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RESEARCH ARTICLE

Living with and without an intestinal stoma: Factors that promote psychological well-being and self-care: A cross-sectional study

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Abstract

Aims: This study compared those living with and without an intestinal stoma in relation to physical and psychological health, stress and coping, quality of life and resilience. Also, identifying factors that could be used to promote better self-care in stoma patients in the future.

Design: A cross-sectional and comparative study design was employed.

Methods: Participants were recruited via email and social media (Facebook and Twitter) between August 2018 and March 2019, to complete an online survey. The data were analysed using analysis of variance to examine group difference and a series of hierarchical linear regression analyses determining predictors of psychological well-being.

Results: Of 278 participants aged 18–68 years who completed the survey, 129 (46%) had a stoma and reported significantly poorer physical health. Approximately one-fifth experienced problems with stoma management. Psychological well-being was mediated by the duration of living with a stoma (under 3 years) and frequency of leaks (weekly and monthly).

KEYWORDS
nursing, psychiatric morbidity, psychological well-being, quality of life, resilience, self-care, stoma, stress and coping

1 | INTRODUCTION

The prevalence of those living with a stoma in the UK is subject to some debate, with rates ranging from 1 in 500 (Colostomy UK, 2019; Temprado et al., 2019) to 1 in 385, or as high as 1 in 341 (Kettle, 2019). Creation of a stoma is an invasive surgical procedure that leads to changes in appearance, functioning and sensation (Thorpe et al., 2016). Intestinal stoma, the most common of which are ileostomy or colostomy, functions to divert faecal flow through a surgically created opening in the abdominal wall (Pine et al., 2020) and can be temporary or permanent depending upon the pathology (Pine et al., 2020). Stoma are necessary to alleviate symptoms of chronic illness, or to prolong life, often as a consequence of inflammatory bowel disease or gastrointestinal cancer (Spiers et al., 2017). The creation of an intestinal stoma results in loss of control over the elimination of bowel content with the latter collected in a disposable pouch which is adhered to the abdomen via an adhesive wafer. Changes in the mode through which faeces and gases are evacuated from the intestine can be challenging, leading to alterations to the digestive system that may impact on nutrient malabsorption, dehydration, high gastrointestinal output, dermatitis and malnutrition (Mathis et al., 2013; Michońska et al., 2023). This can be complicated further by the presence of odour, leakage of secretions from the adhesive collecting pouch and damage to the integrity of the peristomal skin (Perrotta & Guerrieri, 2022). Research in the UK or Ireland looking at the psychosocial impact of intestinal stoma is sparse (Silva et al., 2017); the current study addresses this gap.

2 | BACKGROUND

Learning to live with a stoma necessitates adjustment, acceptance of the condition, coupled with good self-care and coping strategies to maintain health and well-being (Mathis et al., 2013; Vonk-Klaassen et al., 2016). Daily management of a stoma requires time with some patients experiencing difficulties with leaks and sore skin for several years following surgery (Haughey & McGroggan, 2017; NHS, 2014; Silva et al., 2017). Indrebø et al. (2023) identified poor knowledge and skills needed to manage a stoma, reliance on others and poor relationship with medical staff as predictors of stoma leaks. This has the potential to impact upon their quality of life (QoL) (Diniz et al., 2023), leading to psychological difficulties for around 20% of patients (Ludvigsson et al., 2021; Stoma Care High Impact Steering Group, 2010), such as increased depression symptoms reported in 50% within one cohort of patients (Kovoor et al., 2023). Stoma leaks, smell, peristomal skin irritation, stoma location, depression and problems finding clothes to hide the bag (Goldstine et al., 2019; Indrebø et al., 2023; Ketterer et al., 2021; Liao & Qin, 2014) are associated with poorer QoL in some stoma patients (Perrotta & Guerrieri, 2022). These may act as stressors that contribute to a decline in psychological well-being and QoL (Bird, 2019; Gooszen et al., 2000; Mahjoubi et al., 2010). However, a decline in QoL with stoma is not observed in all studies (Dossa et al., 2018; Pachler & Wille-Jørgensen, 2012), as for some it represents a better QoL and a return to normality and freedom from toilet restraints (Diniz et al., 2021). Better QoL poststoma was associated with being able continue to wear everyday clothes, being sexually active and being older (Ketterer et al., 2021) and having higher emotional intelligence and higher self-esteem (Saati et al., 2021). Resilience, or the ability to deal effectively with stressful situations, can help to maintain psychological well-being and may explain why some people adapt more effectively to intestinal stoma that others (Bonanno et al., 2008). Some research suggests greater resilience is a predictor of better quality of life in stoma patients (Temprado Albalat et al., 2018) and better mental health in patients with advanced colorectal cancer (Jiang et al., 2023). Stoma creation is also associated with changes in body image and identity, reduced autonomy, decreased social interactions, sexual dysfunction and decline in self-esteem (Kenderian et al., 2014; Nicholas et al., 2008; Thorpe & McArthur, 2017), all potential sources of stress and impacting on psychological well-being and QoL (Alenezi et al., 2023). There is a need to establish the psychosocial health needs of those living with stoma to inform policy and care pathways.

Previous psychological research has relied on cross-sectional survey designs (see Silva et al., 2017 for an iterative review) or qualitative studies focusing on experience of individuals with different types of intestinal stoma, (e.g. Thorpe & McArthur, 2017), biographical narratives (e.g. Polidano et al., 2020) and the lived experience assessed by Interpretative Phenomenological Approach (IPA) (Horgan et al., 2020; Jordan et al., 2018). Reducing psychological distress is part of the UK healthcare policy for stoma patients (Department of Health, 2011) and remains a challenge due to a lack of understanding of psychological health needs (Bianchi et al., 2022; Wallace, 2016), which was addressed in the current study.

3 | THE STUDY

3.1 | Aims and objectives

This study focused on community-based participants with and without self-reported stoma and looked at differences between these two groups on aspects of physical and mental health. There were three main objectives. Firstly, the study determined the differences in stoma/non-stoma adults in relation to their physical and psychological health, stress and coping, QoL and resilience. The second objective was to determine the differences in stoma participants with and without leaks in relation to physical and psychological health, stress and coping, QoL and resilience. The third object was to identify factors, such as coping styles that could be targeted, via stress management techniques, to improve psychological well-being (Reese et al., 2017) and more effective routes to intervention. Fourthly, it determined any changes that may be necessary in intestinal stoma patients pre/postsurgery care, to enhance the current person-centred approach, which is central to the care needs of such patients (McCormack et al., 2011).

