inductive analysis followed Braun and Clarke's reflective thematic analysis (RTA) and recursive six phase process wherein the researchers remained active in the process of data familiarization, initial coding, theme development, review, defining, and reporting (Braun & Clarke, 2021). Two researchers were involved in the coding process with themes refined through reflexive dialogue. The subjective interpretation was strengthened and supported by the presentation of verbatim quotations retaining the participants' original meanings.

Ethical Considerations

This research was approved by the Sydney Local Health District Human Research Ethics Committee - Concord Repatriation General Hospital on the 6th February, 2024. The institutional review board approval number is HREC: CH62/6/2023-168.

Results/Findings

Nineteen in-depth interviews were conducted with 11 patients and 8 HCPs between February and September 2024. Interview duration ranged from 23 to 107 minutes, with patient interviews generally longer (mean 55 minutes) than HCPs (mean 43 minutes).

Characteristics of the Patient Participants

Eleven patients participated (5 TO, 6 PO), including 8 females and 3 males, with a mean age of 49 years (range 25-74); TO participants were older on average (mean 55.6 years). Most underwent ostomy surgery for inflammatory bowel disease (IBD), while others had colorectal cancer, diverticulitis, fecal incontinence, genetic disorders, or ischemic bowel. Five had acute illnesses requiring surgery within 1 day to 5 weeks of diagnosis, and six had chronic illnesses with surgery 1-19 years post-diagnosis. Mean ostomy duration was 1.7 years for TO and 8 years for PO. Diagnoses and timelines are anonymized in Table 1, and participants were assigned pseudonyms.

Table 1
Characteristics of Patient Participants

Participant Study Pseudonym	Age range (years)	Type of ostomy (ileostomy / colostomy)	Ostomy duration (temporary / permanent)
Xanthe	40-59	Ileostomy	Permanent
Annie	20-39	Ileostomy	Permanent
Pamela	40-59	Ileostomy	Permanent
Maeve	40-59	Colostomy	Temporary
Lindy	40-59	Colostomy	Permanent

Kathryn	40-59	Colostomy	Permanent
Joshua	20-39	Ileostomy	Permanent
Kristoff	20-39	Ileostomy	Temporary
Luke	60+	Colostomy	Temporary
Charlotte	60+	Ileostomy	Temporary
Janelle	60+	Colostomy	Temporary

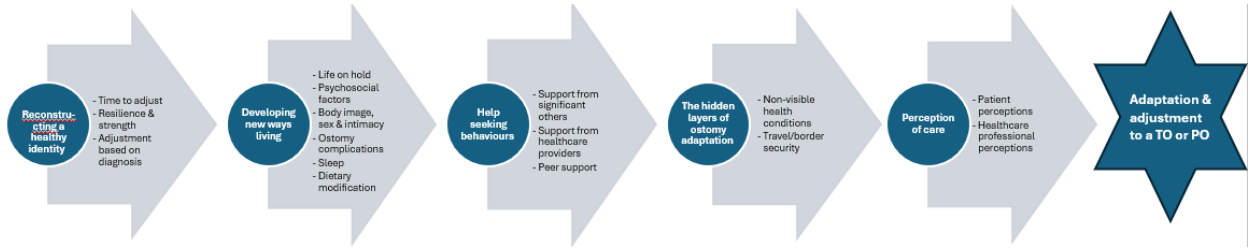
Characteristics of HCPs

Eight HCPs participated, representing an interdisciplinary cohort comprising: nursing (clinical nurse consultants, clinical nurse specialists, clinical nurse educator), allied health (dietitian, exercise physiologist) and colorectal surgeon. There was a mean age of 40 years (range 31–60) and an average of 10 years' experience (range 5–24) in ostomy care.

Findings

Using RTA, the authors generated 5 themes and 16 sub-themes (Figure 1).

Figure 1
Themes and Sub-themes



Reconstructing a Healthy Identity

With appropriate care and support, many participants adapted successfully, leading active and healthy lives. They described finding a 'new normal' and embracing the freedom an ostomy can offer. The three sub-themes are: time to adjust; resilience and strength; and adjustment based on diagnosis.

Time to Adjust

Acceptance was described as a gradual, non-linear process often marred by setbacks, with most TO and PO participants estimating an adjustment period between 3-12 months. Successful adjustment was evident when the ostomy ceased to interfere with daily life. Several TO and PO patients, along with health professionals, reported improved quality of life (QoL) following surgery.

> (Annie: PO) It took probably about 9 months until I felt like myself again … It's just a process; it's a massive adjustment.

HCPs described ostomy adjustment as highly variable, occurring over days to months. Adjustment was influenced by preoperative education, underlying disease, cultural background,

personality, and mental health history. Staff perceived that most ostomates adapt well over time, while a minority never fully adjust.

> (Sophia: staff) The ones that I've seen, the impact hasn't been huge. Everyone just seems to be doing what they did before. I follow them for five years, and they holiday, they work, and they have relationships with their partners.

Resilience and Strength

Resilience and strength were identified as key factors in ostomy adjustment, though many participants experienced significant psychological distress following surgery or when ostomy complications were encountered. Both TO and PO participants described their initial experiences using the following language; devastation (Kathryn: PO), traumatic (Xanthe: PO), uncertainty (Pamela: PO), shocked, raw emotion, trauma (Lindy: PO), daunting and intense (Kristoff: TO), I just wanted to die, but not commit suicide, I just wanted to not wake up (Maeve: TO), and horrible (Charlotte: TO). Over time, PO participants were more likely to embrace a proactive mindset, engaging in self-reflection, peer support, and advocacy. These actions fostered resilience and facilitated the reclamation of a healthy identity.

