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Literature Review

Common factors affecting quality of life scores in patients with newly created stomas: A review of the literature

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Key Words: Stomas; quality of life; nursing interventions; evidence based care

Abstract

Introduction: Nurses have a key role in promoting and optimising the quality of life of patients adapting post-operatively to newly formed stomas. There are common factors negatively impacting on nursing care such as inconsistent Government strategy, poor evidence-based care informing organisations and inadequate resource allocation in localised care. Due to the number of patients living with stomas expected to rise to impact on service provision, this literature review aims to identify key factors nurses should be aware of when promoting health-related quality of life care post-operatively. Methodology: A search was conducted using CINAHL Ultimate and Medline to identify key factors affecting the quality of life of patients with newly formed stomas. n=66 papers were identified using search-specific criteria between 2014 and 2024. n=26 research studies were retrieved, and after inclusion and exclusion criteria were considered, n= 13 papers were critically appraised. Findings: Common factors identified were the importance of quality-of-life assessment tools used to assess health related quality of life, tackling peristomal skin issues (inflammation, injury or damage to surrounding), and a lack of available suitable facilities affecting privacy. Discussion: It is important to understand the difficulties ostomates face post-operatively and follow evidence-based guidelines irrespective of national pandemic emergencies. Conclusion: This paper highlights a significant research gap into the facilities available for people living with a stoma; and the evidence identifies negative factors impacting on quality-of-life scores for both male and female ostomates.

Introduction

In 2022 the World Health Organisation (2024) estimated there were 22 million new cancer cases, 9.7 million deaths, with 53.5 million alive after five years. This was predicted to increase to 35 million new cases of cancer

by 2050. Currently about 1 in 5 people develop cancer in their lifetime, with 1 in 9 men and 1 in 12 women being diagnosed (WHO, 2024). A key target for the NHS Long term plan (2019, sections 3.51-3.65) aimed for 75% of patients to be diagnosed with stage 1 or 2 cancers, faster diagnosis, treatment and higher rates of recovery, and the modernisation of bowel cancer screening (section 3.53, p. 58). The United Kingdom (UK) response in the Health and Social Care Act (2022, 2A) was for NHS England to "...include objectives relating to outcomes for cancer patients, and those objectives are to be treated by NHS England as having priority over any other objectives relating specifically to cancer." However, as we later discuss, this depended on Global events.

Colorectal cancer

Colorectal cancer is the third most common cancer worldwide, with 10% of all cancers and the second cause of death (WHO, 2023). Around one in every 500 people with stomas, called ostomates in the UK live with one form of ostomy and depending on the anatomical placement and underlying reasons for its formation, an ostomy may include ileostomies, colostomies and urostomies (Delon et al., 2022). Colorectal cancer ranked third in the list of cancers with 9.3% of deaths globally per year (900,000). Ferlay et al. (2022) on colorectal cancer in the UK report 10.9%, for both sexes with 49, 429 new cases (ranked 4th) in 2022 with a death rate of 12.6%, 22, 868 (ranked 2nd) and a 5-year prevalence of 243.4 per 100,000 (160, 578).

Defining an ostomy and a brief history

Derived from the Latin word 'ostium' meaning an 'opening' between the alimentary canal or urinary tract and body surface (Wilson, 2019), the history of ostomies or stomas (terms often used interchangeably) dates before the 1700's. Despite standard management of perforated

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intestines and surgery not being seen as life-saving, due to further imperilling a patient's life, wounds related to colorectal cancer were often closed up. In 1793 a surgeon successfully performed a colostomy on a 3-day old infant born with an imperforate anus to develop the first stoma, living to the age of 45 years (Wilson, 2019). Advances in anaesthesia and sterilisation in the mid-nineteenth century and decreased mortality, made surgery a viable option, but surgeons had continued difficulties with stoma positioning, fistula formation, leakage of the anastomosis and recurrence of malignancy (Wilson, 2019). In the early twentieth century, Dr Charles Mayo (1904) and Sir Ernest Miles (1908) developed the abdominal perineal resection, which included the removal of the recto-sigmoid canal, perirectal lymphatics, and the formation of a permanent colostomy with loop colostomies and mucosal surfaces exteriorised (Wilson, 2019). Further advances in the late twentieth century were surgical maturation, where the distal bowel is everted and sutured to the skin surface to expose the mucosal layer (Wilson, 2019). Later developments were the opening and maturation of the loop colostomy at the time of surgery, which remains the current standard of care (Wilson, 2019).

Health related quality of life

Bahayi et al. (2018) identified several physical and psychosocial issues affecting ostomates such as skin integrity, body image issues, and changes to the patient's quality of life (QoL) and adjusting to living with a stoma. Health-related quality of life (HRQoL) is a complex issue encompassing an individual's general well-being and is dependent upon subjective positive and negative health-related factors (Zhang et al., 2019). Despite progress made in the treatment of colorectal cancer there remains differences between high- and low-income regions but also within each country and this review of the literature aims to identify common themes affecting patients with newly created stomas to inform nurses and help improve the QoL of patients post-operatively. However, a global universal health screening survey on cancer care found that only 39% of participating countries financed core health services or offered the basics of cancer management (WHO, 2024). In addition, only 28% of the participating countries funded palliative care, including pain relief.