4 | METHODS

4.1 | Design

A cross-sectional and comparative design was employed to compare a community sample of adults with a self-reported stoma, taking into consideration the length of time they had their stoma. Stoma leaks have the potential to impact on quality of life and general well-being, if they are not easily managed, this will impact significantly on everyday life. We wanted to establish the extend of leaks experienced in this sample and the severity of these, by looking at their frequency and to determine their impact on health and well-being. They were compared to a group of adults who did not have a stoma. The outcome variables were symptoms of psychiatric morbidity, psychological well-being, stress and coping, QoL, resilience and general health, all assessed using well-validated instruments.

4.2 | Instrument with validity and reliability

The survey was designed and presented on Qualtrics (Qualtrics, Provo, UT), a web-based survey tool, via a link included within an invitation email for the study. This link included the consent form and participant information sheet, the former having to be completed prior to the questions assessing a range of variables outlined below.

Socio-demographic variables of age, sex, education, marital status and parity were measured with questions specifically designed by the researchers for the purpose of this study and were based on previous lifestyle research questionnaires looking at healthy ageing (Simpson et al., 2005).

History of stoma was assessed by a series of open and closed questions to give a brief overview of duration and management of the condition. Participants were asked about their current stoma management system (one or two pieces), how often the bag was replaced, and the frequency and impact of leaks. Health needs were assessed by a series of open-ended questions to determine what other support and help this group require. These questions were designed by a panel of experts from within the research team and were representative of academics, clinicians and experts by experience, working in the area of stoma. This ensured that the questions were appropriate and fit for purpose for the current study.

The remaining parts of the survey were comprised of validated questionnaires described below.

Psychiatric morbidity was assessed using the 12-item General Health Questionnaire (GHQ - 12) (Goldberg, 1972), a measure for mental health problems, referred to as psychiatric morbidity, with proven internal reliability, with a Cronbach's alpha of 0.90 (King et al., 2023) and validity (McCabe et al., 1996), as it is highly correlated to similar measures (Hardy et al., 1999). The questions were answered on a 4-point Likert scale ranging from 0 to 3 and adjusting for positive and negative items, with an overall score ranging from 0–36, with higher scores indicative of poorer mental health. This scale is a screening measure for non-psychotic mental health problems associated with anxiety/depression, social dysfunction and confidence (Graetz, 1991).

Positive psychological well-being was assessed using the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) (Tennant et al., 2007), which is a 14-item scale assessing positive mental health with proven reliability (Cronbach's alpha = 0.91) and construct validity (Stewart-Brown et al., 2011). It employs a 5-point Likert scale, ranging from 1 = "none of the time" to 5 = "all of the time," the items are summed to get an overall score that can range from 14–70, with higher scores indicating better positive well-being.

A global measure of stress, the 14-item Perceived Stress Scale (PSS) (Cohen et al., 1983), was used. The questions are answered on a 5-point Likert scale ranging from 0 = "never" to 4 = "very often." The overall stress score is derived from the sum of the item scores, after reverse coding (items 4, 5, 6, 7, 9, 10, and 13), with higher scores indicating a greater level of stress. It has proven reliability, with a Cronbach's alpha of 0.84 and had good predictive validity (Cohen et al., 1983), confirmed in a review by Lee (2012).

The Brief COPE (Carver, 1997) is a measure of 14 coping styles designed to provide a quick measure of coping. It contains 28 items, with two items per scale, and participants must rate their answer to the items on a 4-point Likert scale ranging from 1 "I do not do this at all" to 4 "I do this a lot." All participants were asked not to think about a particularly stressful situation but rather to indicate generally how they cope with stressful situations. There is evidence of reliability and validity for this measure in adult samples, with Cronbach's alpha reliabilities ranged from 0.50 to 0.90 (Greenhouse et al., 2000). The subscales can be combined to give a measure of emotion-focused coping (acceptance, emotional support, humour, positive reframing and religion: Cronbach's alpha = 0.72), problem-focused coping (active coping, instrumental support and planning: Cronbach's alpha = 0.84) and dysfunctional coping (behavioural disengagement, denial, self-distraction, self-blame, substance use and venting: Cronbach's alpha = 0.75) (DeDios-Stern et al., 2017), used in the current study as they are thought to be more useful in clinical research when identifying health needs for change (Cooper et al., 2008). More recently, evidence supporting the 14-factor structure of the Brief Cope was provided from a review and modelling analysis of the scale (Rodrigues et al., 2022).

QoL was assessed by The World Health Organization Quality of Life (WHOQOL-BREF) questionnaire, which contains 26 items comprising four domains, physical health (Cronbach's alpha 0.82), psychological health (Cronbach's alpha 0.81), social relationships (Cronbach's alpha 0.68) and environment (Cronbach's alpha 0.80), a score can be calculated for each domain, which was the case in the current study when looking at group differences. An overall mean provides a general indication of QoL, each domain loads strongly onto one factor of general QoL (Skevington et al., 2004). This is supported by further studies looking at Cronbach's alpha of 0.92 for the overall scale (Gholami et al., 2013), with higher scores indicating better QoL, this score will be used to predict this in the regression analysis. Data from 23 countries showed good internal consistency reliability (Cronbach's alpha was 0.87) and construct and discriminant validity for the scale (Skevington et al., 2004).

Resilience was assessed using the 25-item Connor-Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003) which is a 25-item scale which taps into five domains personal competence, trust in one's own instincts, positive acceptance of change, control and spiritual influences. The answers employ a 5-point Likert scale, ranging from 0 = "Not true at all" to 4 = "True nearly all of the time" and the questionnaire scores range from 0–100, with higher scores indicating greater resilience. It has proven reliability (Cronbach's alpha is 0.89) and construct validity (Connor & Davidson, 2003; Windle et al., 2011).

4.3 | Sampling and recruitment

Stoma participants were recruited through online forums and support organizations for stoma care (i.e. Ileostomy & Internal Pouch Association NI & UK) and via social media (i.e. Facebook, Twitter). The non-stoma participants were recruited via social media (i.e. Facebook, Twitter) and by a global email sent to all staff and all students within Ulster University. The recruitment invitation to the study provided a link to the online survey, which included the participant information sheet and a consent form, completed prior to beginning the survey. Data were collected between August 2018 and March 2019.

