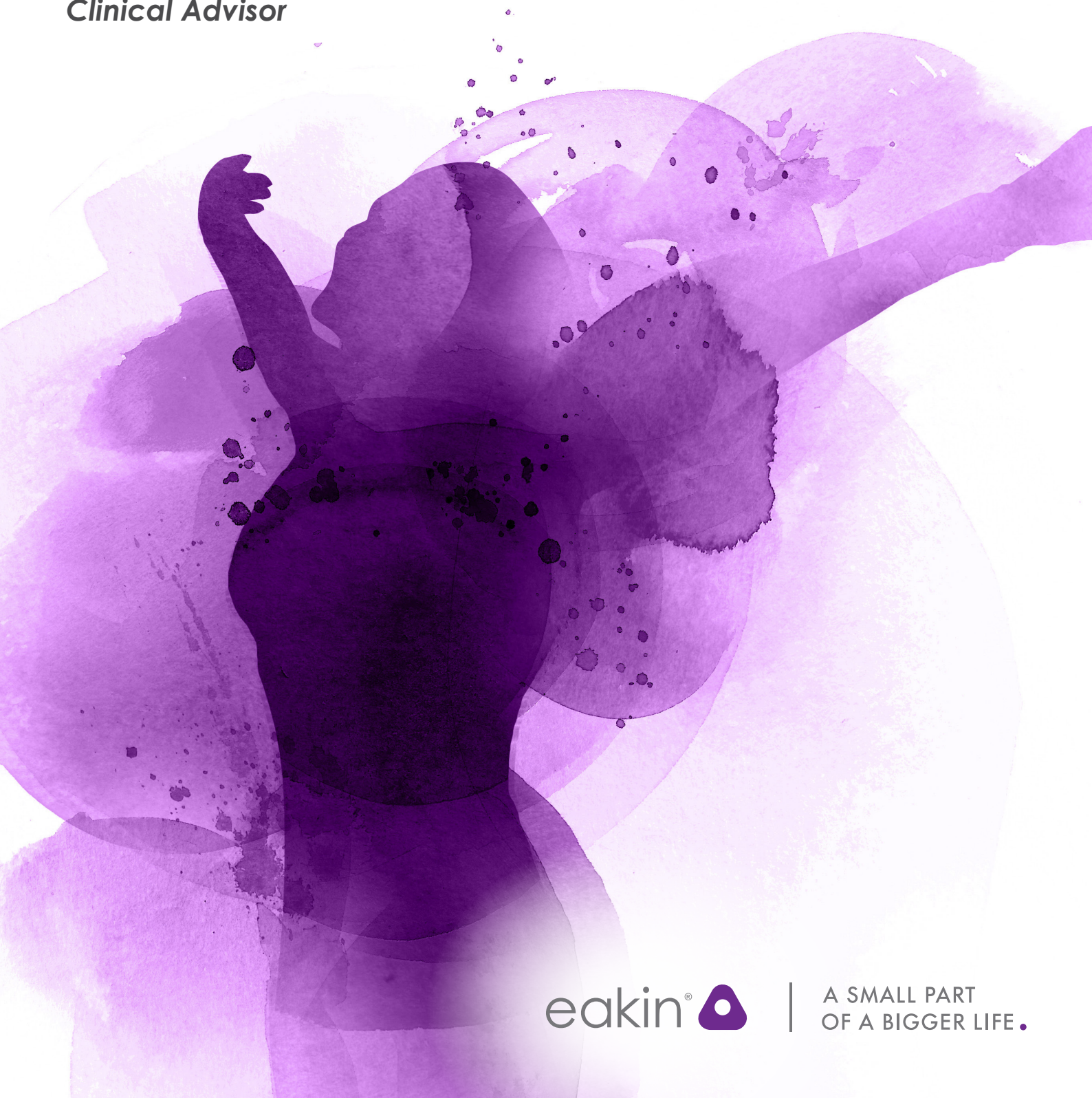


Survivor to **Thrivers**

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Introduction

The primary focus of this paper is to investigate the psychological impact of stoma forming surgery on patients and how it negatively affects mental health outcomes. By highlighting areas of challenge, this paper explores the prevalence and impact of each of these factors and the direct role that a stoma care nurse could play in helping address these challenges.

It is widely acknowledged that the psychological impact of a stoma cannot be underestimated, Pittman et al (2009). Haughey et al (2017) revealed **53% of patients in their study used mostly/all negative words to describe their life within the initial 12 months following surgery however noted that generally ostomates outlook is more positive as time progresses post-surgery**. This aspect of recovery has been examined by Ito et al (2012) who also reported a continued improvement in quality of life within the first year of surgery. However, in contrast to these findings Jayarajah et al (2016) estimated that between **16-26% of patients will experience negative psychological symptoms immediately following stoma creation and alarmingly, a year after surgery, the prevalence of negative symptoms isn't significantly reduced** Jayarajah et al (2016); Kyung et al (2014).