Search strategy

The purpose of the literature search aimed to identify issues affecting the QoL of patients with newly created stomas. A search was conducted utilising CINAHL Ultimate and Medline to find relevant papers. Filters used were peer reviewed, research articles, full text and between 2014 and 2024. The search terms were narrowed using the PICO tool (see table 1). An initial search was conducted to identify currently available bathroom facilities for ostomates. Using the search terms "Colostomy OR ileostomy OR stoma OR ostomy AND inpatient or

hospital or ward or unit" AND "quality of life or well-being or well-being or health-related quality of life," clicking limiters full text, in English, peer-reviewed, abstract available, research studies, yielded n=81 (see figure 1 entitled: Prisma flow diagram). Exclusions (see table 2) included research studies from Africa, Asia (n=14 Chinese excluded) and non-European studies (apart from Turkey), surgical interventions (such as parastomal herniation prevention) and clinical (such as irrigation) procedures (n=21) and systematic reviews (n=14). Research studies for newly created ostomies reduced the search findings to n=13 [Braumann et al., 2016; Claessens et al., 2015; Chrobak-Bie'n et al., 2023; da Silva Teles et al., 2022; Hubbard et al., 2017; Jansen et al., 2015; Momeni Pour et al., 2023; Pendergrast. (2020); Ratcliff et al., (2021); Rolls et al., 2023; van Zutphen et al., 2017; Vonk- Klaassen et al., (2016); Vural and Sütsünbüloğlu, 2021] (see Table 3 entitled: Table of findings). The key issues identified from the literature review are discussed next.

Table 1: PICO

Person	Intervention	Comparator	Outcome			
Patients with newly formed stomas	Improving bath- room facilities	Bathroom facilities available	Improve post-surgical quality of life			
Search terms identified						
Colostomy OR ileostomy OR urostomy OR stoma OR ostomate	Newly formed OR newly creat- ed ostomy	Hospital OR inpatient	Quality of life or wellbeing or well-being or health-related quality of life			

Identified themes

- 1. Quality of life assessment
- 2. Effective nursing interventions
- 3. Peristomal skin issues
- 4. Lack of available suitable facilities and privacy
- 5. Sub-theme: Covid 19

Quality of life assessment

Three out of the seven papers used a mixed methods approach to analysing data (Claessens et al., 2015; Hubbard et al., 2017; Jansen et al., 2015). This involves using qualitative and quantitative data to gain descriptive experiences alongside numerical data to analyse trends, evaluate correlation theories and generalise results (Mullen et al., 2022). Qualitative data employs open-ended questions for participants to describe feelings and experiences (Lin, 2020) and allows for a detailed, reflective experience to be gained lending insight into the current experience of newly formed stoma patients. On its own, quantitative data is limited in providing an "understanding" of experiences. In contrast, the cohort of Hubbard

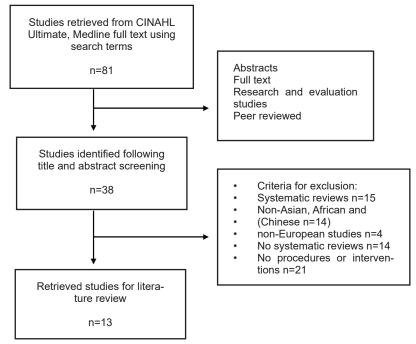


Figure 1: PRISMA flow diagram

Table 2: Inclusion criteria

Inclusion criteria	Exclusion criteria	
Papers published in English Published from 2010 Peer reviewed Qualitative and quantitative research studies Newly formed stomas Post operative Patients with stomas created within the previous 12 months (of the publish date) International research studies Adults Western countries (including Turkey)	 Papers not in English Tracheostomy patients Preoperative Systematic reviews Focus on paediatrics Temporary Community Surgical methods papers/ clinical procedures Papers published by stoma appliance companies Papers regarding adjustment to life/ post-surgical complications Psychological or spiritual focus Paediatrics Eastern countries, Asia and Africa 	

et al. (2017) had 61% males and to complement the qualitative data, included Likert scales allowed participants to rank statements based on how much the factor had affected their QoL. These were analysed using the ANOVA correlation test (compare the means of three or more groups to determine any statistical difference between them) to give an estimate of the overall impact of the stoma formation and its variability in aspects such as age, sex and social status (Hassan, 2024). Furthermore, Hubbard et al. (2017) findings correlate with other studies showing issues affecting stoma patients are not exclusive to a certain gender, age or ethnic group (Claessens et al., 2014; Vural et al., 2020).

Awareness of the psychological impact of ostomates newly formed stoma should ensure holistic nursing care and tailored interventions (Carter, 2020). One tailored intervention is a QoL assessment, which was found to be inconsistently used in clinical practice in two studies (Jansen et al., 2015; Vural and Sütsünbüloğlu, 2020). Developed in 1983 by researchers at the City of Hope

Quality of Life Ostomy (CoH-QoL-OQ) in Duarte, California, the questionnaire standardises assessment of social, psychological, physical and spiritual impact of surgery to ostomates (Grant et al., 2004; Konjevoda et al., 2020). When used in research, a major benefit is that the model helps to replicate the findings from previous studies, to ensure validity and reliability and gaining insight into the patient's QoL (Vural and Sütsünbüloğlu, 2020; Jansen et al., 2015).