The inclusion criteria for both groups were community-based adults aged 18–69 years and all genders. The stoma group had to self-report an intestinal stoma (ileostomy or colostomy). Participants were excluded if they were under the age of 18 years, as the study focused on adults only, to include younger participants would have required additional Research Ethics Committee approval. People over the age of 70 were excluded due to the increased risk of co-morbidities that may impact on daily functioning and confounded predictors of well-being.

4.4 | Sample size and power

Two power calculations were carried out to estimate sample size based on group comparisons and regression analyses. The power calculations were carried out using G*Power (Faul et al., 2007), for each power calculation, a medium effect size of 0.5, with a 80% power and $p < 0.05$ was adopted, and based on medium effect sizes reported for well-being previously (Nicholls et al., 2016). The group comparisons sample size was based on a two-way ANOVA, with post hoc tests, to determine between-group differences (6 groups) and resulted in a total sample size of 216. The power calculation for the hierarchical linear regression analyses was based on nine predictors, to test for change in the R^2 for each step of the model, controlling for variables in the previous step, and to determine the predictors of the dependent variable in the final step of the model, the recommended total sample size was 114.

4.5 | Data analyses

Data were downloaded from Qualtrics (Qualtrics, Provo, UT) into Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp., 2017) and were checked for missing values, prior to scoring the questionnaires ($N = 290$); only those questionnaires with complete data were analysed ($N = 278$). Normality checks were performed on the data prior to analyses, skewness (+2 to −2) and kurtosis (<10) were within an acceptable range for all the variables (Kline, 2010). One-way ANOVA was conducted to establish differences for frequency of leaks (weekly, monthly, and infrequent) and duration of stoma (<1 year, 1–3 years, 4–5 years, 6–10 years and greater than 10 years) compared to non-stoma group, with Bonferroni post hoc tests. Pearson's bivariate correlations were used to explore the relationships between the variables, prior to the hierarchical linear regression analyses (RA). To determine what factors are associated with psychiatric morbidity, positive well-being and QoL separately in the whole sample, three separate hierarchical linear regression analyses were carried out. The independent variables were entered into each RA in the same order, step one included the sociodemographic variables (age, sex and educational level), step two included presence of a stoma, step three included the mediators of distress perceived stress, coping (emotion, problem and dysfunctional coping) and resilience, and the four QoL measures in step 4 (for predicting symptoms of psychiatric morbidity and positive QoL only). Checks on multicollinearity were performed for all hierarchical linear regression analyses, using collinearity diagnostics, two values were given, tolerance and VIF (variance inflation factor), both of which were within the acceptable values of greater than 0.1 and less than 10 respectively (Tabachnick & Fidell, 2007). The contribution of variables in the final step of the regression was examined, reporting significant beta values and the semi-partial correlation squared (SPC^2), which examines the unique contribution of the individual independent variables to the overall variance in the dependent variable.

Open-ended questions were content analysed using inductive and summative methods recommended by Joffe and Yardley (2004). The analysis involved answers to questions being read several times to ensure familiarity with the information and initial observations noted in line with the study aims. This process of immersion in the data resulted in patterns being identified and sequent coding of the data, into categories and applying a summative analysis by counting the number of times a category was mentioned in the answers. This was carried out by two researchers (ES & MS), as multiple coders of the data are recommended to check reliability of themes and their relationships, and considered good practice (Joffe & Yardley, 2004). The researchers discussed their findings and agreed on the categories and sub-categories (Seale, 1999).

4.6 | Validity, reliability and rigour

This study adhered to the guidelines for conducting research set out by the British Psychological Society and University Research Governance. All psychological measures used in the study were selected and interpreted by a registered health psychologist, all had proven reliability and validity. Support and advise were given by experts in the stoma field to ensure the research was fit for purpose and relevant to clinical practice. The protocol was closely followed, and the online nature of the survey ensured that all participants had the same information presented in the same format and order.

5 | RESULTS

5.1 | Sample description

In total, 278 participants completed the survey. Table 1 provides an overview of the sample characteristics for the stoma/non-stoma groups. The stoma group was significantly older in comparison to the non-stoma group ($t=8.23$, $df=263$; $p<0.001$). The groups differed in relation to marital status, with the majority of the stoma group, were either married or in a full-time relationship (77%) ($X^2=38.85$, $df=5$, $p<0.001$). The two groups were comparable in relation to education level.

5.2 | Stoma group sample description

Just under half of the overall sample (46%, $n=129$) reported that they had a stoma. Within the stoma group, 6% reported stoma surgery within the last 6 months ($n=8$), 2% ($n=3$) in the last 6–12 months, 31% ($n=41$) between 1–3 years, 8% ($n=11$) between 4–5 years, 15% ($n=20$) between 6–10 years and 35% ($n=46$) more than 10 years, prior to study and 2% did not give an answer. Just over 70% ($n=92$) of those with a stoma had a one-piece system for body waste collection. Most of the stoma sample (98%, $n=126$) had experienced a leak, 69% of which reported using a one-piece system. Just over one-third of the sample reported weekly (16%, $n=21$) or monthly (16%, $n=21$) leaks, with almost two-thirds reporting infrequent leaks (62%, $n=79$), 6% ($n=8$) did not respond to this question. The majority (78%, $n=101$) reported experiencing sore skin around the site of the stoma.

TABLE 1 Sociodemographic variable for stoma/non-stoma groups, given as percentages.

Variable	Stoma group	Non-stoma group	*p*
Mean (*SD*) age in years	46 (12)	33 (13.5)	**<0.001**
Sex (%)			**0.025**
Male	26%	15%	
Female	74%	85%	
Marital status (%)			**<0.001**
Married	61%	30%	
Fulltime relationship	16%	37%	
Single	16%	32%	
Widowed	1%	0%	
Divorced	5%	1%	
Prefer not to say	1%	0%	
Highest level of education (%)			NS
Secondary	35%	31%	
Tertiary	65%	69%	

Note: $N=278$ (stoma group $=129$; non-stoma group $=149$). Bold values indicates statistical differences.

Abbreviation: NS, non-significant difference.

Stoma participants were asked about the timing of leakages, and their management, the responses to these open-ended questions have been content and summative analysed and reported in Table 2. The main reasons given contributing to leakages were that the bag was not fitted properly and not changing the bag soon enough. The timing of leaks was more likely during the night, especially when lying down, after consuming starchy goods, while exercising or wearing clothes that were too tight. The main coping methods employed were around checking and emptying the bag regularly, checking the seal and skin around the stoma, controlling aspects of the diet associated with increased output into the bag and wearing loose-fitting clothes and maintaining a good posture. Some participants suggested there was a need for a warning system to detect leaks.