> (Annie: PO) I made loads of videos throughout my first surgery, while in hospital, and the recovery. It was more for me, to help me heal and process it, but actually, it makes you connect with a lot more people as well.

Actions to promote resilience were less evident in the TO group although some participants displayed strengths, others focused more on their reversal surgery.

Staff observed comprehensive preoperative education and counselling enhanced psychological resilience. Adaptability was seen to increase over time as individuals gained independence, engaged in self-care, and exhibited enhanced confidence.

> (Gabriella: staff) Most people are daunted by the prospect of a stoma … but seem to cope with it reasonably well if they've been informed beforehand that they're likely to get a stoma.

Adjustment Based on the Diagnosis

Diagnosis played a pivotal role in ostomy adaptation. Participants with symptomatic IBD or fecal incontinence generally adjusted more positively to their TO or PO, citing symptom relief, improved energy, and decreased medication dependence. These improvements facilitated engagement in caregiving to their children, employment, and social activities. Many described their ostomy as a ‘blessing’, expressing feelings of confidence, control, and freedom. Life post-ostomy was no longer dominated by toilet access, incontinence, dietary restrictions, or hospital admissions. Conversely, individuals with a PO due to cancer reported a profound sense of loss, underscoring the emotional complexity of ostomy adaptation in oncological contexts.

> (Joshua: PO) There was daily bleeding, pretty severe symptoms and I was getting close to 10 years with colitis and not really having any relief … Working was quite difficult … And with having the bowel motions through the night as well, I just wasn't sleeping.
>
> (Maeve: TO) It's good where it's taken me off the toilet, and off opioids. Because of the fistula, it was horrific. I couldn't get off the toilet, I was

> crying all the time and taking lots of strong medication … I was exhausted from the pain. It had been going on for 16 exhausting years.

Staff noted that some patients, particularly those without preoperative symptoms, experienced a sense of loss and viewed their ostomy as restrictive. In contrast, patients with symptomatic IBD were seen to benefit from ostomy formation, gaining relief from symptoms and greater freedom in daily life.

> (Isabella: staff) I think it depends on the person and on their individual circumstance leading up to the ostomy surgery. Were they having bowel issues beforehand? They might actually be grateful that it was formed. But if they were feeling fit and well beforehand, then they might be more resentful.

Those with a PO used language to describe their ostomy as, making them stronger, a positive change, the gift of freedom, providing confidence, control, increased energy, and the ability to live life without limitations. One PO participant expressed how her ostomy gave her the freedom and confidence to leave the safety of home.

> (Pamela: PO) The greatest gift of the stoma is freedom.

Staff report patients facing ostomy surgery 'bargain' pre-operatively, wanting to know if they can avoid an ostomy if they, eat better, lose weight, and exercise. Staff also perceived differences in the context of the illness, when an ostomy is required for cancer, it becomes a reminder of their disease and treatment.

> (Ellie: staff) Even then when patients would come back for PREHAB (pre-operative rehabilitation program), one of the questions we would always have to go over was, "am I going to have a stoma"? Can you tell me, "… if I optimize like the surgeon said, if I improve my nutrition, I might not need to have a stoma?". You feel like your heart breaks for them because you can't answer that … If they've got a stoma for cancer, some people might look at it as a constant reminder they had cancer.

Developing New Ways of Living with an Ostomy

Adapting to the formation of a TO or PO requires participants to reconstruct routines and redefine their social roles. This process involves managing physical and emotional challenges while seeking new ways of living. Central to successful adaptation is the individual's ability to reframe personal control, acknowledge the broader implications of their disease, and integrate the ostomy into a revised self-identity. However, this process may be impeded by persistent hope for reversal or adverse psychosocial influences. Sub-themes include life on hold; psychosocial issues; body-image, sex and intimacy; ostomy complications; sleep; dietary changes.

Life on Hold

Patients with TO frequently reported a state of limbo, with reversal as their primary focus. This preoccupation often led to putting their life on hold and the avoidance of social engagement, occupational activities, intimacy, and public transport.

> (Luke: TO) I think I'll choose to defer it (swimming) for the next couple of months. I'm looking forward to having the (reversal) surgery and having it done and getting back to what might be a bit more of a normal situation.

Staff observed patients instinctively checking their abdomen for a TO immediately upon waking from anesthesia and inquired about reversal within days of surgery. They focus intensely on the date of their reversal, viewing it as the definitive endpoint to a distressing chapter in their life and the point at which they return to 'normal'.

In contrast, HCPs perceived adjustment to be more attainable in PO patients, particularly when preoperative expectations were appropriately set. Staff emphasized the need for clear, realistic communication regarding TO reversal timelines.

> (Ellie: staff) Common things that I often would hear patients say is, 'the doctor's told me I just need it for 3 months. So, I'm going to just put up with it' … some patients get a little bit disheartened when they need chemotherapy and that 3 months, becomes 6 months, becomes 12 months, or there's that question mark whether it can be reversed at all.