Vural and Sütsünbüloğlu (2020) conducted their descriptive cross-sectional study using face to face and telephone interviews with n=115 patients recruited in a Turkish university hospital. Participants came from a variety of wards giving a broader picture of how a newly created stoma affected QoL. Vural and Sütsünbüloğlu (2020) evaluated the reliability of the questionnaire by correlating their results against previously reported questionnaire results. They found the re-test correlation was dependable and generalisable to other populations. Jansen et al. (2015) conducted their mixed meth-

Table 3: Table of retrieved papers n=13

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Author year	Study Aim	Participants	Methodology	Study findings	
Braumann et al. (2016) Germany	Which type of ostomy is advantageous for quality of life (QoL)	n= 2647 pa- tients	Observational study, evaluate QoL after colostomy and small bowel stoma formation	QoL differed significantly, but the effect size was marginal. Care of female) patients who receive emergency surgeries need improvement. More professional education and guidance are necessary for a larger proportion of patients	
Chrobak-Bie'n et al. (2023) Poland	To assess the QoL of patients 65+ with an intestinal stoma, created for treatment of severe colorectal disease	n=100 patients (n=52 women, n=48 men)	Collected demographic and medical information. Patients completed diagnostic surveys using the SF-36v2 questionnaire and authors questionnaire	QoL affected significantly by stress, demographics apart from gender stressors, acceptance related to marital status, place of living and education	
Claessens et al. (2015) Multi-national	To gain a better understanding of the challenges people living with a stoma face in their everyday lives	n= 4138 from n=11 countries (55% male 45% female)	Mixed methods Cross sectional online survey	Leakage causing peristomal skin complications has massive impact on Quality of life More resources should be allocated to ensure ostomates get necessary care and guidance from specialised nurses	
da Silva Teles et al. (2022) (low case d) Brazil	To evaluate the symptoms of anxiety, depression, and perceived stress in patients in the preoperative period of the first surgical procedure	n=57 patients, male (54%), with an average age of 63.3 years	Descriptive, cross-sectional, and prospective study	Elderly patients had higher depression and perceived stress scores Women had higher anxiety, depression, and perceived stress scores compared to men.	
Hubbard et al. (2017) UK	To improve quality of life by recognising patients' research priorities in stoma care	n=225 patients- (n=164 female n=59 male)	Mixed methods Online pilot survey using open and closed questions Thematic analysis	Stoma patients have specific concerns but this varies based on gender, underlying disease, and length of time the stoma has been in situ Findings highlighted potential issues to concentrate future research priorities on to improve quality of life such as lack of available facilities and more nursing interventions required	
Jansen et al. (2015) The Nether- lands	Compare QoL between cancer and non-cancer reasons for newly formed stomas	n= 668 patients n=379 cancer n=289 non-can- cer related. (n=361 male, n=307 female)	Mixed methods cross-sectional cohort study	Female patients reported lower quality of life in both groups Gas, odour, and noise top issues Highlighted the need for available bath- room facilities	
Momeni Pour et al. (2023) Iran	To investigate the effects of education based on the nursing process on ostomy self- care	n=52 elderly patients	Intervention group educated on the nursing process, and the control group received traditional training	Self-care knowledge increased in both groups, however significantly greater in the intervention group	
Pendergrast (2020) United States	Evaluate the effectiveness of a 20 day post discharge follow up programme	n=91 patients interviewed	Interviewed at home	Some patients refused home care due to the cost, educational level an issue, leaking pouches, negative QoL, nutrition goals, hydration, and access to ostomy supplies an issue	
Ratcliff et al. (2021) United States	To promote best practices for peristomal skin care	Panel of n=5 experts met to discuss the scoping review findings and reach consen- sus on best practice	Scoping literature review	Definition of peristomal skin care required, assessment of peristomal skin care using a validated tool, modifiable associated factors, non-modifiable factors (age, sex, ostomy type, time since surgery), pouching care education by specialist nurse, more research required on pouching care, social determinants of health impacted on peristomal care	
Rolls et al. (2023) UK/ Denmark/ Multi-national	Retrospective, self-reported ques- tionnaires for patients and stoma care nurses	n=6500 patients from 12 coun- tries participat- ed self-report concerned with pre and post operation expe- riences n=250 nurses from 15 coun- tries invited to participate, 45% female	98%planned stoma surgery had pre-operative consultations with health professionals in contrast to 36% of patients with unplanned surgery, who did not. 30% patients with unplanned surgery did not feel prepared for life with a stoma based on the information provided during their hospital stay. Two thirds of the nurses reported having sufficient time to prepare patients for stoma surgery and to life with a stoma	Stoma care nurses are key in preparing patients for surgery and for life with a stoma. Variations in care were experienced by patients having planned versus unplanned surgeries	

