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British Journal of Nursing

Survivor to thriver: identifying and overcoming the psychological effects of a stoma

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ABSTRACT

Stoma-forming surgery can have extensive, negative impacts on a patient's psychological wellbeing. Although this has been known for several decades, little progress has been made in addressing the issue. Several areas of concern have been repeatedly identified in the literature: loss of control; reduced self-esteem; psychosexual issues; and the impact of enhanced recovery on psychological outcomes. While these issues have the potential to significantly affect patients undergoing stoma-forming surgery, they can be mitigated against. While identifying and addressing psychological morbidity at an early stage is the most effective approach, additional interventions can also be useful. The promotion of self-care and independence can minimise the feeling of loss of control, the selection of discreet, leak-proof products can help address self-esteem issues, and open, honest conversation can significantly improve a patient's feelings regarding sexuality and intimacy.

Key words: Psychological impact ■ Psychosexual ■ Self-esteem
■ Prehabilitation ■ Ostomy

The psychological impact of a stoma is significant and should not be underestimated (Pittman et al, 2009; Clark et al, 2023). In 2017, Haughey and McGrogan showed that 53% of surveyed ostomates in Ireland and Northern Ireland used mostly or entirely negative words to describe their life during the initial 12 months following surgery. However, ostomates' outlook generally becomes more positive as time progresses after surgery (Haughey et al, 2017). This psychological recovery was also examined by Ito et al (2012), who reported a continued improvement in self-reported quality of life in the first year after stoma-forming surgery. Kovoor et al (2023) also found the incidence of depressive symptoms significantly decreased not just immediately postoperatively but also during subsequent years. Furthermore, a 2016 study by Jayarajah et al estimated that between 16% and 26% of patients will experience negative psychological symptoms immediately following stoma creation.

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Accepted for publication: July 2024

While it appears inevitable that ostomates will experience a decline in psychological wellbeing, several matters can make this significantly more likely. For example, it has recently been shown that, in UK ostomates, self-reported quality of life is directly correlated with a number of factors, including how quickly the individual is able to return to normal daily activities and how often they experience leakage from their pouch system (*Figure 1*) (data on file at Eakin Healthcare, 2024).

Nearly three decades ago, White and Hunt (1997) were the first to highlight that around one in four stoma patients experienced clinically significant psychological symptoms postoperatively. Despite this, these disorders are not routinely detected by those involved in stoma care, even today. Past psychiatric history, dissatisfaction with preoperative preparation for surgery, postoperative physical symptomatology and the presence of negative stoma-related thoughts/beliefs have all been shown to be significantly associated with psychological morbidity after surgery (White and Hunt, 1997). Following their seminal findings, White and Hunt (1997) suggested that health professionals, especially surgeons, should discuss these issues with all patients both before and after surgery. However, this responsibility will likely fall to stoma care nurses (SCNs).

While MM has observed a huge progression in both the quality and efficacy of products and services over the past 30 years, it is clear that the psychological impact of stoma-forming surgery continues to be an ongoing issue. Progress in this key area is lacking so it is paramount that all practitioners working in stoma care collaborate to tackle and solve these issues.

The primary aims of this paper are to highlight and discuss the psychological impacts of stoma-forming surgery and common stoma-related issues on patients. The authors will explore how factors negatively impact mental health outcomes. Furthermore, this paper will suggest a number of simple steps that SCNs can take to help minimise these negative effects. By highlighting these difficulties and mitigation strategies, the authors aim to emphasise the direct role that an SCN can play in helping address these challenges.

Psychological areas of concern

A number of studies have focused on the negative psychological impact stoma forming surgery can have on a patient. These studies consistently highlight four key areas of concern:

- Loss of control
- Altered body image and the associated reduced self-esteem
- Fear of intimacy, which can result in psychosexual issues