While some patients with POs expressed a wish for a reversal solution, they generally did not allow the ostomy to restrict daily life. Feelings of sadness were reported upon hearing of others undergoing reversal, with some patients expressing hope for future medical innovations, such as organ transplantation, stem-cell regeneration, or implantable devices, that might enable reversal. Strategies to enhance adaptation included colostomy irrigation for improved bowel control, or seeking multiple medical opinions before accepting the permanence of their ostomy.

> (Kathryn: PO) I'll never accept it, never. I think I tolerate it because I have to, I don't have an alternative at the moment. But I'm 100% sure there will be an alternative even if it's when I'm 80, I'm getting reversal when they grow me a new anus.

Participants with both TO and PO acknowledged adaptation without full acceptance, describing an incomplete adjustment process.

> (Charlotte: TO) You live with it. You never adjust to it. You never accept it because it's something foreign and it's outside your body.

Psychosocial Factors

For those with both TO and PO, anxiety increased when undertaking experiences with the ostomy for the first time, such as socializing, returning to work, taking a flight or public transport, or participating in sport and exercise. Anxiety also increased when ostomy complications were encountered. The following quote illustrates the psychological adjustment required following TO formation;

> (Kristoff: TO) A pouch leak would keep it on your mind for a little while because you're trying not to think about it obviously … I realized that the main way I was dealing with it was not thinking about it. So that when you're forced into thinking about it was pretty intense, there was a lot to deal with.

Both PO and TO groups reported a psychological benefit from engaging with mental health professionals. Timely psychological support should be offered when patients are receptive and able to engage and ongoing community-based psychological care should be considered to support long-term adjustment.

> (Kathryn: PO) I think that you have to find somebody who can really tune into the fact that you are mourning the death of your old self … The only other person I spoke to was the lady from psychology at (hospital name

> redacted) who came to see me twice and she was lovely, but I think I was pretty out of it, and I felt embarrassed.

HCPs perspectives differed notably from patients regarding psychological adjustment. Most staff believed the underlying diagnosis and the presence of a new TO or PO exacerbated anxiety and depression. Adjustment was perceived to be influenced by personality traits and coping style, with pragmatic and actively engaged patients adapting more readily than those with passive approaches. Contrary to patient views, staff generally did not consider referral to a psychologist essential, suggesting that adequate support could be provided by family, nursing staff, dietitians, and particularly OCNs.

Body-image, Sex and Intimacy

Body-image adjustment was recognized by both patients and staff as a highly individual experience. Participants with TO and PO commonly reported self-consciousness, often becoming preoccupied with pouch fullness, leakage, and visibility. Strategies to conceal the ostomy were frequently described, with particular concern expressed around clothing choices, swimwear, and during intimacy. Intimacy required deliberate planning, including pre-emptive pouch emptying or changing, and dietary modifications to reduce pouch activity.

The following quotes describe the lengths taken to disguise the ostomy both in public and during intimacy.

> (Maeve: TO) I have to carry a large handbag to hold in front of me or big shopping bags, or I wear wrap around jumpers.
>
> (Kristoff: TO) It's affected my self-image to an extent. I pretty much wear a shirt all the time, or a singlet during intimacy. It's just not very erotic, is it?

In the longer-term the ostomy became integrated into their self-concept and some with a PO became more body confident, with ostomy care becoming routine.

> (Joshua: PO) I'll go swimming without my shirt on; I don't really mind if people see it. I see people look at it and wonder what it is, but if they ask me then I'll tell them.

While others with a PO continued to be conflicted with self-doubt and took longer to adapt.

> (Annie: PO) The only areas where I've struggled is going down the beach and swimming and during intimacy. It's taking me quite a while to build up the confidence to wear a normal bikini. It’s taken me about three years to get to that point … I still find it quite difficult to be intimate with the bag. I always like to strap it down, just to hold it in place.

HCPs found some patients with TO defer sexual activity until after reversal surgery. Initiating new relationships was perceived as particularly challenging, with male patients viewed as potentially disadvantaged due to lower emotional expressiveness. Staff referred to discussions regarding sex and intimacy as ‘difficult conversations’ and typically referred such inquiries to OCNs.

> (Gabriella: staff) It's probably a bit harder for people who, are starting a new relationship. It's hard to imagine that it wouldn't affect someone's body-image, which then affects their ability to feel confident in their body. I'm sure it has a big impact. But it's a bit awkward to talk about it between (HCPs) and patients, so we tend not to.

Ostomy Complications

Ostomy participants and HCPs consistently identified ostomy-related complications, particularly pouch leaks and hernias, as contributing to anxiety, altered body-image, and disrupted adaptation. Additional patient concerns included skin irritation, bowel obstruction, high output, flatus noise, ostomy visibility, bleeding, retraction, and infertility. One PO patient expressed distress over ostomy visibility, fearing social stigma and being mistaken for a thief.

> (Kathryn: PO) I developed a parastomal hernia quickly, I put on weight, I felt horrible about myself … I felt so inhibited by the fact that somebody's going to think I'm shoplifting because THAT is my biggest fear. I'm petrified somebody's going to turn around and say, lift your shirt up.

Leaks from the pouch remain one of the greatest concerns for participants with both TO and PO. This impacts confidence and adaptation.

> (Kristoff: TO) One of the more significant leaks was at a work event. After work one day we were playing touch footy and I fell over, and it tore my bag half-off … I just said I had to go, I packed up and got an Uber and it was very, very, stressful.