White et al (1997) highlighted that around **one-quarter of stoma patients experienced clinically significant psychological symptoms post-operatively however often these disorders are not detected by those involved in stoma care**. 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. Whites findings suggested that healthcare professionals (especially surgeons involved with this patient population) should cover these factors with all patients both before and after surgery.

Whilst there has been huge progression within the quality and efficacy of products and services over the last 30 years, it is abundantly clear that the psychological impact of stoma forming surgery continues to be an ongoing issue. It appears that progress within this key area is lacking and therefore it is paramount that we work together to tackle and solve these issues.



Psychological areas of concern

Studies on the negative psychological impact of surgery consistently highlight 3 main areas of concern for ostomates:

- **Loss of control leading to a grieving process**
- **Altered body image with reduced self-esteem**
- **Fear of intimacy resulting in psychosexual issues**

Within each of these areas are overarching themes that emerge regarding loss of confidence with subsequent fear of losing control over their activities of daily living and potential lifestyle. For people to psychologically process their emotions and resume psychosocial wellbeing, they have to be able to regain acceptance and adjust and adapt to life with a stoma, Brown (2017). The role of the specialist stoma care nurse is to provide ongoing holistic assessment and support as determined by the individual's needs.

Due to advanced recovery, there is no doubt stoma care nurses (SCNs) are increasingly under pressure to prepare patients physically for earlier discharges. However, it is the author's opinion that psychological/psychosexual rehabilitation should in the case of every patient be prioritized alongside areas such as siting stoma, and practical stoma management.

Loss of control leading to a grieving process

Although stoma formation often represents 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 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 as cited in Grant 2019).

The 5 stages of grief and loss are described as:

1. **Denial and isolation**
2. **Anger**
3. **Bargaining**
4. **Disclosure**
5. **Acceptance**

It is important to note that people do not necessarily go through the stages of grief in the same order or even experience all of them.

Promoting self-care and independence with stoma management brings acceptance.

However, as stoma care nurses we should ask ourselves if we have the skills and specialist training to recognise when a patient is struggling towards ultimate acceptance. White et al (1997) suggested questionnaires could be used to screen for difficulties and/or staff could undertake training aimed at improving the detection of psychological morbidity and endeavour to strengthen links with liaison mental health services. However, in the author's clinical experience 25 years on, it appears this approach has not been incorporated into routine clinical practice.

With acceptance comes power and control. As stoma care nurses we should ideally be equipped to support each patient towards a level of acceptance and when this is not possible direct them to the appropriate professional with the ultimate goal to provide the support required for ostomates to gain back control.

Altered body image with reduced self-esteem

Body image is significantly disturbed by stoma formation, affecting self-esteem and satisfaction with self, Tripaldi (2019). Self-esteem concerns the positive and negative feelings people have about themselves. In other words, it shows how valuable people consider themselves to be, Coopersmith (1990).

Lim, Siew Hoon et al (2019) describe how with distorted body image and the loss of essential body function, stoma patients 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 Chelvanayagom 2005 as cited in Williams 2012). Parents teach children these rules, so that children associate wetting or soiling their clothes as bad behaviour. These rules are instilled through life so that when loss of control over elimination occurs through ill-health, public humiliation is evident which in turn represents a major threat to self-esteem.

The fear of potential public humiliation can lead ostomates to avoid circumstances where they might be at risk of a leak, often significantly curtailing aspects of their social, professional, and intimate lives, Houston (2017). This social isolation is itself linked with anxiety, depression, and loss of self-esteem, Grant (2019).

Nasiriziba et al (2020) found there was a positive, significant 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 finish tasks. In patients with an intestinal stoma, higher self-efficacy is a predictor for fewer psychological problems in the early postoperative years. The study concluded that social self-efficacy had the greatest influence on self-esteem therefore, educational and supportive interventions should be designed to improve patients' self-esteem and social interaction.

Alternatively, Altuntas et al (2012) and Karabulut et al (2014) examined the intervention of health professionals in the form of group interaction and education with results revealing a significantly improved score in psychosocial health following intervention. This underlines the fundamental value of the knowledge and education imparted by health professionals to empower people to accept responsibility and regain autonomy.

In the author's opinion we should not underestimate the value and power of mutual support. Mota et al (2015) discuss the importance of contact with people who are in similar situations and how this helps the individuals realize 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.