van Zutphen et al. (2017)	To study recovery of physical functioning after hospital discharge, before and after surgery	n=327 patients	Prospective observational study Use of questionaires	Patients who increased activity by at least 60 minutes per week were 43% more likely to recover physical function post colorectal surgery
Vonk- Klaassen et al. (2016) Multi-national	To examine patient related studies describing ostomy related problems and their impact on QoL	n=14 studies indicated a negative QoL impact for osto- my patients	PubMed (MEDLINE), CINAHL, Cochrane library and PsycINFO systematically searched	Ostomy related problems included sexual problems, depressive feelings, gas, constipation, dissatisfaction with appearance, change in clothing, travel difficulties, feeling tired and worried about noise
Vural and Sütsünbüloğlu (2021) Turkey	Aimed to evaluate quality of life for pa- tients with a recently formed stoma	n=115 patients (n=76 male n=39 female)	Descriptive cross-sectional study over 3 months from stoma formation	Quality of life adversely affected Lack of available clean facilities and too low toilets identified as significant issues for stoma patients. Peristomal skin complications major factor in Quality-of-life scores

ods, cross-sectional cohort study using n=668 patients recruited through the Dutch ostomy association. They asked each participant to complete a standard health-related quality-of-life questionnaire (RAND-36) and CoH-QoL-OQ. Jansen et al. (2015) then used linear regression analysis to compare health related QoL and ostomy related QoL to determine the degree of effect of having a stoma. This allowed the results to be generalised to a wider population. In agreement with the other papers (Claessens et al., 2015; Hubbard et al., 2017; Vural and Sütsünbüloğlu, 2020), their findings concluded ostomy patients reported lower QoL in all sections (social, psychological, physical, and spiritual) compared to non-ostomy patients. However, they were the only study to discuss the positive aspects of having a stoma, comparing cancer to non-cancer patients. They determined cancer patients reported a higher QoL, this could in part be due to the cancer being removed when the stoma was created and therefore prolonging life expectancy. They agreed ostomy QoL was lower than normal QoL, with women having lower overall QoL scores.

Other research studies used other QoL questionnaires. Claessens et al. (2015) in conjunction with 193 specialist nurses from 10 countries created an online questionnaire to establish the everyday challenges faced by people with ostomies. With n=4000 participants from 11 countries responding, there was a good cross-section of participants making the results generalisable, particularly to the NHS healthcare setting as nearly n=600 respondents were from the UK. The study had 55% male and 45% female participants which correlated to the general worldwide population (United Nations, 2023). The research was not based in a hospital setting, but peristomal skin issues and ballooning were very common and likely to occur within the early stages of stoma formation whether in an in-patient ward setting or at home. The study concluded more resources should be allocated to provide specialist stoma care and guidance pre and post-operatively to improve ostomates QoL and health outcomes.

Chrobak-Bie'n et al. (2023) used the authors' and the SF-36v2 questionnaire (NIH, 2000), a multipurpose, ge-

neric short form health survey, to measure health status rather than targeting a specific age, disease or treatment group (Ware Gandek, 1998). n=100 patients participated (n=52 male and n=48 women) and results identified support for patients begins in hospital with acceptance of the stoma, support from partners, family and friends, a return to work, adapting their social life and a changed body image (Chrobak-Bie'n et al., 2023). The authors found correlations between co-morbidities and dependence on environmental factors, QoL indicators, or an individual's perception of all aspects of everyday living post-surgery. These QoL indicators related to demographic factors such as age, marital status, place of living and education.

Effective nursing interventions

A theme identified in Hubbard et al. (2017), Jansen et al. (2015) and Vural and Sütsünbüloğlu (2020) was the need for effective nursing interventions to improve QoL. In the study by Rolls et al. (2023), extensive research (n=6500 patients from 12 countries and n=25 nurses from 15 countries), found the most unprepared patients were likely to have received emergency surgery. Nurse teaching and support for patients' positively improved self-worth, confidence, independence and QoL health outcomes. In particular, the clinical nurse specialist role in stoma care were significant in supporting ostomate self-care (Claessens et al., 2015) and promoting NICE (2020) guidance to inform, support patients and follow up to detect cancer recurrence and metastases. The specialist role ensured pre and post-surgical care included psychological and physical health assessments (Vural and Sütsünbüloğlu., 2020).

van Zutphen et al. (2017) studied the impact on mobilising after colorectal surgery and found patients post colorectal surgery who increased their activity levels to moderate, had a higher chance of recovering physical functioning. Therefore, encouraging patients to practice changing their own stomas whilst mobilising, reduced patients' length of hospital stay and assisted them in getting back to baseline mobility pre-surgery (van Zutphen et al., 2017). However, nurses being required to care for high numbers of patients, often with multiple co-morbidities and increasing dependence on care reduced the stand-

ards of care and availability of holistic, tailored teaching interventions (Haddad et al., 2023). Numerous studies highlighted the need for patients' mental well-being to be incorporated into nursing interventions to provide training and coping techniques (da Silva Teles et al., 2020).