HCPs perceived ostomy complications heightened anxiety, self-consciousness, and social withdrawal. In contrast, individuals with well-positioned, complication-free ostomies were perceived to adapt more successfully. While staff echoed patient concerns, they identified additional complications of electrolyte imbalance, odor, stenosis, prolapse, and mucocutaneous separation, as factors contributing to increased preoccupation and disrupted adaptation.

> (Gabriella: staff) If they have a smooth, well-formed stoma in a good spot and everything heals well, I think that helps people to adjust. But then sometimes people get complications from their stoma, and that can make things go backwards.

Sleep

The need to alter sleep position was a universal theme expressed by the TO and PO groups, with most saying they do not sleep on their front or the side with their ostomy.

> (Luke: TO) Sleep has been a significant thing … because of the stoma bag I've had to sleep on my back or even partially sitting up for most of the time.

A subset of PO patients gradually resumed their pre-ostomy sleep positions, including modified front or side sleeping. TO participants with non-IBD indications reported poorer sleep quality, whereas those with TO or PO due to IBD described improved sleep post-operatively, attributed to cessation of steroid therapy and reduced nocturnal bowel urgency.

> (Joshua: PO) It was quite hard at first … I couldn't sleep on my stomach and I'm a stomach sleeper. But I've managed to work out a position where I'm not quite lying flat on my stomach, where I've sort of just got a bit of a gap to let my stoma empty and fill up.

According to staff, sleep-related concerns were infrequently raised by patients, though some reported difficulty sleeping in preferred positions. Staff perceived sleep disturbances to be

primarily associated with ileostomies, however, patient accounts indicated those with colostomies also experienced altered sleep quality and positioning.

> (Olivia: staff) I don't usually get asked questions about sleep.

Dietary Modification

Dietary modification was commonly reported among both TO and PO groups, regardless of whether they had a colostomy or ileostomy. Food avoidance strategies were employed to prevent appliance leakage, flatus noise, reduce output, and avoid blockages. Notably, even PO participants who claimed they could eat freely, often proceeded to list specific foods they continued to avoid, highlighting the persistence of dietary caution despite perceived adaptation.

> (Pamela: PO) Initially I was being very mindful of how liquid the output was and then making sure I was drinking things like hydralyte. I still had the list of what you should and shouldn't eat and what would thicken your output on my fridge … before my surgery I used to have a million and one dietary requirements. So, it's definitely been really liberating, being able to eat anything and everything.

Oddly, TO participants reported receiving comprehensive education from a dietitian, while those with a PO reported receiving no, or only basic education and support literature. Several participants identified an easing of their self-imposed dietary restrictions over time.

> (Annie: PO) I never saw a dietitian. I think I've found a lot of that information through talking to people and reading, and I found the low residue diet.

Dietary guidance for ostomy patients was primarily provided by dietitians, OCNs, and surgeons. While ward nurses reported frequent patient inquiries regarding diet, some were willing to offer basic advice, but were inclined to refer these questions to the dietitian or OCN.

> (Ellie: staff) I think there's a big knowledge deficit amongst clinicians about what patients with an ileostomy should eat … Patients get very confused with it all. So, I tend to strip it back and just focus on one or two key points and, say, "if you've got issues or concerns, call or email me or ask stomal therapy, or your surgeon". We mainly focus on patients who have an ileostomy, more to make sure they avoid being dehydrated and having to come into hospital … I think in terms of eating, patients do adapt to it.

Help Seeking Behaviors

As participants adapted to life with an ostomy, they actively sought meaningful ways to connect and relate to others. This theme encompasses; seeking support from significant others; support from HCPs; and peer support. The OCN played a pivotal role, serving as a bridge between patients and staff, and offering guidance to both groups. While most HCPs felt confident managing basic ostomy-related issues, they commonly relied on the expertise of OCNs for more complex concerns and complication management.

Support From Significant Others

Overall, participants from both TO and PO ostomy groups reported positive support from significant others, enhancing their ostomy adaptation.

> (Charlotte: TO) My husband is wonderful in that regard, he didn't care as long as he got his wife back. I don't think the stoma was either here or there to him.
>
> (Annie: PO) I couldn't cope with what was going on without family. I'm so lucky, my husband's never drawn attention to it and says it doesn't bother him'.

However, one participant with a PO noted adverse psychological effects when she sensed family members lacked empathy.

> (Kathryn: PO) They (husband and mother) don't know the complexity of what I'd had done in my surgery. I remember feeling absolutely horrified that my husband was going to work telling everybody I'd had my rectum removed. That horrified me, and my mum was also telling people, and yet I hadn't told anybody. And I'm like, 'this isn't your story to tell'!

Staff emphasized the critical role of family support in successful ostomy adaptation, identifying the importance of OCNs actively involving family members in educational sessions.

Support From Healthcare Providers

Participants from both TO and PO groups highlighted the central and enduring role OCNs played in facilitating adaptation. The forms of support included, answering questions, offering reassurance and encouragement, alleviating anxiety, selecting appropriate appliances, managing complications, and guidance throughout pregnancy.

> (Joshua: PO) They (surgical / medical teams) were more focused on treatment and getting me in and out of surgery safely. Then they kind of palmed me off to [OCN] and after that it was pretty amazing really. I felt really supported, and it definitely made it a lot easier. Just talking me through realities of it made a big difference…being able to understand life after the fact.

To a lesser degree there were acknowledgements from both the TO and PO groups of the support provided by psychologists, dietitians and members of the medical and nursing teams. One TO participant needed daily support from OCNs, highlighting that care must be individualized.