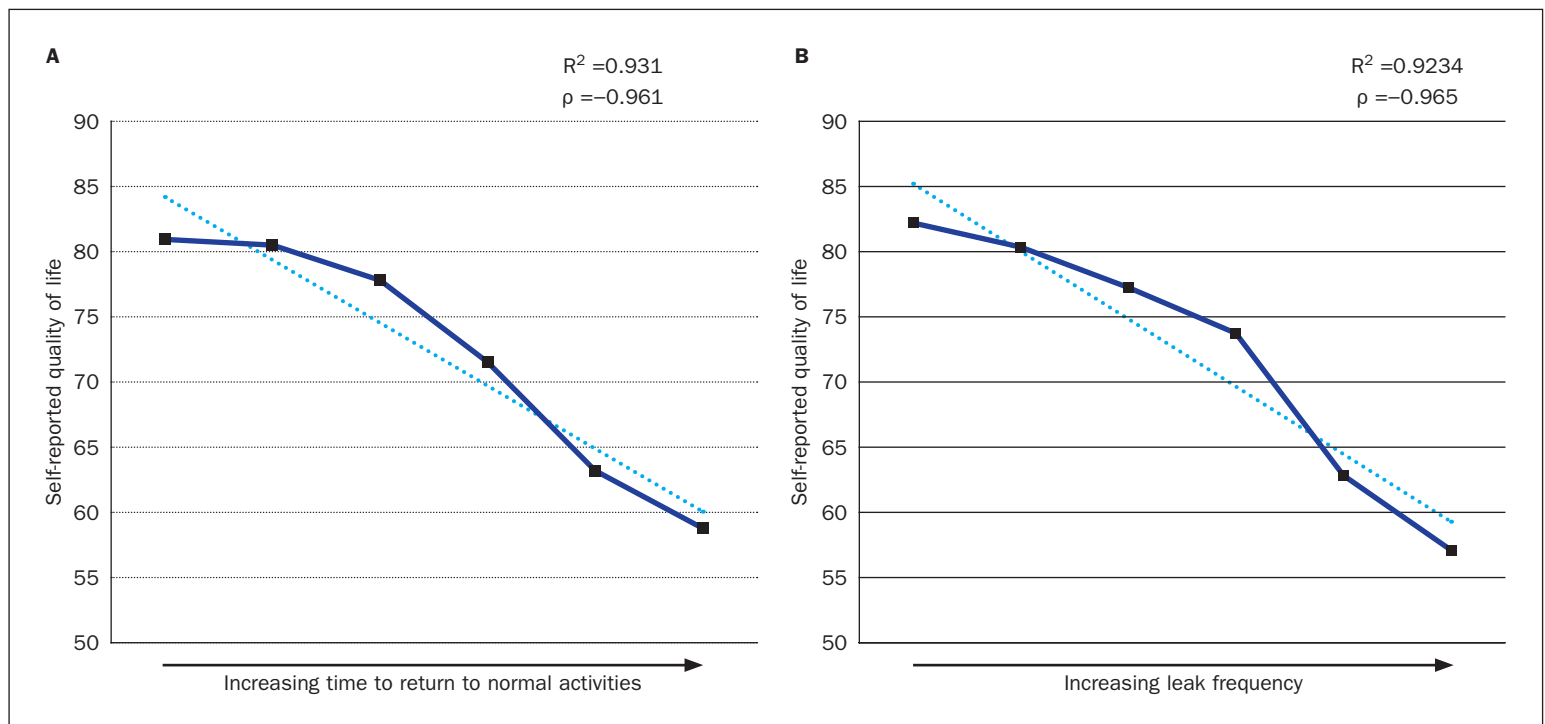


Figure 1. Relationship between (A) an ostomate's time to return to normal activities and their self-reported quality of life, and (B) the frequency with which ostomates experience leakage from their device and their self-reported quality of life. Ostomates were asked how long it took them to return to normal activities after surgery, how often they experienced leakage from their pouch system and to report their perceived quality of life on a scale from 1 (very poor) to 100 (excellent). Pearson's correlation coefficient shows a strong negative correlation between time to return to normal activities and quality of life ($\rho = -0.961$; $n = 1992$), and a strong negative correlation between leak frequency and quality of life ($\rho = -0.965$; $n = 1703$). Source: Eakin Healthcare

■ Impact of enhanced recovery after surgery (ERAS) on psychological outcomes.

Colwell et al (2019) stated that when a patient undergoes ostomy creation, a process of psychological adaptation begins; they suggested that, to facilitate that adjustment during the postoperative period, a secure pouching system seal must be selected and introduced to the patient.