5.3 | Differences on psychological measures with stoma duration and non-stoma group

To determine if there were any differences in the psychological variables in relation to duration of stoma and compared to non-stoma group. A minimum of 10 participants per group is recommended for ANOVA analysis; therefore, those reporting 1–6 months and 6–12 months were combined to meet this criteria ($n=11$). The following five stoma groups were defined by duration of stoma as follows, less than one year, 1–3 years, 4–5 years, 6–10 years and over 10 years, and compared to the non-stoma group (see Table 3). Differences by duration of stoma on psychological well-being and health, compared to non-stoma participants, were evident for symptoms of psychiatric morbidity, emotion-focused coping and QoL in relation to physical health. From the post hoc tests, there is a trend towards those living with a stoma for one to three years exhibited higher symptoms of psychiatric morbidity symptoms, in comparison to those living with their stoma for over 10 years, these just failed to reach statistical significance ($p=0.073$). Greater use of emotion-focused coping in those living with a stoma for less than one year compared to those living with their stoma for over 10 years was evident ($p=0.041$). Those living with a stoma for one to three years reported reduced physical health in comparison to those living with a stoma for more than 10 years ($p=0.013$) and the non-stoma group ($p=0.001$). Reduced physical health was also noted between those living with a stoma for 6–10 years and the non-stoma group ($p=0.045$).

A closer look at specific emotion-focused coping styles used by those more recently living with a stoma revealed group differences for acceptance (F (5215)$=5.387$, $p=0.006$), emotional support (F (5215)$=2.692$, $p=0.022$), humour (F (5215)$=2.645$, $p=0.024$), see Table S1. Key differences were identified using Bonferroni post

TABLE 2 Categories associated with leaks, when leaks occurred and how they are managed.

Reasons for leaking		Management of leaks	
Major	**Minor**	**Major**	**Minor**
Self-care of stoma		Dietary intake	Dietary control (9) Not eating too late at night (2) Avoiding alcohol (2) Drinking more fluids (1) Do not eat fibre (1)
Reasons for bag leaking	Bag not attached properly (23)	Knowledge	Know when it is going to happen (2) Pancaking (2)
Should this be rephrased as it in effect repeats the column heading....	Not changing the bag enough (21) Random leaks (10) Adhesive is poor (9) Skin is sore (5) Bag is too full (2) Hole in bag (2)		
Stoma bag usage—better?			
		Bag management	Checking/changing the bag more frequently (31) Especially before bed (6) Checking during the night (2)
Clothing	Clothes are too tight (8)	Checking seal	Checking seal (18) Checking the skin (8)
Time when leaks are more likely to occur	During the night/sleeping (42) Lying on side (9) After showering (4) Pancaking (7) Getting hot and sweaty (2)	Clothing	Avoid tight clothes (6) Avoid bending too much (2)
Exercise	Exercise (11) Bending over (6)	Other	Imodium (3) Stoma rings (2)
Dietary intake	Diet (4) Consuming veg/fruit (5) Other foods—starch, fibre (21) Large meal (2) Alcohol (1)	Needs	Warning system for early leak detection (2)
Health	Being unwell (4)		

Note: $N=129$ stoma participants, this table reflects the content and summative analysis of three open-ended questions asking about when a leak is more likely to occur, how and if they prevent leaks from happening, and information about how they prevent leaks.

hoc comparisons and included greater utilization of acceptance as a coping mechanism for those with a stoma up to one year compared to those over 10 years ($p=0.025$), and trends towards emotional support coping appeared to be greater in those under one year compared to those over 10 years ($p=0.061$) and the non-stoma group ($p=0.083$) but were just outside the level of significance. Humour was used more in those under one year and one to two years postsurgery compared to those over 10 years, but the p value was just outside the level of significance ($p=0.078$ and $p=0.081$ respectively).

5.4 | Differences in psychological measures with leakage frequency

To establish if variations in frequency of leaks would influence health and psychological well-being, the stoma participants were grouped according to leak frequency (weekly, monthly and infrequent) and compared to the non-stoma group (Table 4). The groups differed on symptoms of psychiatric morbidity, positive well-being, stress, dysfunctional coping and all four QoL subscales: physical and mental health, social relationships, and environment. Psychiatric morbidity

TABLE 3 Differences for duration from stoma, compared to non-stoma on symptoms of psychiatric morbidity, positive well-being, stress, coping, resilience, and QoL.

	<12 mths (*n* = 11)	1–3 yrs (*n* = 41)	4–5 yrs (*n* = 11)	6–10 yrs (*n* = 20)	>10 yrs (*n* = 46)	Non-stoma (*n* = 149)			
Variables	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***M* (*SD*)**	***F***	***df***	***p***
General Health Questionnaire −12	17.70 (6.44)	16.55 (7.39)	13.90 (7.66)	14.63 (8.24)	12.45 (6.06)	13.36 (5.79)	2.602	5237	**0.026**
Warwick—Edinburgh Well-being Scale	44.30 (9.59)	42.76 (10.58)	46.36 (8.78)	41.84 (12.49)	48.52 (10.81)	46.63 (9.98)	1.946	5235	0.088
Perceived Stress Scale	27.67 (7.68)	28.12 (9.87)	25.55 (7.09)	28.40 (10.32)	23.32 (9.10)	25.74 (8.94)	1.348	5213	0.245
Brief COPE									
Emotion-focused coping	27.00 (6.83)	24.28 (5.34)	24.09 (6.78)	22.27 (7.66)	20.23 (6.09)	21.49 (6.26)	3.146	5214	**0.009**
Problem-focused coping	16.70 (3.40)	14.51 (4.12)	13.81 (5.49)	13.50 (4.55)	13.52 (4.76)	14.10 (4.71)	0.878	5213	0.497
Dysfunctional coping	23.30 (5.41)	22.23 (6.58)	20.36 (3.61)	21.66 (6.22)	18.63 (5.50)	21.18 (6.14)	1.864	5214	0.102
WHO QOL BREF									
Physical health	22.50 (4.40)	21.91 (7.74)	24.90 (6.42)	22.05 (6.87)	26.82 (5.85)	26.77 (5.24)	5.301	5207	**<0.001**
Mental health	20.20 (3.99)	18.67 (5.48)	21.00 (5.36)	19.05 (5.20)	21.58 (5.04)	20.02 (5.13)	1.294	5207	0.268
Social relationships	9.70 (1.76)	10.17 (3.23)	10.36 (2.65)	9.29 (2.86)	10.35 (2.75)	10.69 (3.04)	0.834	5204	0.527
Environment	28.50 (6.62)	29.41 (6.18)	31.72 (5.86)	28.88 (6.04)	31.26 (5.20)	30.92 (5.13)	1.179	5207	0.321
Resilience	67.66 (14.35)	58.87 (18.59)	64.90 (23.07)	60.18 (16.79)	67.70 (16.68)	63.66 (18.00)	1.031	5198	0.401

Note: $N = 278$. This table provides an overview of the ANOVA used to determine group differences for duration of stoma and non-stoma groups. Bold values indicates statistical differences.