> (Maeve: TO) I was seeing my stoma team every day, five days a week. Because I could not face changing it by myself, I couldn't look at it. I couldn't touch it, I couldn't face this thing that was attached to my body, I couldn't face how ugly it was, how it moved, how it felt, how it smelt, everything about it. So, the stoma nurses mentally gave me my independence, by being able to change this thing by myself and to be able to leave the house.

Staff universally acknowledged their role in delivering essential ostomy care, including identifying complications and addressing basic patient concerns. However, the majority deferred to OCNs for specialized support. Given that most HCPs are involved primarily during the acute postoperative phase, OCNs were regarded as pivotal in providing sustained, long-term expert care.

> (Gabriella: staff) I usually try to reinforce for people that they're still going to be able to do all the things that they want to do (with an ostomy). But I have to admit, I leave a lot of that discussion to the stomal therapists to go into detail. Having the ongoing support of a stomal therapist is important.

Peer Support

Peer support was emphasized by TO and PO participants as a valuable source of hope, connectedness, and practical guidance, fostering a sense of connection and understanding that was difficult to obtain from other sources. Traditional support methods delivered by peers with similar diagnoses, age, and lived experience and at a contextually appropriate stage in the adaptation process was particularly important for those with a PO. TO participants gravitated toward social media platforms, often following inspirational ostomy advocates or joining Facebook groups. They typically described themselves as passive observers rather than active contributors within these online communities.

> (Kristoff: TO) I joined some stoma Facebook groups ... I didn't ever interact directly with anyone, but just saw what people were talking about. It was helpful and interesting seeing people talk about their experiences, discussing difficulties and positives openly and very frankly. I was in a pretty fragile state … and it was helpful seeing people talk about how they live with it, how they get past it, and adapting and getting back to normal life.

PO participants were more actively engaged in social media, sharing personal narratives, uploading video blogs, and offering in-person support to newly diagnosed ostomy patients.

> (Annie: PO) I think one of the ways that I came to accept it a lot quicker was through things like Instagram … I got really heavily involved, spoke to loads of people, joined groups, and asked loads of questions. I got a lot of information through people from there and made some really nice contacts. Probably one of the biggest things I would recommend is to reach out through those mediums cause there's so many people that can give you reassurance and some positivity.

Some participants with POs actively engaged in hospital-based peer support programs, offering guidance and encouragement to new ostomates. Motivated by their own lived experiences, they demonstrated a commitment to helping others navigate the challenges of early adjustment. Participants described peer support as personally meaningful and emotionally rewarding.

> (Xanthe: PO) For something that is quite drastic, I think to be able to help someone and say, hey, 'I know what you're going through and I know how you're going to feel or expect to feel'. So that was my way to 'pay it forward', and I hope the people that I've met along the way are all very well and thriving, like I am.

While some HCPs endorsed traditional formats, such as in-person peer support groups and one-to-one engagement with another ostomate, they also acknowledged the benefits and pitfalls of patients searching for information and support online. Staff observed, online ostomy content is not uniformly reassuring and may, in certain instances, exacerbate patient anxiety. Overall, staff deemed peer support valuable.

> (Isabella: staff) I think peer support is a very underrated form of support. I think it plays a massive role in normalizing something that is quite foreign for people.

The Hidden Layers of Ostomy Adaptation

Understanding life before and after ostomy surgery is essential to contextualizing patient experiences within the environments and circumstances from which they are constructed. Individual responses to living with an ostomy vary, influenced by prior experiences and personality traits that inform coping mechanisms.

Non-visible Health Conditions

Ostomy formation is frequently associated with non-visible illnesses, rendering the condition largely hidden from others. Participants reported internal deliberation regarding ostomy disclosure. Several noted a perceived lack of empathy compared to individuals with more overt health conditions. This theme was consistently observed across both TO and PO cohorts.

> (Maeve: TO) I think people have more empathy and compassion if they see someone that's visibly disabled. My disease isn't visible, so people don't understand it, it's different. That's what I'm angry about, not that I want it to be visible, it's hidden under my dress, so, people think I'm doing really well.

In general, most staff did not identify having a hidden or non-visible health condition as noteworthy.

Travel/Border Security

Participants reported challenges when traveling with an ostomy, including pouch management, dietary modifications, cabin pressure changes, and interactions with airport security. Anxiety related to flatus noise and ostomy visibility was common across both TO and PO groups. Whilst participants acknowledged the important role of border security, perceptions of border security encounters were shaped by the degree of sensitivity, as well as the individual's emotional state, body-image, and level of ostomy acceptance. Notably, some PO participants demonstrated greater comfort, openly disclosing their ostomy and responding to such interactions with humor.

> (Xanthe: PO) At the airport when you go through that big, curved machine, the stoma comes up in the X-ray. The guard said, 'Can you please step aside, ma'am'? The first time that happened was in the United States and I got taken to a room and then I got 'pat down' and they wanted to see my stoma bag. I laughed it off because I was like, alright, let me show you … I actually I think it's quite fun [laughing]. Maybe it's because I'm young and I look very normal.

Several participants with TO and PO valued their privacy, did not wish to disclose their ostomy to border security, and found the process stressful and invasive. This sentiment persisted despite proactive measures, such as wearing a 'Sunflower Lanyard' and carrying medical documentation. One participant's account underscored how insensitivity toward vulnerable individuals can escalate routine procedures into traumatic encounters.