Peristomal skin issues

Nurse education, support and empowerment improved QoL (Roya et al., 2023), correlates to reduced skin integrity issues, fewer hospital re-admissions and improved patient self-care (Pendergrast, 2020). Peristomal skin issues refers to inflammation, injury or irritation to the skin surrounding the stoma and affected up to 70% of patients (Michalak et al., 2023). Furthermore, self-confidence, general activities of daily living, sexual relationships and overall QoL were found to be affected (Hubbard et al, 2017; Vonk-Klaason et al, 2016). Skin complications negatively affected patients' QoL and their ability to return to their usual activities due to pain, discomfort, and embarrassment (Salvadalena, 2013). The causality of these issues could be attributed to several factors: lack of knowledge, having a poor skin seal, and not emptying the waste pouch enough, leading to excoriation and maceration of surrounding skin, alongside the risk of leakage and ballooning [an inflated bag due to stomach gases] (Pendergrast, 2020). However, good nurse education improved skin complications, reduced 30-day hospital re-admissions, and overall patient satisfaction (Coluso et al., 2020). Some patients were more prone to skin issues, in particular the elderly population who were less dextrous and had other health complications (Ratcliff et al., 2021). Overall, skin issues were still one of the main factors affecting QoL but with improved teaching interventions these were better managed (Isaac, 2017; Yeo and Park, 2022).

Lack of available suitable facilities and privacy

Jansen et al. (2015) and Vural and Sütsünbüloğlu (2020), identified the lack of suitable facilities limited stomah patients social interactions. Jansen et al. (2015) found providing a designated stoma changing area, patients could practice replacing their stoma bags within a hospital environment with nurses on hand to guide them. The study also found by providing a full-length mirror, at the correct height and a shelf for belongings, replicated a home environment and promoted confidence and competence when caring for their stoma and reducing the risk of skin related damage.

Stavropoulou et al. (2021) found the lack of privacy on an open ward when teaching stoma care, negatively affected patients with new stomas, particularly due to faecal smell. Providing a designated stoma area in a private place, such as a patient bathroom affords patients the privacy and dignity they deserve (Rolls et al., 2023). A further benefit of a designated stoma changing area allowed patients to ask questions, build confidence and learn in an area similar to their home. Vural and Sütsün-

büloğlu (2020) found patients were anxious to find a clean toilet and emphasised the importance of providing privacy to the patient, better replicated their home environment. Ultimately, this improved patient's self-efficacy regarding their newly created stoma and reduced the risk of skin related complications.

Suitable facilities that provided privacy had a number a benefits: decreasing stress levels, reducing the worry of odours and helping build self-esteem, often lacking in patients with newly formed stomas (Gautam Poudel, 2016). Yamaguchi et al. (2018) investigated two Japanese cities for the availability of ostomate-friendly facilities and found that hospitals and many public places had ostomy changing facilities which included a large wide sink, a shelf for supplies, and a hook for a changing bag. Yamaguchi et al. (2018) acknowledged there were a greater number of ostomate-accessible facilities in Japan compared to the rest of the world and a need for more research to be conducted in this area to improve facilities, both in hospitals and in public spaces.

Sub-theme: Covid 19 pandemic

Rolls et al. (2023) and Chrobak-Bie'n et al. (2023) collected QoL survey data from research participants in early 2022 until mid- 2022 during the Covid 19 pandemic, yet neither referred to the pandemic influencing QoL. From January 2020 until its end in May 2023 the Covid 19 pandemic led to delays of diagnosis and treatment and its impact on mortality is yet to be determined globally (Lofters et al., 2023). Cancer screening was largely discontinued worldwide with people on low incomes suffering the most disparities in health outcomes (Barclay et al., 2024; Olesen et al., 2023). In relation to colorectal cancer in the UK pre pandemic cases of n=6023 (January 2017 to February 2020), reduced to n=349 (March 2020 to June 2020) during the lockdown and n=2234 post lockdown (July 2020 to December 2021).

The National Bowel Cancer Audit (NBCOA, 2024) found that many key targets had not been met and 37% of hospitals in England and Wales failed to meet patient targets for meeting a clinical nurse specialist, and 39% of patients within 18 months not having their temporary stomas reversed after anterior resection. With 210,000 people per year screened in the UK before the Covid 19 pandemic, 45,000 patients started their treatments late and since screening returned, there were 380,000 fewer referrals than normal (Roberts, 2021). Not meeting these targets, and in some cases with worsening trends, reduced to 42% in 2021/22, was partially explained by longer surgical waiting lists post Covid 19 pandemic (NBCOA, 2024), and postponed cancer screening in general (e.g. 18,000 breast, 13,000 colorectal, 10,000 lung and 21,000 prostate cancers) were missed between March 2020 to December 2021). In short, the response to the pandemic delayed diagnosis, treatment efficacy and increased mortality of cancer patients (Barclay et al., 2024).

Discussion

The discussion highlights key themes from the retrieved studies impacting on QoL outcomes for ostomate patients; a need for effective nursing interventions, peristomal skin issues and a lack of privacy and adequate spaces for ostomates to care for their needs. Yet n=2 retrieved research studies within this period did not mention the effect of Covid 19 pandemic (e.g. Chrobak-Bie'n et al. 2023; Rolls et al., 2023) on QoL health outcomes for ostomates, which reinforced why the identified themes continue to be an issue within healthcare.