Fear of intimacy resulting in psychosexual issues

The practical care of the stoma is, for most people, quickly learned while in hospital after the stoma forming surgery. Integrating the stoma into everyday life can take longer. Having a stoma at any stage of life or for any reason can affect people in several ways, and this can include body image, which in turn may affect intimacy, Burch (2016). Expressing sexuality is more than sexual intercourse. Ultimately it is the human contact, comfort, and security as a measure of self-worth providing cohesion in a relationship, Borwell (1997).

Bell 1989 as cited by Williams 2012 identifies three challenges for nurses when promoting sexual well-being for patients. Initially, nurses must feel comfortable in addressing such issues and therefore examine feelings about their own sexuality. They must be knowledgeable in areas including anatomy and physiology, pathophysiology and psychosexual development and functioning. They must also be sensitive to patients' cultural and religious backgrounds, and the ethical implications of a patient's situation.

Odey (2009) states as sexuality is broadly a taboo subject, nurses often struggle to discuss it, out of embarrassment or 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, Humphries (2017).

As Healthcare Professionals we need to recognize if there are pre-conceived ideas or gaps in our ability to address psychological and psychosexual issues with our patients.

In the author's experience attending psychosexual workshops with peers in the mid 1990's was conducive to gaining the confidence to approach this subject with patients. It is paramount that we develop the skills and confidence to discuss these sensitive issues and perhaps look towards Industry to provide much needed training and education within this specialized area.

Humphries (2017) also stresses it is of great importance to discuss changes in body image and how the patient is feeling to help them to manage their altered body, which may involve practical advice as well as psychological support. Simply offering practical solutions to patients in relation to intimate moments also gives them permission to discuss underlying fears and anxieties.

Again, we should look to Industry to continue developing more discreet and appropriate appliances for use during intimate moments.

Impact of Enhanced Recovery and Prehabilitation on Psychological Outcomes

Over the past decade, there has been a growing realisation that successful surgery is not dependent solely on the operation alone but, rather, on how well the patient is able to return to a physically and psychologically healthy state.

Enhanced Recovery After Surgery (ERAS) has been associated with a risk reduction in postoperative complications and shorter hospital stays without increasing re-admission rates.

There is also growing evidence supporting the introduction of prehabilitation whereby interventions such as exercise, nutrition and anxiety reduction, in the preoperative period, can complement the enhanced recovery programme and facilitate the return to baseline activities of daily living.

Interventions implemented before surgery, such as relaxation techniques (deep breathing, progressive muscle relaxation and meditation) or guided imagery, have been shown to have a positive effect on pain severity, fatigue and quality of life, Scheede-Bergdahl (2019).

However, as ERAS is now embedded into practice, stoma care nurses are increasingly under pressure to prepare patients for earlier discharges. The increasing workloads placed on stoma nurses often puts the focus on the practicalities of living with a stoma with the result being that the emotional impact is overlooked, Haughey (2017). Patients are bombarded with lots of information both pre- and post-operatively and often struggle to process it all. Historically stoma care nurses met with the ostomate 1-2 times prior to surgery with most patients remaining in hospital for 7-10 days thus ensuring adequate time to teach stoma care skills, promote independence and to support patients through their psychological adjustment. ERAS results in shorter length of hospital stays and therefore the priority focus will be teaching the practicalities of stoma care.

Evidently there is now a clear need to introduce novel means to support more intensive physical and psychological preparation before admission and following discharge therefore ensuring appropriate psychological recovery.

Conclusion

There has been huge progression with the quality and efficacy of products and services over the last 30 years, however past and current research reveals negative psychological impact following stoma forming surgery continues to be a considerable issue. 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 resulting in psychosexual issues for many patients.

Enhanced recovery is now embedded into clinical practice meaning stoma care nurses are under increasing pressure to prepare patients for earlier discharges therefore reducing time available to provide psychological support within the immediate post-operative period. There is now a clear need to introduce novel means to ensure more intensive physical and psychological preparation both before admission and following discharge.

As stoma care nurses we should be equipped to support each patient towards a level of acceptance and be equipped with the skills to address highly sensitive issues. To offer this level of support, we need to recognize if there are pre-conceived ideas or gaps in our ability to address these areas and be willing to acquire the skills through appropriate specialized training and education. Social self-efficacy has the greatest influence on self-esteem therefore, incorporating mutual support, educational, and supportive interventions should be integral within each patient's care plan.

Abundant evidence indicates that supporting psychological/ psychosexual rehabilitation is paramount in achieving overall positive patient outcomes and should be considered as crucial as patients physical recovery. Addressing these challenges will minimise the negative impact of adjusting to life with a stoma. Empowering patients will ultimately give greater control and enable them on their journey from survivor to thriver.

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