> (Kathryn: PO) When I left the country, they picked up my colostomy on the scan. Everyone in the security line was looking at me and I had one of those sunflower lanyards as well, and I had an ostomy travel certificate from my stoma nurse. I didn't know what to do. I felt so embarrassed. Two young officers took me into a room away from everybody, and then asked me to lift up my shirt, checked my passport and then asked me to do bomb residue testing. Then I had to touch all around my stoma bag, but not take it off … I felt devastated. It was a really awful experience.

Although HCPs did not raise travel-related challenges, it was evident OCNs had addressed this topic with patients by providing ostomy travel certificates and travel tips.

Perception of Care

TO, PO, and HCP participants shared common views on the importance of individualized care. However, discrepancies emerged regarding the adequacy of information exchanged and its role in supporting adjustment. TO and PO participants perceived some HCPs as inattentive or lacking empathy, while staff reported challenges with patient understanding, adherence, and engagement in self-care. These divergent perspectives influenced patient satisfaction, educational uptake, and overall ostomy adaptation.

This theme consists of the two sub-themes; perceptions of care from patients and from HCPs.

Patient Perceptions

Patients are vulnerable during initial ostomy adaptation, and interactions with HCPs can alter the trajectory of adjustment. Both TO and PO participants reported variability in the quality of nursing care, noting that while some demonstrated strong training and empathy, others fell short in providing adequate support. Positive descriptors such as, fabulous, brilliant, kind, and compassionate, characterized nurses who were perceived as instrumental in fostering early confidence and acceptance. These individuals were fondly remembered for their role in facilitating a smoother transition to life with an ostomy.

> (Kathryn: PO) There was a [nurse]. I can't remember her name, but she was great, and she helped me. She checked if I was okay.
>
> (Luke: TO) The stoma nurses were very helpful. And I remember some of the nursing staff were very helpful as well and they asked me if I needed any help with it (stoma). They would talk to me about it and help me empty it.

Conversely, some participants perceived certain nurses as lacking the knowledge, confidence, or willingness to provide effective ostomy care. Descriptions such as, avoidant, scared, inexperienced, and lacking confidence, were used to characterize these encounters. When patients sensed uncertainty or disengagement from staff, it led to feelings of isolation and diminished trust, hindering early ostomy adjustment.

> (Lindy: PO) I had the nurses that weren't really trained helping me … I remember leaking everywhere and thinking, 'is this my new life'?

A TO participant emphasized the importance of being treated as an individual, with acts of kindness and care being perceived as instrumental in fostering resilience and acceptance.

> (Charlotte: TO) They see so much here and I don't think to them I'm any different. That's what they deal with day in and day out. They're all helpful, but they don't all know what they're doing in regards to the stoma … They get a little bit scared of doing the wrong thing … And it's a bit comical watching them find out which is which and what to put on (laughing).

Healthcare Professional Perceptions

The quality of care delivered by HCPs shapes the patient's overall experience and ostomy adaptation. The provision of individualized, compassionate, and attentive care was perceived to reduce anxiety and foster positive healthcare/patient experiences. HCPs emphasized the importance of engaging both patients and their families to promote open communication, encourage questions, and support help-seeking behaviors.

> (Olivia: staff) I want patients to try and change their bag themselves, with me there as a support person … having a nurse there, it gives them confidence. It gives them control. It gives them power, because at the end of the day it's theirs and when they go home, they have to deal with it. If the patient is struggling with the whole idea, that's where you have to teach family members as well.

Individualized care may be unintentionally overlooked as stoma management becomes routine and normalized within clinical practice. Staff must recognize ostomy formation represents a profound and unfamiliar life change for patients, and this disconnect highlights the importance of maintaining empathy and tailoring care to meet each patient's unique emotional and practical needs.

> (Ellie: staff) I think one thing we're potentially missing is really tapping into what the patient wants because as clinicians, we're very used to talking about stomas. But as a patient, they're not.

Nursing staff acknowledged their pivotal role as the first line of care, providing continuous support throughout hospitalization. They emphasized the importance of demonstrating both competence and willingness in delivering practical ostomy care, education, and emotional support. Nurses recognized their response to stoma-related events, such as managing pouch leaks, can influence a patient's emotional adjustment and ostomy acceptance.

> (Olivia: staff) Nurses are the front line, they're the first point of call because the Stomal Therapists aren't going to be here 24/7. It's definitely very important because some pouch leaks happen in the middle of the night. If that nurse doesn't know what to do, then the staff lose credibility and the patient loses confidence with the staff.

Some HCPs acknowledged limitations in their own or their colleagues' skills related to ostomy care. They expressed a need for further education and training to enhance their ability to provide comprehensive, confident, and patient-centered support.

> (Violet: staff) It's not something that we get trained in and it's just things that we've learned along the way. And then I pass that down to students and junior staff members. But I feel that I could benefit greatly from some more stoma education.

Understanding the factors that shape HCPs willingness to support ostomy patients is essential for improving quality of care. HCPs reported time constraints, competing clinical

demands, and concerns about disturbing other patients that often led to reliance on 'quick fix' solutions. Several participants expressed limited confidence in ostomy-related knowledge, hindering their ability to answer questions and troubleshoot effectively. Additionally, ostomy care was perceived to be compromised when delivered by junior or casual staff, or when patients were managed outside of specialized colorectal units.

> (Gabriella: staff) I think that it's a bit strange nurses patch up a leaking stoma bag, because that's a band-aid solution. I think it probably relates to the nurses' confidence in assisting with the stoma bag change.