Irrespective of the countries where the research studies were from, education and training for nurses remains a key priority to improved patient health outcomes. Nursing skills and knowledge reinforced a need for evidence-based nursing interventions to inform best practice (Claessens et al., 2015). Nurses also needed to be mindful of person-centred care and patient health education, to promote optimal care and reduce further complications such as peristomal skin issues [e.g. parastomal herniation] (Pendergrast, 2020). The issue of patients mental health and well-being was discussed with limitations placed on nurses due to high workloads but the profound experience of receiving a cancer diagnosis, prognosis and stoma surgery was life changing and required extensive support from nurses if patients were to adapt, transition and accept their new body shape and stoma.

Conclusion

In conclusion, QoL for ostomates is a complex, multifaceted topic. Many factors were found to affect individuals with ostomies based on gender, health literacy, and personal experience. However, for overall QoL scores to be lower for ostomates indicated they encounted hurdles the public do not. Whilst academic research into specific facility adaptions for ostomates was limited, we can conclude from the available evidence of the effects of a newly created stoma and the life-limiting impact it had. The review of the literature emphasised the need for more research to be conducted in this area to improve facilities for patients with stomas to promote optimal person-centred care and QoL.

References

- Bahayi, K., Attaallah, W., Yardımcı, S., Bulut, H., Özten, E. (2018). Depression, anxiety, sexual dysfunction and quality of life in patients with ileostomy or colostomy. Turkish Journal of Colorectal Disease, (28), 2, https://doi.org/10.4274/tjcd.87369
- Barclay, N.L., Moncusi, M.P., Jödicke, A.M., Prieto-Alhambra, D., Ravento's B, Newby, D., Delmestri, A., Man, Y. W., Chen, X., Català, M. (2024). The impact of the UK COVID-19 lock-down on the screening, diagnostics and incidence of breast, colorectal, lung and prostate cancer in the UK: A population-based cohort study. Frontiers of Oncology. 14:1370862. https://doi.org/10.3389/fonc.2024.1370862

- Braumann, C., Müller, V., Knies M., Aufmesser, B., Schwenk, W., Koplin, G. (2016). Quality of life and need for care in patients with an ostomy: a survey of 2647 patients of the Berlin OStomy-Study (BOSS). Langenbecks Arch Surg. 401(8):1191-1201. https://doi.org/10.1007/s00423-016-1507-z
- Carter, P. (2020). Recognising the importance of stoma care nurse specialists. British Journal of Nursing, 29 (6), s6. https://doi.org/10.12968/bjon.2020.29.6.S4
- Chrobak-Bie ´n, J., Marciniak, A., Kozicka, I., Lakoma Kuiken, A., Włodarczyk, M., Sobolewska-Włodarczyk, A., Ignaczak, A., Borowiak, E. Quality of life in patients over age 65 after intestinal ostomy creation as treatment of large intestine disease. Int. J. Environ. Res. Public Health 2023, 20, 1749. https://doi.org/10.3390/ijerph20031749
- Claessens, I., Probert, R., Tielemans, C., Steen, A., Nilsson, C., Dissing Andersen, B., Størling, Z.M. (2015). The ostomy life study: The everyday challenges faced by people living with a stoma in a snapshot. Gastrointestinal Nursing, 13(5), 18-25. http://doi.org/10.12968/gasn.2015.13.5.18
- Coluso, K.A., Pattavana, F., Hung, A., Belardo, J., Cabato, C., Castro, P., Cho, D., Eziakonwa, C., Hanohano, J., Vance, J., Dickson, S., Modequillo, I., Abraham, L. (2020). Developing a nursing service model to improve patient access and outcomes 2020. Journal of Wound, Ostomy Continence Nursing, 47, https://search.ebscohost.com/login.aspx?direct=truedb=culAN=145177184site=ehost-live
- da Silva Teles, A.A.; Correa Júnior, A.J.S.; Aguiar, J.C.; Neves, W.F. dos S.; Paraizo-Horvath, C.M.S.; Russo, T.M. da S.; Dessotte, C.A.M.; Sonobe, H.M. (2022). Anxiety, depression and perceived stress in preoperative colorectal cancer patients: a cross-sectional study. Research, Society and Development, [S. I.], v. 11, n. 8, p. e3811830475, 2022. https://doi.org/10.33448/rsd-v11i8.30475
- Delon, C., Brown, K.F., Payne, N.W.S., Kotrotsios, Y., Vernon, S., Shelton, J. (2022). Differences in cancer incidence by broad ethnic group in England, 2013–2017. British Journal of Cancer, (126), 1765-1773. https://doi.org/10.1038/s41416-022-01718-5
- Gautam, S., Poudel, A. (2016). Effect of gender on psychosocial adjustment of colorectal cancer survivors with ostomy. Journal of Gastrointestinal Oncology, 7(6), https://jgo.amegroups.org/article/view/9375
- Grant, M., Ferrell, B.R., Dean, G., Uman, G., Chu, D., Krouse, R.S. (2004). Revision and psychometric testing of the city of hope quality of life ostomy questionnaire. Quality of Life Research, 13(8), 1445-1457. https://doi.org/10.1023/B:QURE.0000040784.65830.9f
- Haddad, L.M., Annamaraju, P., Toney-Butler, T.J. (2023). Nursing shortage. https://www.ncbi.nlm.nih.gov/books/ NBK493175/
- Hassan, M. (2024). ANOVA (Analysis of variance). Formulas, types, and examples. https://researchmethod.net/anova/
- Health and Social Care Act (2022). C.35. NHS England mandate: Cancer outcome targets https://www.legislation.gov.uk/ukpga/2022/31/section/5
- Hubbard, G., Taylor, C., Beeken, B., Campbell, A., Gracey, J., Grimmett, C., Fisher, A., Ozakinci, G., Slater, S., Gorely, T. (2017). Research priorities about stoma-related quality of life from the perspective of people with a stoma: A pilot survey. Health Expectations, 20(6), 1421-1427. https://doi.org/10.1111/hex.12585
- Ferlay, J., Ervik, M., Lam, F., Laversanne, M., Colombet, M., Mery, L., Piñeros, M., Znaor, A., Soerjomataram, I., Bray, F. (2024). Cancer tomorrow. International Agency for Research