Because of ERAS, there is no doubt stoma SCNs are increasingly under pressure to prepare patients physically for earlier discharge. However, in MM's opinion, specialist SCNs providing ongoing holistic assessment are crucial to fully support an individual's needs. This means psychological and psychosexual rehabilitation should be prioritised for every patient alongside issues such as stoma siting and practical stoma management.

Loss of control

Loss of confidence and a consequent fear of losing control over their activities of daily living and potential lifestyle are common in ostomates. In order for ostomates to psychologically process their emotions and return to psychosocial wellbeing, they must be able accept, adjust and adapt to life with a stoma (Brown, 2017).

Although stoma formation often represents a cure or recovery from a serious illness, surgery can still be experienced as a loss (Grant, 2019). Grief is a natural response to losing someone or something and, for many patients, particularly if surgery has been an emergency event, the loss of a normal bodily function may lead to a lack of emotional control. The object of mourning is not to 'get over' a loss but to allow a person to affirm their

own existence despite what has happened to them (Thompson and Neimeyer, 2014). SCNs should ask themselves if they have the skills and specialist training to recognise when a patient is struggling to accept their new normal. A lack of true acceptance will, ultimately, lead to feeling a significant loss of control.

It is not just a lack of acceptance that leads to ostomates perceiving a loss of control. Problems such as recurrent leaks in a pouching system can also contribute to the ostomate feeling a diminished sense of control over their bodily functions and their ability to lead a 'normal' life (Rutherford et al, 2020).

The early detection of such negative feelings is essential to minimise their impact on patients. In 1997, White and Hunt suggested that screening questionnaires could be used to good effect to identify psychological difficulties. They also noted that staff could undertake training to improve the detection of psychological morbidity, and endeavour to strengthen links with liaison mental health services.

This approach was recently examined by Koover et al (2023), who suggested that perioperative care may be enhanced by increased psychological evaluation to identify vulnerable individuals preoperatively. This would allow depressive symptoms to be detected in the postoperative period so that psychosocial adjustment can be optimised via psychotherapy. While these interventions represent a clear improvement in care in ostomates, in MM's clinical experience, this approach has not yet been adequately incorporated into routine clinical practice.

While early identification of psychological morbidity is essential, the root cause of the feelings should also be addressed

as a priority. This could involve simple steps such as providing the ostomate with products to prevent leakage and which are as discreet as is required for the individual's lifestyle. Having a secure, leak-proof pouching system will often be one of the most empowering interventions for an ostomate.

Promoting self-care and independence with stoma management brings acceptance. With acceptance comes power and control. SCNs should ideally be equipped to support each patient towards acceptance and, when this is not possible, direct them to an appropriate professional with the goal of providing the support that individual needs to gain back control.

Altered body image and reduced self-esteem

Body image is significantly disturbed by stoma formation. This shift in body image can have a major impact on an individual's self-esteem and self-satisfaction (Tripaldi, 2019).

Lim et al (2019) described how stoma patients experiencing altered body image can face difficulties in everyday life on physical, psychological and social levels. In western society, complex illogical 'rules' have developed for acceptable elimination behaviour (Norton and Chelvanayagam, 2005). Parents teach children these rules, so children associate wetting or soiling their clothes as a bad or negative behaviour. This means that when loss of control over elimination occurs through ill health, public humiliation is almost inevitable. This in turn represents a major threat to an individual's self-esteem. Humphreys (2017) also stresses that it is of great importance to discuss changes in body image and how the patient is feeling in order to help them to manage their altered body perception. This support may involve practical advice as well as psychological support. Offering practical solutions to patients in relation to intimate moments also gives them permission to discuss underlying fears and anxieties.

Fear and anxiety around public humiliation can lead ostomates to avoid circumstances where they might be at risk of a leak. This avoidance often significantly curtails aspects of their social, professional and intimate lives (Houston, 2017). This social isolation is itself linked with anxiety, depression and a loss of self-esteem (Grant, 2019). These negative effects can be mitigated against with interventions such as finding the best combination of products. Such products may be a well-fitting pouch or an accessory product such as a seal that can provide additional reassurance and confidence to that individual, allowing them to build their confidence. In addition to considering the fit and function of a product, efforts should be made to select a product that perhaps feels less like a medical device and more in keeping with the patient's lifestyle.