TABLE 4 Differences in psychological measures (psychiatric morbidity, positive well-being, stress, coping, resilience, and QoL) with frequency of leaks compared to non-stoma group.

	Weekly leaks (*n* = 21)	Monthly leaks (*n* = 21)	Infrequent leaks (*n* = 79)	Non-stoma (*N* = 149)			
Variables	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*F*	*df*	*p*
General Health Questionnaire −12	17.05 (6.33)	18.60 (9.12)	12.85 (6.25)	13.45 (5.84)	6.17	3236	**<0.001**
Warwick Edinburgh Well-being Scale	39.25 (11.78)	40.50 (14.16)	47.96 (8.97)	46.61 (9.92)	5.93	3234	**0.001**
Perceived Stress Scale	30.39 (8.42)	31.23 (9.46)	23.63 (8.78)	25.73 (8.87)	5.60	3212	**0.001**
Brief COPE							
Emotion-focused coping	21.57 (6.88)	24.84 (6.26)	22.68 (6.56)	21.46 (6.24)	1.72	3213	0.162
Problem-focused coping	13.78 (4.34)	14.84 (4.33)	14.05 (4.69)	14.09 (4.71)	0.19	3212	0.903
Dysfunctional coping	22.15 (6.55)	24.15 (6.99)	19.39 (5.03)	21.30 (6.18)	3.85	3213	**0.010**
WHO-QOL—BREF							
Physical health	19.22 (7.60)	19.72 (6.82)	26.38 (5.45)	26.64 (5.35)	14.92	3206	**<0.001**
Mental health	17.83 (6.10)	17.83 (6.42)	21.41 (4.19)	20.01 (5.04)	4.26	3206	**0.006**
Social relationships	8.38 (2.97)	9.38 (3.86)	10.76 (2.20)	10.64 (3.06)	4.25	3206	**0.006**
Environment	26.16 (7.28)	29.94 (5.15)	31.42 (5.00)	30.65 (5.26)	4.66	3206	**0.004**
Resilience	60.16 (22.24)	58.66 (18.71)	66.00 (16.48)	63.40 (17.91)	1.06	3198	0.366

Note: *N* = 278, *n* = 8 of the stoma group did not indicate the frequency of leaks and were excluded from the analysis. Bold values indicates statistical differences.

symptoms were higher for those who leak weekly ($p = 0.05$) and monthly ($p = 0.002$) in comparison to those who report infrequent leaks and those who do not have a stoma (compared to monthly leakers: $p = 0.006$). Better positive well-being was reported for those who had infrequent leaks in comparison to those who reported weekly ($p = 0.005$) and monthly ($p = 0.024$) leaks and non-stoma participants (compared to weekly leakers: $p = 0.019$). Lower stress levels were reported for those experiencing infrequent leaks, in comparison to those reporting weekly ($p = 0.017$) and monthly ($p = 0.006$) leaks. Participants who reported monthly leaks also reported greater use of dysfunctional-focused coping in comparison to those participants experiencing infrequent leaks ($p = 0.013$). QoL: Physical health was poorer for participants who reported weekly ($p < 0.001$) and monthly ($p < 0.001$) leaks compared to infrequent leaks and non-stoma participants ($p < 0.001$ for both weekly and monthly leakers). QoL: Mental health was poorer for those experiencing weekly ($p = 0.028$) and monthly ($p = 0.046$) leaks compared to participants with infrequent leaks. QoL: Social relationships ($p = 0.013$) and QoL: Environmental factors ($p = 0.002$) were not as good for participants who experienced weekly leaks in comparison to those reporting infrequent leaks. Non-stoma participants had better social relationships ($p = 0.015$) and environment ($p = 0.008$) compared to those reporting weekly leaks.

Those who reported more frequent leaking used more dysfunctional-focused coping styles, to determine which dysfunctional coping styles were more likely to be employed, and group differences for the individual coping styles on the Brief COPE were determined using ANOVA (see Table S2). Group differences were found for behavioural disengagement (F (3,214) = 3.162, $p = 0.026$) and denial (F (3,214) = 4.444, $p = 0.005$), but not for self-distraction (F (3,214) = 1.748, $p = 0.158$), self-blame (F (3,214) = 1.027, $p = 0.381$), substance use (F (3,213) = 4.192, $p = 0.117$) and venting (F (3,214) = 2.129, $p = 0.098$). Bonferroni post hoc comparisons revealed the main differences between the groups for behavioural disengagement showed a trend towards higher behavioural disengagement in monthly leakers compared to infrequent leakers ($p = 0.076$). For denial, weekly leakers used denial more, in comparison to infrequent leakers ($p = 0.002$) and non-stoma participants ($p = 0.031$).

5.5 | Relationship between the variables

To examine the relationships between the variables, prior to conducting the hierarchical linear regression analyses, a series of Pearson bivariate correlations were carried out and the results are presented in Table 5, separately for each group (stoma/non-stoma). The correlations range from moderate to low and are similar across groups.

5.6 | Correlates with psychiatric morbidity, positive well-being and QoL

To determine the main factors that influence symptoms of psychiatric morbidity, positive psychological well-being, and QoL in this sample, a series of hierarchical linear regression analyses were carried out for each (see Table 6). Symptoms of psychiatric morbidity: in step one of the model, socio-demographic variables account for almost 8% of the variance, a significant change in the R^2 occurred with the addition of whether or not they had a stoma to almost 12%, a further increase in the R^2 occurred with the addition

TABLE 5 Bivariate correlations for stoma ($n=120$) and non-stoma ($N=118$) groups.