- on Cancer. https://gco.iarc.fr/tomorrow/en/about
- International Agency for Research on Cancer. (2022). United Kingdom. Global cancer observatory. https://gco.iarc.who.int/media/globocan/factsheets/populations/826-united-king-dom-fact-sheet.pdf
- Isaac, D. (2017). Using videotaping on a smart device to reinforce ostomy education before discharge. Journal of Wound, Ostomy Continence Nursing, 44, https://doi.org/10.1097/WON.00000000000000331
- Jansen, F., Uden-Kraan, C., Braakman, J., Keizerswaard, P., Witte, B., Verdonck-de Leeuw, I. (2015). A mixed-method study on the generic and ostomy-specific quality of life of cancer and non-cancer ostomy patients. Supportive Care in Cancer, 23(6), 1689-1697. https://doi.org/10.1007/s00520-014-2528-1
- Konjevoda, V., Zelić, M., Munjas Samarin, R., Petek, D. (2020). City of hope quality of life-ostomy questionnaire validity and reliability assessment on a Croatian sample. International Journal of Environmental Research and Public Health, 17(3), 768. https://doi.org/10.3390/ijerph17030768
- Lofters, A.K., Wu, F., Frymire, E., Kiran, T., Vahabi, M., Green, M.E., Glazier, R.H. (2023). Cancer Screening Disparities Before and After the COVID-19 Pandemic. JAMA Network Open. 2023;6(11):e2343796. https://doi.org/10.1001/jama-networkopen.2023.43796
- Michalak, J., Spitler, C., Simman, R., Sharp, K., Pei, M. (2023). Stomal and peristomal complications management: A retrospective study. Journal of Wound Care; 32(1), 35-42. https://doi.org/10.12968/jowc.2023.32.1.35
- Momeni Pour R., Darvishpour A., Mansour-Ghanaei R., Kazemnezhad Leyli E. (2023). The effects of education based on the nursing process on ostomy self-care knowledge and performance of elderly patients with surgical stoma. Nursing Research Practice.; 2023:2800796. https://doi.org/10.1155/2023/2800796
- Mullen, R.F., Fleming, A., McMillan, L., Kydd, A. (2022). Methodology: Quantitative aspects of data analysis in a study of student nurse perceptions of dignity in care. SAGE Publications, Ltd.
- National Institutes of Health (2000). Quality of life questionnaire (SF- 36v2 TM Health Survey, form 38). Copyright Holder Quality Metric Incorporated, LLC., an IQVIA business. https://repository.niddk.nih.gov/media/studies/halt_pkd_a/Forms/F038%20Quality%20of%20Life.pdf
- National Institute for Health and Clinical Excellence (2020). Colorectal cancer: Guidance. NG151. https://www.nice.org.uk/guidance/ng151/chapter/recommendations#ongoing-care-and-support.
- National Health Service Act (2006). Chapter 41. F161(2A), p.41. https://www.legislation.gov.uk/ukpga/2006/41/data.pdf
- National Health Service (2019.) Long term plan. 3.51-3.65. https://www.longtermplan.nhs.uk/wp-content/up-loads/2019/08/nhs-long-term-plan-version-1.2.pdf
- National Health Service Digital. (2021). Hospital admitted patient care activity 2020-21. https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity/2020-21#
- National Bowel Cancer Audit (2024). Quarterly report: Data quality (England), Oct.2024. NBCOA. https://www.nboca.org.uk/reports/quarterly-report-data-quality-england-oct-2024/
- Olesen, T.B., Jensen, H., Møller, H., Jensen, J.W., Andersen, B., Rasmussen, M. (2023). Nationwide participation in FIT-based colorectal cancer screening in Denmark during the COVID-19 pandemic: An observational study. Elife. 25;12:e81808. http://doi.org/10.7554/eLife.81808.