In addition to leak-preventing products to give reassurance, early psychological support can have a substantial positive effect on a patient's self-esteem. Nasiriziba et al (2020) found there is a significant positive correlation between total self-efficacy and its dimensions with self-esteem in patients with an intestinal stoma. Self-efficacy is described as the 'belief of the individual' in their ability to undertake and finish tasks. In patients with an intestinal stoma, higher self-efficacy is a predictor for fewer psychological problems in the early postoperative years (Nasiriziba et al, 2020). This study concluded that social self-efficacy had the greatest positive influence on self-esteem.

Therefore, educational and supportive interventions should be designed to improve patients' self-esteem and social interaction.

Altuntas et al (2012) and Karabulut et al (2014) examined interventions by health professionals in the form of group interaction and education for patients with an intestinal stoma. There was a significantly improved score in psychosocial health following the intervention, which had included sharing their feelings and experiences, and consequently discovering practical solutions to problems in their daily lives. These findings were recently supported by Kittscha et al (2023), who showed ostomates gained a number of significant benefits from attending peer support groups and proposed that nurse facilitation of these groups could be of further advantage to ostomates.

This again highlights the fundamental value of knowledge and education imparted by health professionals to empower people to accept responsibility, develop greater self-efficacy and regain autonomy.

Furthermore, nurses should not underestimate the value and power of mutual support. Mota et al (2015) discussed the importance of contact with people who are in similar situations and how this helps individuals realise they are not alone. Through mutual support, they seek encouragement, acquire knowledge about self-care, renew their hope, find group cohesion through altruism and universality, and gradually rediscover their social life.

While mutual social support can help ostomates, there may be many topics, such as intimacy, which they are unwilling to discuss in such a setting.

Fear of intimacy resulting in psychosexual issues

The practical care of the stoma is, for most people, learned while in hospital after the stoma-forming surgery. However, integrating the stoma into everyday life can take longer. As discussed, having a stoma at any stage of life and for any reason can affect body image and self-esteem. Both of these can, in turn, have a detrimental effect on intimacy (Burch, 2016). Expressing sexuality is more than just engaging in sexual intercourse. Ultimately, it is the human contact, comfort and security that people often use as a measure of self-worth and to provide cohesion in a relationship (Borwell, 1997).

As early as 1989, Bell identified three primary challenges nurses will face when promoting sexual wellbeing for patients. Initially, nurses must feel comfortable addressing such issues so they must examine feelings about their own sexuality. They must be knowledgeable in areas including anatomy, physiology, pathophysiology and psychosexual development and functioning. Finally, they must also be sensitive to patients' cultural and religious backgrounds, and the ethical implications of a patient's situation. Furthermore, Humphreys (2017) stated that, as sexuality is broadly a taboo subject, nurses often struggle to discuss it. This may simply be out of embarrassment or a lack of knowledge. However, not discussing sexual health with patients may be detrimental to their quality of life and make their adaptation to a stoma more difficult (Humphreys, 2017).

As health professionals, SCNs need to recognise if they have preconceived beliefs or if there are gaps in their ability to address psychological and psychosexual issues with their patients. In

MM's experience, attending psychosexual workshops with peers is conducive to gaining the confidence to approach this subject with patients. In a 2021 survey on sexuality and intimacy, 86% of ostomates ($n=31$) noted that they had never had a discussion about sex or intimacy with their SCN (Figure 2) (data on file at Eakin Healthcare, 2021). It is paramount that nurses develop the skills and confidence to discuss these sensitive issues. Perhaps SCNs need to look to education providers such as specialist health professionals (eg psychologists and psychotherapists), higher education providers and, perhaps, the ostomy industry to fulfil this need.

In addition to having more open discussions around intimacy, appropriate product selection can have a significant positive impact on patients' comfort with intimacy. Whether these products are more discreet so as not to be obvious during intimacy or provide greater protection or reassurance against leaks, finding the best products will make patients' lives better. Again, nurses should look to industry to continue developing more discreet, secure and appropriate appliances for use during intimate moments.