Stoma group variables	GHQ-12	WEWBS	PSS	EFC	PFC	DFC	QOL1	QOL2	QOL3	QOL4	Res
GHQ-12	1	−0.842**	0.777**	−0.101	−0.039	0.602**	−0.604**	−0.800**	−0.552**	−0.551**	−0.640**
WEWBS	−0.776**	1	−0.842**	0.207*	0.105	−0.538**	0.615**	0.860**	0.602**	0.613**	0.684**
PSS	0.754**	−0.758**	1	0.032	0.083	0.655**	−0.639**	−0.792**	−0.530**	−0.589**	−0.694**
EFC	−0.041	0.274**	−0.124	1	0.758**	0.263**	−0.087	0.185	0.187	0.097	0.298**
PFC	−0.124	0.397**	−0.158	0.808**	1	0.274**	−0.097	0.107	0.126	0.070	0.236*
DFC	0.608**	−0.533**	0.556**	0.279**	0.153	1	−0.487**	−0.619**	−0.463**	−0.429**	−0.493**
QOL1	−0.506**	0.514**	−0.501**	0.160	0.229*	−0.412**	1	0.744**	0.468**	0.685**	0.464**
QOL2	−0.778**	0.835**	−0.709**	0.231*	0.311**	−0.592**	0.685**	1	0.641**	0.763**	0.769**
QOL3	−0.492**	0.589**	−0.537**	0.159	0.263**	−0.426**	0.369**	0.551**	1	0.570**	0.574**
QOL4	−0.412**	0.476**	−0.495**	0.236*	0.281**	−0.453**	0.595**	0.593**	0.453**	1	0.624**
Res	−0.622**	0.800**	−0.626**	0.409**	0.485**	−0.460**	0.585**	0.820**	0.495**	0.555**	1

Note: Grey shading denotes correlations for the non-stoma group.

Abbreviations: DFC, dysfunctional-focused coping; EFC, emotion-focused coping; GHQ-12, General Health Questionnaire; PFC, problem-focused coping; PSS, Perceived Stress Scale; QOL 1, physical health; QOL2, mental health; QOL3, social relationships; QOL 4, environment; Res, resilience; WEWBS, Warwick-Edinburgh Mental Well-being Scale.

** Denote correlation is significant at the 0.01 level (2-tailed). * Denote correlation is significant at the 0.05 level (2-tailed).

of stress, coping styles and resilience to 67% of the variance being explained in step 3, increasing further to 72% in the final step of the linear regression with the addition of the four QoL subscales. In terms of the unique contribution to variability in psychiatric morbidity in the final model, see Table S3, the main predictors were sex ($\text{spc}^2=0.003$), stoma ($\text{spc}^2=0.024$), stress ($\text{spc}^2=0.168$), DFC (spc2 = 0.025) QOL 2 (psychological health) ($\text{spc}^2=0.136$) and QOL 4 (environment) ($\text{spc}^2=0.024$). The results indicate that being male ($\beta=0.102$, $p=0.018$), having a stoma ($\beta=-0.097$, $p=0.039$), higher stress levels ($\beta=0.402$, $\text{p}<0.001$), greater dysfunctional forms of coping ($\beta=0.131$, $p=0.034$), lower levels of QoL 2 (mental health) ($\beta=-0.521$, $p<0.001$) and higher environmental factors related to QoL 4 ($\beta=0.123$, $p<0.039$) were associated with higher levels of distress and poorer mental health.

Positive psychological well-being: in step one of the model, socio-demographic variables account for 11% of the variance, a significant change in the R^2 occurred with the addition of whether or not they had a stoma to 14%, a further increase in the R^2 occurred with the addition of stress, coping styles and resilience to 76% of the variance being explained in step 3, increasing further to almost 83% in the final step of the linear regression with the addition of the four QoL subscales. In terms of the unique contribution to variability in positive psychological well-being in the final model, see Table S4, the main predictors were sex ($\text{spc}^2=0.020$), tertiary level education ($\text{spc}^2=0.024$), stoma ($\text{spc}^2=0.056$), stress) ($\text{spc}^2=0.248$), and QoL 2 (mental health) ($\text{spc}^2=0.226$). The results indicate that being female ($\beta=-0.065$, $p=0.05$), not having a tertiary level education ($\beta=-0.074$, $p=0.037$), not having a stoma ($\beta=0.120$, $p=0.001$), lower stress levels ($\beta=-0.406$, $p<0.001$) and higher levels of QoL 2 (mental health) ($\beta=0.563$, $p<0.001$) are associated with more positive psychological well-being.

QoL: in step one of the model, socio-demographic variables account for 13% of the variance, a significant change in the R^2 occurred with the addition of whether or not they had a stoma to 16%, a further increase in the R^2 occurred with the addition of stress, coping styles and resilience to almost 67% of the variance being explained in step 3. In terms of the unique contribution to variability in QoL in the final model, see Table S5, the main predictors were stoma ($\text{spc}^2=0.026$), stress ($\text{spc}^2=0.163$), DFC ($\text{spc}^2=0.051$) and resilience ($\text{spc}^2=0.128$). The results indicate that not having a stoma ($\beta=0.109$, $p=0.028$), lower stress levels ($\beta=-0.385$, $p<0.001$) and lower levels of dysfunctional coping styles ($\beta=-0.191$, $p<0.002$) and higher resilience ($\beta=-0.349$, $p<0.001$) are associated with better overall QoL. Greater psychological support is needed for stoma patients who may face challenges related to their self-care, especially in those less than three years postsurgery and those experiencing frequent leaks.

6 | DISCUSSION

This novel study contributes to the growing psychological research looking at the impact of having an intestinal stoma in adults on

TABLE 6 Summary of hierarchical linear regression analyses with socio-demographic, stoma, stress, coping and resilience, and quality of life as predictors of symptoms of psychiatric morbidity, positive psychological well-being and quality of life.