Discussion

In this study we found that there were many common experiences between the TO and PO groups including time to adjust, ostomy complications, dietary modifications, support from HCPs, non-visible health conditions, and travel/border security. Within these themes there were some variations in the perceptions from the HCPs as highlighted in the findings. Differences become apparent between the TO and PO groups and the HCPs in areas such as resilience and strength, adjustment based on diagnosis, placing life on hold, psychosocial factors, body-image, sex and intimacy, sleep, and peer support. The discussion predominantly focuses on points of difference and what is new.

Whilst body-image concerns are commonly reported in ostomy adaptation (Aibibula et al., 2022), and can be linked to Roy's self-concept mode (Roy & Andrews, 1999), the prominence of discussions centered around swimming and swimwear offer a unique perspective in our findings. Australia's coastal regions offer access to more beaches than any other country, facilitating a vibrant swimming and beach culture (Carter, 2002), and likely accounting for the prominence of this topic. Despite practical online advice from ostomy supply companies, research supporting aquatic participation for ostomy patients remains limited (Mørkhagen & Nortvedt, 2023). Evidence-based guidance is lacking on pouch security, body-image, and suitable swimwear for ostomy patients which led to both adaptive responses where some participants developed body confidence and ineffective responses where some participants avoided swimming.

Differences in perceptions of care were evident between HCPs and participants with either TO or PO. While HCPs expressed confidence in delivering basic ostomy care and advice, they frequently referred patients to OCNs for concerns related to intimacy or clinical complications. In contrast, individuals with both TO and PO reported variability in the quality of physical care and information received, and perceived care lacked personalization. These findings underscore the need for HCPs to adopt a more proactive approach in supporting new ostomy patients. Prior research suggests that nurses' limited familiarity with ostomy-specific needs may contribute to unmet care requirements (Whiteley, Stanaway, & Randall, 2025). Strengthening interdisciplinary education is essential to equip staff with the resources to deliver practical care and lifestyle support. The RAM interdependence mode focuses on the quality of relationships and social interactions, including those with HCPs to promote a sense of belonging and confidence (Roy & Andrews, 1999). HCPs can assess patient responses to identify coping mechanisms and develop interventions to better promote adaptive responses.

All three groups identified OCNs as the key source of support and information helping to reduce anxiety. Ongoing, scheduled access to an OCN is essential for early detection and management of complications, promoting better adaptation (McNichol, Markiewicz, Goldstine, & Nichols, 2022). Anxiety increased in the ostomy groups when attempting to return to previous

activities, engage in new activities, or when pouch leaks or sleep disturbances were encountered. They acknowledged professional psychological support services were beneficial or would have been, had they been offered. Ostomy-related anxiety is common both in the short-term (Farahani et al., 2022) and long-term (Knowles, Cook, & Tribbick, 2013), although in this study anxiety lessened over time, particularly for PO patients. HCPs require training to ensure referrals to psychology services are offered to ostomy patients. Within the RAM self-concept mode, adaptive responses may emerge when individuals have access to consistent support and effective problem resolution (Roy & Andrews, 1999). Conversely, limited access to expert HCPs can contribute to ineffective responses, such as self-imposed isolation and heightened anxiety.

TO patients tend to have ineffective responses and fixate on their reversal date, sometimes deferring resumption of usual activities while awaiting reversal surgery (Chery et al., 2024; Whiteley et al., 2025). These dynamic influences individuals' role function, interdependence, and self-concept adaptive modes, as they allow their TO to dictate how they perceive themselves, their social position, and the nature of their relationships. This raises the importance of setting realistic expectations, as reversal is not guaranteed at 3 months and the ostomy may become permanent. Recent data shows median reversal times of 5.5 months for ileostomies (Boyer et al., 2025) and 16.9 months for colostomies (MacDonald et al., 2025). While some with a PO hoped for future medical advances to eliminate the need for their ostomy, they recognized the value of staying positive, taking control, and developed adaptive coping responses. For those with PO due to chronic conditions like IBD, this mindset reflected the sub-theme of Resilience and Strength, acknowledging the life-saving and QoL benefits of ostomy formation. Studies show resilience supports successful adjustment (Scardillo et al., 2016), and those with a PO for IBD experience better symptom control, reduced reliance on steroids, and improved remission rates without diminished QoL (Abdalla et al., 2016).

Both TO and PO participants noted that having a non-visible condition impacted adjustment, often leaving them feeling misunderstood and not worthy of the empathy received by those with visible illnesses. Both the ostomy and its underlying conditions, like IBD, are often non-visible (Mørkhagen & Nortvedt, 2023) and this is linked to the self-concept mode in the RAM (Roy & Andrews, 1999). Anxiety around ostomy disclosure is deeply personal (Lazenby, Guidry, Donovan, Dailey, & Ivatury, 2024) and is especially heightened during airport security checks, where privacy and dignity were compromised, making disclosure overwhelming, particularly the first time, culminating in ineffective responses in some participants. These experiences caused travel-related anxiety, despite support tools like ostomy travel certificates and Hidden Disabilities Sunflower Lanyards (Hidden-Disabilities, 2025). Ostomates should prepare for travel by understanding border security protocols, declaring medical supplies, and anticipating body scanner alerts (Department of Home Affairs, 2025). Ostomy awareness training for border security is key to fostering sensitive, empathetic interactions.