Impact of enhanced recovery and prehabilitation on psychological outcomes

Over the past decade, realisation has been growing that successful surgery is dependent not solely on the operation but also on how well the patient is able to return to a physically and psychologically healthy state (Scheede-Bergdahl, 2019). ERAS has been associated with a reduction in the risk of postoperative complications and shorter hospital stays without increasing readmission rates. While the postoperative focus of ERAS is on medical and physical intervention, there is also growing evidence supporting the introduction of robust prehabilitation to improve psychological wellbeing following surgery (Levett and Grimmett, 2019).

In this preoperative prehabilitation period, interventions around exercise, nutrition and anxiety reduction can complement ERAS and facilitate better psychological health and a more rapid return to baseline activities of daily living. While prehabilitation has been suggested as an effective intervention, the increasing workloads placed on stoma nurses often mean they have little to no time to undertake it. This means SCNs must focus on the practicalities of living with a stoma, with the result being that the emotional impact is often overlooked (Haughey, 2017).

Patients are bombarded with lots of information both before and after surgery and often struggle to process it all. Historically, SCNs met with the ostomate once or twice before surgery, with most patients remaining in hospital for 7–10 days, so there was adequate time to teach stoma care skills, promote independence and support patients through their psychological adjustment. ERAS has resulted in shorter hospital stays and, in MM's experience, the priority in hospital is to teach the practicalities of stoma care.

It is clear there is now a need to introduce novel means to support more intensive physical and psychological preparation both before admission and following discharge thus ensuring psychological recovery. Preoperatively, nurses should focus on

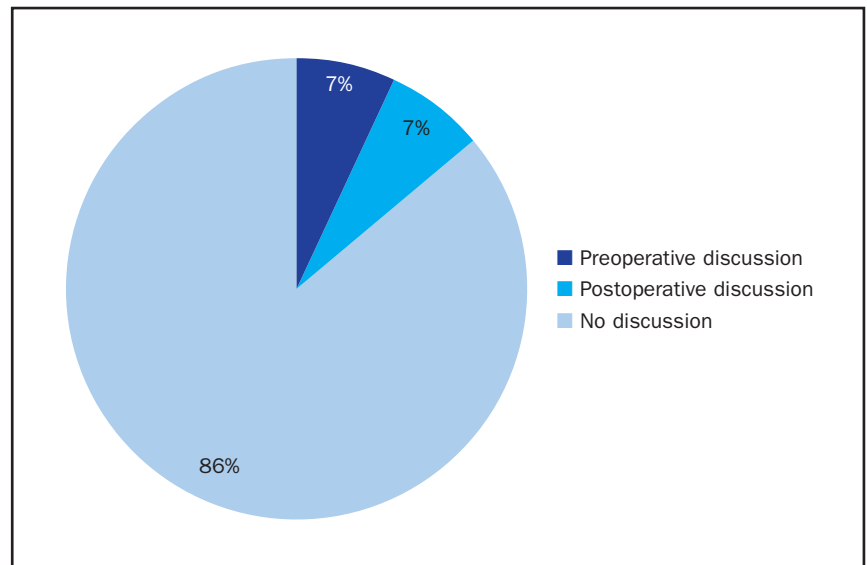


Figure 2. In a survey on sexuality and intimacy, 86% of ostomates reported that they never had a conversation about sex and intimacy with a stoma care nurse before or after their stoma forming surgery ($n=31$). Source: Eakin Healthcare

psychologically preparing patients for the upcoming procedure and identify patients who are at risk of poorer psychological outcomes where possible. Postoperatively, they should focus on supporting individuals in returning to a normal level of daily activity through exercise, stress reduction and ensuring a leak-free experience through the selection of appropriate products (Colwell et al, 2022).

Conclusion

There have been significant improvements in the quality and efficacy of products and services over the past 30 years. However, past and current studies have shown that negative psychological outcomes following stoma-forming surgery continue to be a considerable issue for many ostomates. Studies on the psychological impact of surgery consistently report many patients experience a loss of control leading to a grieving process, altered body image, reduced self-esteem and fear of intimacy. These factors often occur in tandem and can result in psychosexual issues for many patients.

SCNs want to be able to support each patient towards gaining a level of acceptance and to be equipped with the skills to address these potentially sensitive issues. To offer this level of support, SCNs need to identify preconceived beliefs and gaps in their ability to address these and be willing to acquire the skills through specialised training and education.