Dependent variable	Step	Independent variables	R^2	ΔR^2	*F*	*df*	*p*
Psychiatric morbidity	1	Socio-demographic variables	0.092	0.092	6.286	3186	**<0.001**
	2	Stoma	0.119	0.027	5.645	1185	**0.019**
	3	Stress, coping and resilience	0.670	0.551	60.091	5180	**<0.001**
	4	Quality of life measures	0.723	0.053	8.507	4176	**<0.001**
Positive psychological well-being	1	Socio-demographic variables	0.113	0.113	7.866	3186	**<0.001**
	2	Stoma	0.143	0.030	6.522	1185	**0.011**
	3	Stress, coping and resilience	0.766	0.623	95.840	5180	**<0.001**
	4	Quality of life measures	0.827	0.061	15.576	4176	**<0.001**
Quality of life*	1	Socio-demographic variables	0.133	0.133	9.480	3186	**<0.001**
	2	Stoma	0.158	0.026	5.688	1185	**0.018**
	3	Stress, coping and resilience	0.669	0.510	55.436	5180	**<0.001**

Note: $N = 190$ Step one: socio-demographic variables (age, sex and educational level) were added. Step two included presence of a stoma. Step three included the addition of stress, emotion, problem-focused and dysfunctional coping and resilience. Step four included the four quality of life domains or physical health, mental health, social relationships and environment, except *. After step one, each subsequent step included the variable(s) from the previous step. Significant ($p < 0.05$) increases in R^2 indicated in bold.

well-being and QoL. It is one of the few known UK studies to compare stoma and non-stoma participants on a range of psychological measures (Bianchi et al., 2022; Silva et al., 2017; Temprado Albalat et al., 2018). The findings elucidate a better understanding of the psychological needs of those living with a stoma and establish the importance of stoma-related factors such as the early years following surgery and those experiencing frequent leaks, as being detrimental to psychological well-being and QoL in some participants. Well-being and QoL for some of the stoma group is mediated by the amount of psychological stress the person is experiencing, the coping styles they employ and their resilience. This research provides much-needed information that should inform policy and practice around stoma self-care, ensuring that patients are given greater tangible support in the home, following their stay in hospital, with the everyday practicalities of managing a stoma and the impact and how to adapt to this on normal daily functioning as the main focus. Patients and staff should have greater awareness that ongoing problems with self-care can lead to poor mental health in some patients, so for some, there will be a need for ongoing psychological support. Some NHS trusts follow patients up at one year postsurgery, and this may vary depending on the reason for the stoma, but perhaps more frequent follow-up visits is needed in the first year to ensure optimal adaptation and positive mental health outcomes. Health psychologists could provide valuable support with adaptation to lifestyle change and teaching of better coping strategies to deal with the challenges of self-care in the early weeks and months postsurgery.

Adapting and learning to cope with a stoma over time should improve well-being and QoL, this is partially supported in the current study; however, some participants continued to have leaks years after stoma surgery, suggesting they may still need support with self-care management. The findings suggest that the early years of living with a stoma can be characterized by poorer physical and mental health, and greater utilization of emotion-focused coping (acceptance, emotional support, use of humour), lending some support to previous research looking at patients with irritable bowel disease. One study looked at predictors of psychiatric morbidity in a prospective Swedish population (Ludvigsson et al., 2021), with psychiatric morbidity and risk of suicide being higher in those with irritable bowel disease. Overcoming the stigma of this condition, having better social support and resilience was associated with mastery of the condition in a qualitative UK study (Dibley et al., 2018), and quality of life reported by intestinal stoma patients was mediated by psychological and social well-being (Diniz et al., 2023). Emotion-focused coping is thought to be important for acceptance, adjustment, and better self-management of a stoma (Reji & Sharma, 2020; Sehgal et al., 2021; Sirois & Hirsch, 2017; Wang et al., 2021) and has been linked to resilience in self-care of a stoma (Temprado Albalat et al., 2020; Wang et al., 2021). Acceptance of a chronic condition is important both to management and promotion of health and well-being in patient groups (Knowles et al., 2014). The need for emotional support from others is an attempt to cope with a stressful situation (Alenezi et al., 2023), as it acts as a stress buffer, and was an effective coping strategy used by ostomy teenagers (Nicholas et al., 2008), but not so in a qualitative study on adult stoma patients who reported avoidance of emotional focused coping styles (Thorpe & McArthur, 2017). Some studies have reported other coping styles such as the use of self-distraction, substance use and problem-focused forms of coping for managing a stoma as result of cancer (Priscilla et al., 2011; Reji & Sharma, 2020). The current findings suggest that adjustment in the early years of having a stoma can be difficult and may require additional psychological support and that this may differ depending on the circumstances around the creation of the stoma. This may require a more universal recognition of the psychological challenges that such patients face across healthcare providers and professionals, in order to develop appropriate support packages. A recent integrative review suggests more longitudinal studies are needed to fully understand adjustment to stoma over time and how best to intervene and support patients for longer (Kittscha et al., 2022).

Frequent leaks (weekly and monthly) in the current study were attributed to poor fitting and problems with the seals on the pouch. Leaks were associated with situations where participants were lying down or had consumed certain foods that affected output, similar to reasons for leaks given in a recent study of 203 UK adult stoma patients (Ber, 2021). More effective ways to support and manage such situations for stoma patients are needed (Perrotta & Guerrieri, 2022), with a suggestion from some participants that technology to provide early warnings to prevent leaks would reduce the stress associated with this. In the current study, coping strategies reported to deal with leaks were regular checking and changing the bag to reduce leaks, wearing loose-fitting clothes to avoid pancaking and retaining good posture to avoid bending or squashing the bag. More frequent leaks were associated with greater psychological distress, reduced well-being, and greater use of dysfunctional coping (behavioural disengagement and denial) and reduced QoL (physical and mental health, social relationships and environment) supporting the findings of previous research (Claessens et al., 2015; Haughey & McGroggan, 2017; Liao & Qin, 2014).

These findings point to a need for greater support with managing stoma over time and lend support to previous findings looking at the impact of stoma and leaks. Claessens et al. (2015) looked at over 4000 adult participants who had a stoma (18 years and above) from eleven countries, including the UK, USA and Europe, of all ages and sexes (55% male), they reported that the majority of participants expressed issues related to stoma leakage, which had a negative impact on sleep and well-being. Haughey and McGroggan (2017) found living with stoma produced both positive (participants reported feeling happier, healthier, and freer poststoma) and negative responses (participants reported feeling restricted, embarrassed, difficulties managing the stoma and that it was inconvenient) from 547 Irish participants, aged 18–92 years, with a range of stoma durations from 1–31 years. Liao and Qin (2014) looked at factors that mediated quality of life in a sample of 76 stoma patients from Beijing, they reported that managing the stoma, in relation to emptying the bag and leaks, especially in social or work situations was problematic for them. They also expressed issues with sexuality and body image as a result of their stoma. The combination of positive and negative consequences of stoma reported in these studies makes the psychological impact of stoma more difficult to establish.