Despite the prevalence of chronic and serious conditions, there remains a widespread reluctance to acknowledge illness as a routine aspect of life. This hesitancy is often driven by fear of stigma, judgment, or perceived weakness, leading many individuals to conceal their ostomy and avoid open discussion. Consequently, silence around illness becomes normalized, new ostomates become isolated and the culture of treating illness as an abnormality is perpetuated (Hueso-Montoro et al., 2016). The motivation for ostomy adaptation and adjustment is frequently driven by the desire to restore a sense of normalcy following an illness related disruption (J. Kittscha et al., 2022). The concept of normalization influenced participants' experiences of ostomy adaptation and adjustment and was identified across all three study groups and was prevalent across several

themes with a strong desire for those with TO or PO to 'feel normal'. This pursuit of normalcy extended into intimate relationships, body-image, dietary habits, sleep patterns, and travel routines. These findings align with prior research indicating that normalization serves as a motivational framework for individuals navigating ostomy-related changes, prompting engagement with resources that foster adjustment and integration (Mohr & Hamilton, 2016). This reflects a determination to reclaim pre-ostomy life and avoid the stigmatization or being viewed as sick (Mohr & Hamilton, 2016; Whiteley & Gullick, 2018).

Support came from HCPs, predominately OCNs, family, or peers, with participants choosing support sources based on personal needs and preferences. Peer support fosters interdependence, social connection, aids adaptation and generates adaptive responses (Roy & Andrews, 1999). Peer support helps ostomates reengage in activities and normalize life (J. Kittscha et al., 2022), and has the potential to enhance all four adaptive modes of the RAM by providing psychological reassurance, fostering a shared group identity, and supporting both physical and social integrity. Through the exchange of experiential knowledge, practical advice, and emotional encouragement, peer interactions can help individuals meet adaptive needs while cultivating both existing and new relationships. While asking for support can be difficult, greater social support has a strong positive effect on QoL and is beneficial to ostomy adjustment (Lazenby et al., 2024; Yu et al., 2023). Access to peer support is shifting from traditional groups to more immediately accessible, potentially anonymous, online platforms (Prescott, Rathbone, & Brown, 2020). TO participants engaged passively with social media, while PO participants actively engaged, and shared experiences to help others. Social media's growing role in emotional support and information exchange is well documented (Yu et al., 2023). The anonymity afforded by online communities increased the willingness of some participants to share private experiences and engage in discussions with others facing similar challenges (Yu et al., 2023). Caution is warranted, however, as the information available via social media may lack accuracy, and cause distress. As social media is an emerging area in ostomy support, education of HCPs is paramount.

This study extends existing literature by examining how individuals adapt and adjust to a TO or PO from the perspectives of both patients and the HCPs who support them and by explicitly linking the findings to the adaptive modes of the RAM. Individuals with a TO tended to prioritize ostomy reversal over adaptation, which shaped how they integrated the ostomy into their daily routines and broader life context. Several novel insights emerged, including the influence of Australian swimming culture on adaptation, the unique challenges associated with travelling with an ostomy, and the differing ways individuals with a TO or PO engage with peer support. It further advances the field by presenting divergent perceptions between HCPs and individuals with an ostomy regarding the care provided, highlighting the need for ongoing interdisciplinary ostomy education.

Conclusion

This study provides valuable insights into the individualized adaptation and adjustment processes associated with both TO and PO, drawing on perspectives from ostomates and HCPs. While perceptions of adaptation and adjustment showed areas of convergence among individuals with TO, PO and HCPs, several notable distinctions were identified. Individuals with TO often postponed the resumption of routine activities and exhibited a heightened focus on the anticipated reversal date. In contrast, participants with PO demonstrated greater resilience, facilitating the formation of a new health identity. The underlying diagnosis influenced the adaptation process, and

those with a PO for cancer experienced a more complex adjustment trajectory. Peer support preferences also varied, TO participants tended to favor the anonymity of social media and engaged passively, whereas PO individuals were more likely to participate actively and share personal experiences. The four adaptive modes of the RAM were integrated into the discussion, enabling evaluation of participant responses as either adaptive or ineffective.

While adaptation is recognized as a dynamic and ongoing process, participants across all study groups generally reported progressive improvement over time. To facilitate successful integration of the ostomy into daily life, equitable access to education, psychosocial support, and encouragement should be provided to both TO and PO patients. OCNs play a pivotal role in this continuum of care and must remain consistently accessible to patients throughout the adaptation process.

Author Contributions

IW conceived the study. All authors contributed to the study design and IRB application. IW carried out the interviews. IW and SR analyzed the transcripts and interpreted the findings. All authors contributed to revising the manuscript.

Funding

No funding was received for this project.

Institutional Review Board Statement

The project titled “A qualitative exploration of adjustment to an ostomy from the perspective of patients and health care professionals’, was approved by the Sydney Local Health District Human Research Ethics Committee - Concord Repatriation General Hospital on the 6th February, 2024.

Informed Consent Form

All patient and health care professional participants provided signed informed consent documents. These forms were approved by the IRB and a copy of these forms are available by request from the corresponding author.

Data Availability Statement

Interview data is not available for public use. An application to the IRB is required to access the transcription data for use in another study. The corresponding author can assist with this application process.

Acknowledgments

We would like to extend our gratitude to each of the participants who engaged in this project and willingly shared their personal insights.

Conflicts of Interest

The authors have no conflicts of interest to disclose.

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