Current evidence indicates that supporting psychological and psychosexual rehabilitation is paramount to achieving overall positive patient outcomes and should be recognised as being as important as physical recovery. Whether this support is in the form of in-depth discussions of intimacy, encouraging open discussion around psychological struggles or simply by offering products that make ostomates feel more secure and confident, psychological and psychosexual support is invaluable.

Addressing the challenges discussed here will minimise their significant negative impact on adjusting to life with a stoma.

KEY POINTS

- While there has been huge progression in the quality and efficacy of products and services over the past 30 years, the psychological effects of stoma-forming surgery are an ongoing issue
- Self-reported quality of life is directly correlated with several factors, including how quickly an individual can return to normal daily activities and how often they experience leakage from their pouch system
- Supporting psychological and psychosexual rehabilitation is key to achieving positive patient outcomes and should be recognised as being as important as physical recovery
- Ensuring a leak-free experience for patients will support both physical and emotional recovery, fostering a sense of normalcy and wellbeing

Empowering patients will let them take back control of their lives and enable them move along on their journey from being merely a survivor to becoming a thriver. **BJN**

Declaration of interest: Both MM and CP are employees of Eakin Healthcare

Data sharing: data are available from the authors upon reasonable request

Funding: this study was carried out in the course of the authors' employment

Altuntas YE, Kement M, Gezen C et al. The role of group education on quality of life in patients with a stoma. *Eur J Cancer Care (Engl)*. 2012;21(6):776–781. <https://doi.org/10.1111/j.1365-2354.2012.01360.x>

Bell N. Sexuality. Promoting fulfillment. *Nurs Times*. 1989;85(6):35–37

Borwell B. Psychological considerations of stoma care nursing. *Nurs Stand*. 1997;11(48):49–53. <https://doi.org/10.7748/ns.11.48.49.s45>

Brown F. Psychosocial health following stoma formation: a literature review. *Gastrointestinal Nursing*. 2017;15(3):43–49. <https://doi.org/10.12968/gasn.2017.15.3.43>

Burch J. Intimacy for patients with a stoma. *Br J Nurs*. 2016;25(17):S26. <https://doi.org/10.12968/bjon.2016.25.17.S26>

Clark M, Chur-Hansen A, Mikocka-Walus A. Systematic review with meta-analysis: current and emerging models of preoperative psychological preparation for individuals undergoing stoma surgery. *J Psychosom Res*. 2023;168:111211. <https://doi.org/10.1016/j.jpsychores.2023.111211>

Colwell JC, Bain KA, Hansen AS, Droste W, Vendelbo G, James-Reid S. International consensus results: development of practice guidelines for assessment of peristomal body and stoma profiles, patient engagement, and patient follow-up. *J Wound Ostomy Continence Nurs*. 2019;46(6):497–504. <https://doi.org/10.1097/WON.0000000000000599>

Colwell JC, Stoia Davis J, Emodi K et al. Use of a convex pouching system in the postoperative period: a national consensus. *J Wound Ostomy Continence Nurs*. 2022;49(3):240–246. <https://doi.org/10.1016/j.WON.0000000000000874>

Grant M. Creative arts therapy in stoma care: workshops exploring grief, body

image and sexual intimacy. *Gastrointestinal Nursing*. 2019;17(2):24–29. <https://doi.org/10.12968/gasn.2019.17.2.24>

Haughey S, McGroggan G. Living well with a stoma: a descriptive evaluation. *Gastrointestinal Nursing*. 2017;15(7):41–48. <https://doi.org/10.12968/gasn.2017.15.7.41>

Houston N. Reflections on body image and abdominal stomas. *Journal of Stoma Therapy Australia*. 2017;37(3):8–12.