- Pendergrast, R. A. (2020). Patient and family centred ostomy care: An evaluation of patients who utilize the teaching and resources of the enhanced recovery after surgery program (ERAS). Journal of Wound, Ostomy & Continence nursing, 47, https://www.gapna.org/sites/default/files/documents/conference/2021-pharma/poster-presentations/18_Pendergrast.pdf
- Roberts, K. (2021). One year on: How has Covid-19 affected cancer services? Cancer Research UK. https://news.cancerresearchuk.org/2021/05/14/one-year-on-how-has-covid-19-affected-cancer-services/
- Rolls, N., Gotfredsen, J.L., Vestergaard, M., Hansen, A.S., Koblauch, H. (2023). Importance of stoma care nurses in preparing patients for stoma surgeryand adjustment to life with a stoma. British Journal of Nursing, 32, (16), s32-s41. https://www.britishjournalofnursing.com/content/stoma-leakage/importance-of-stoma-care-nurses-in-preparing-patients-for-stoma-surgery-and-adjustment-to-life-with-a-stoma/
- Roya, M.P., Darvishpour, A., Mansour-Ghanaei, R., Leyli, E.K. (2023). The effects of education based on the nursing process on ostomy self-care knowledge and performance of elderly patients with surgical stoma. Nursing Research and Practice. 2023, 1-8. https://doi.org/10.1155/2023/2800796.
- Salvadalena, G.D. (2013). The incidence of stoma and peristomal complications during the first 3 months after ostomy creation. Journal of Wound, Ostomy Continence Nursing, 40(4), 400-406. https://doi.org/10.1097/WON.0b013e318295a12b
- Stavropoulou, A., Vlamakis, D., Kaba, E., Kalemikerakis, I., Polikandrioti, M., Fasoi, G., Vasilopoulos, G., Kelesi, M. (2021). Living with a stoma: Exploring the lived experience of patients with permanent colostomy. International Journal of Environmental Research and Public Health, 18(16), 8612. https://doi.org/10.3390/ijerph18168512
- United Nations. (2023). Population. https://www.un.org/en/global-issues/population
- van Zutphen, M., Winkels, R.M., van Duijnhoven, F.J.B., van Harten-Gerritsen, S.A., Kok, D.E.G., van Duijvendijk, P., van Halteren, H.K., Hansson, B.M.E., Kruyt, F.M., Bilgen, E.J.S., de Wilt, J.H.W., Dronkers, J.J., Kampman, E. (2017). An increase in physical activity after colorectal cancer surgery is associated with improved recovery of physical functioning: A prospective cohort study. BMC Cancer, 17, 1-9. https://doi.org/10.1186/s12885-017-3066-2
- Vonk-Klaassen, S.M., de Vocht, HM., den Ouden, ME., Eddes, E.H, Schuurmans, M.J. (2016). Ostomy-related problems and their impact on quality of life of colorectal cancer ostomates: a systematic review. Quality of Life Research. 25(1):125-33. https://doi.org/10.1007/s11136-015-1050-3
- Vural, F., Sütsünbüloğlu, E. (2021). Quality of life of patients with a stoma: A descriptive study. Turkish Journal of Colorectal Disease, 31(3), 246-251. https://doi.org/10.4274/tjcd.galenos.2020.2020-7-11
- Ware, J.E., Gandek, B. (1998). Overview of the SF-36 health survey and the international quality of life assessment (IQO-LA) project. Journal of Clinical Epidemiology, 51, (11). 903-912. https://doi.org/10.1016/S0895-4356(98)00081-X
- Wilson, F. (2019). History of ostomy and urinary diversions. Urologic Nursing, 39(5), 242-248. https://doi.org/10.7257/1053-816X.2019.39.5.242.
- World Health Organisation. (2023). Colorectal cancer: Key facts. https://www.who.int/news-room/fact-sheets/detail/

colorectal-cancer

- World Health Organisation. (2024). Global cancer burden growing, amidst mounting need for services. https://www.who. int/news/item/01-02-2024-global-cancer-burden-growing-amidst-mounting-need-for-services
- Yamaguchi, Y., Nishino, E., Abe, K., Sugawara, Y., Onozato, T., Muhamad, N., Rozali, N. (2018). Explore Ostomate-Compatible Toilets. Juntendo Medical Journal. 64. 223-226. https:// doi.org/10.14789/jmj.2018.64.JMJ18-CR01
- Yeo, H., Park, H. (2022). Benefits of providing a single session, in-hospital pre-operative education program in patients undergoing ostomy: A randomised control trial. World Council of Enterostomal Therapists Journal, 42(3), https:// search.ebscohost.com/login.aspx?direct=truedb=cu-IAN=159187646site=ehost-live
- Zhang, Y., Xian, H., Yang, Y., Zhang, X., Wang, X. (2019). Relationship between psychosocial adaptation and health-related quality of life of patients with stoma: A descriptive, cross-sectional study. Journal of Clinical Nursing, 28(15-16), 2880-2888. https://doi.org/10.1111/jocn.14876

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