Humphreys N. Sexual health and sexuality in people with a stoma: a literature review. *Gastrointestinal Nursing*. 2017;15(10):18–26. <https://doi.org/10.12968/gasn.2017.15.10.18>

Ito N, Ishiguro M, Uno M et al. Prospective longitudinal evaluation of quality of life in patients with permanent colostomy after curative resection for rectal cancer: a preliminary study. *J Wound Ostomy Continence Nurs*. 2012;39(2):172–177. <https://doi.org/10.1097/WON.0b013e3182456177>

Jayarajah U, Samarasekera AM, Samarasekera DN. A study of postoperative anxiety and depression among patients with intestinal stomas. *Sri Lanka Journal of Surgery*. 2016;34(2):6–10. <https://doi.org/10.4038/slj.v34i2.8261>

Karabulut HK, Dinç L, Karadağ A. Effects of planned group interactions on the social adaptation of individuals with an intestinal stoma: a quantitative study. *J Clin Nurs*. 2014;23(19–20):2800–2813. <https://doi.org/10.1111/jocn.12541>

Kittscha J, Wilson V, Fairbrother G, Bliokas V. The role of peer support groups in adjustment to stoma: a qualitative study. *Collegian*. 2024;31(3):173–179. <https://doi.org/10.1016/j.colegn.2024.03.002>

Kovoor JG, Jacobsen JHW, Stretton B et al. Depression after stoma surgery: a systematic review and meta-analysis. *BMC Psychiatry*. 2023;23(1):352. <https://doi.org/10.1186/s12888-023-04871-0>

Levett DZH, Grimmett C. Psychological factors, prehabilitation and surgical outcomes: evidence and future directions. *Anaesthesia*. 2019;74 suppl 1:36–42. <https://doi.org/10.1111/anae.14507>

Lim SH, Chan SWC, Lai JH, He HG. A qualitative evaluation of the STOMA psychosocial intervention programme for colorectal cancer patients with stoma. *J Adv Nurs*. 2019;75(1):108–118. <https://doi.org/10.1111/jan.13821>

Mota MS, Von Schustuschnitz do Rios TR, Gomes GC, Barros EJJ, Oliveira Nörnberg PK, da Silveira Chagas MC. Stomized patients' perception of the stoma therapy service: a descriptive study. *Online Brazilian Journal of Nursing*. 2015;14(3). <https://doi.org/10.17665/1676-4285.20155085>

Nasiriziba F, Saati M, Haghani H. Correlation between self-efficacy and self-esteem in patients with an intestinal stoma. *Br J Nurs*. 2020;29(16):S22–S29. <https://doi.org/10.12968/bjon.2020.29.16.S22>

Norton C, Chelvanayagam S (eds). *Bowel continence nursing*. Beaconsfield Publishers, Beaconsfield; 2005. ISBN: 978-0906584521

Pittman J, Kozell K, Gray M. Should WOC nurses measure health-related quality of life in patients undergoing intestinal ostomy surgery? *J Wound Ostomy Continence Nurs*. 2009;36(3):254–265. <https://doi.org/10.1097/WON.0b013e3181a39347>

Rutherford C, Müller F, Faiz N, King MT, White K. Patient-reported outcomes and experiences from the perspective of colorectal cancer survivors: meta-synthesis of qualitative studies. *J Patient Rep Outcomes*. 2020;4(1):27. <https://doi.org/10.1186/s41687-020-00195-9>

Scheede-Bergdahl C, Minnella EM, Carli F. Multi-modal prehabilitation: addressing the why, when, what, how, who and where next? *Anaesthesia*. 2019;74 suppl 1:20–26. <https://doi.org/10.1111/anae.14505>

Thompson BE, Neimeyer RA. *Grief and the expressive arts: practices for creating the new York (NY): Routledge; 2014.* <https://doi.org/10.4324/9780203798447>

Tripathi C. Sexual function after stoma formation in women with colorectal cancer. *Br J Nurs*. 2019;28(16):S4–S15. <https://doi.org/10.12968/bjon.2019.28.16.S4>

White CA, Hunt JC. Psychological factors in postoperative adjustment to stoma surgery. *Ann R Coll Surg Engl*. 1997;79(1):3–7

CPD reflective questions

- Consider how increased psychological assessment in the perioperative period could help to identify more vulnerable patients so mental health support can be incorporated earlier
- Consider the impact of both pre- and postoperative exercise on the patient's holistic recovery
- Reflect on the value that peer support, both digital and in person, may offer to new ostomates and how this could be incorporated into practice
- Reflect on how educational and supportive interventions could enhance patients' confidence and boost self-esteem