This suggests that for some patients, where adaptation is slower or more problematic, there may be a need for greater or more personally tailored psychological support and supporting previous findings (Black & Notter, 2021). Such problems can also lead to reductions in social encounters for the stoma patient and isolation (Perrotta & Guerrieri, 2022; Smith et al., 2017), reducing their opportunities for support and to promote psychosocial adaptation to their condition (Black & Notter, 2021). This coupled with the use of dysfunctional coping styles, also noted in previous research (Priscilla et al., 2011), may prolong the adaptation process and a lack of willingness to try to resolve the situation. More appropriate coping skills may be needed to promote more effective self-management (Dibley et al., 2018), replacing the use of dysfunctional forms of coping with a greater use of emotion or problem-focused coping styles, to enhance resilience and impact positively on psychological adjustment and management of stoma.

Stress, coping styles and resilience in this study appear to mediate both psychological well-being and distress, lending some support to previous research in stoma patients (Temprado et al., 2019), and contradicting others that did not find a decline in QoL with stoma (Dossa et al., 2018). There is a suggestion that resilience underlies adaptation and adjustment to chronic conditions (Shi et al., 2015), which may influence physical and mental health by promoting better coping with the more negative aspects of illness (Connor & Davidson, 2003), in this case leaks. More effective coping leads to better psychological well-being and a reduction in psychological distress (Shi et al., 2015). This information could be used to design more effective interventions to promote well-being in this cohort. There has been some success promoting QoL in Chinese adult stoma patients with an intervention promoting self-efficacy in self-care of stoma (Xu et al., 2018; Yin et al., 2021), compared to standard stoma advice and care given. A cross-sectional study of interventions used in 102 adult patients with intestinal stoma in Spain suggests that decision-making and ostomy care are the most common interventions, inclusion of psychological and social factors in interventions are also prevalent (Capilla-Díaz et al., 2019), but mainly during hospitalization. There was no information on fidelity of the interventions or evaluation of process and outcome, which should be addressed by future research if effectiveness of the interventions is to be established.

The strengths of this study are that it was powered to make comparisons between stoma and non-stoma participants, with a wide age range of participants and duration from stoma, to give a varied sample and to meet a gap in the existing literature. The discovery of factors that mediate psychological well-being related to stoma, may directly inform future interventions to improve poststoma surgery management in patients. Moreover, the psychological measures employed were all validated, the selection of which and administration were overseen by a health psychologist and suitable for use in this cohort.

Some limitations of the study should be considered. The online survey was distributed via social media platforms and may have influenced who responded to the questionnaires, self-referring participants may potentially be those who are in greater need of psychological support (Jordan et al., 2018). The online distribution also made it impossible to determine how many people had received information about the study, so a response rate was not possible to calculate. Also, given anonymity of participation, it was not possible to member check the categories generated by the open-ended questions, although results were presented to the Ileostomy & Internal Pouch Association NI who confirmed that the issues raised were relevant and experienced by their members, providing some anecdotal support. The sample may not be representative as the majority were female and were well-educated, results need to be interpreted with this in mind, future studies need to address the representativeness of their samples. Stoma status, skin irritations and stoma leaks were self-reported in this study, although participants were recruited from the Ileostomy & Internal Pouch Association NI & UK, lending some credence to their condition. In future, this could be verified by a nurse or doctor if participants were recruited from a clinical setting. Participants were not asked to specify if the stoma was permanent or temporary, or to elaborate on the aetiology leading to it, any peristomal complications experienced, which may influence their psychological well-being linked to their experience of, and adjustment to, the stoma (Spinelli et al., 2014), and should be taken into consideration when looking at quality of life and psychological well-being in further studies to determine the causal relationships between these variables. This was a cross-sectional study therefore we cannot examine causal relationships between the variables. It is not possible to say if the sample is representative of intestinal stoma groups as there are so few studies carried out looking at this. Further research is needed to confirm the findings and to address the limitations of the current study. Future research needs to follow patients up from pre- to poststoma surgery, especially over the first couple of years, as the current findings suggest there is poorer physical and mental health during this time and a greater reliance on emotion-focused coping. A longitudinal approach is needed to fully understand psychological adjustment to stoma, how health needs vary across this transition and between those who cope and adapt well, and those that do not, providing insight into the optimal timing for psychological support, and the types of intervention required along the journey.

7 | CONCLUSION

This research suggests that psychological well-being and general physical health may be reduced in the early months and years following a stoma for some people. Frequent leaks impact on psychological well-being and the participants in this study engaged in constant checking to avoid this, more innovative approaches to the design of the stoma appliance are necessary and should include early warning devices to alleviate concern. There is a need for further research to focus on the longitudinal patient journey to better understand their particular issues and challenges and to make recommendations for psychological support. As such, there is a need to take a more holistic approach and promote more appropriate forms of coping, to enhance adaptation and well-being, such as identifying and encouraging emotional support and humour. Also being mindful of reducing dysfunctional coping styles, that may exacerbate psychological distress in this group. These results should be used to prompt improvements in care delivery and disease management and inform policy and interventions used with stoma patients. There needs to be an interactive approach taken, involving patients with the decisions made around their care, to determine what best suits their needs. This needs to happen in full consultation with the wider medical team (such as nurses, doctors, nutritionists, psychologists etc.), ensuring treatment is fit for purpose and appropriate to the patient's needs. Given the impact and problems with adaptation in the early stages of living with a stoma, the promotion of psychological well-being and QoL should be central to normal stoma care package.

AUTHOR CONTRIBUTIONS

Ellen Simpson, PhD, was responsible for the study design, questionnaire development, data analysis and original draft of the paper. Kirsty Pourshahidi, PhD was responsible for participant recruitment and data collection and reviewing and editing the paper. James Davis, PhD, was involved in the study design and questionnaire development, reviewing and editing the paper. Mary Slevin, PhD, was responsible for project administration, database management, she helped with the qualitative data analysis and reviewed the paper. Roger Lawther MD and Gloria O'Connor, PhD, advised on the questionnaire and recruitment strategy for this project, review and editing of the paper. Terri Porrett, PhD, was involved in the initial conceptualization of the project from a clinical relevance perspective and edited the paper. Jerome Marley provided input into the study design and participant recruitment strategy and reviewed the paper. Chris Gill, PhD, was involved in the overall conceptualization of this study, informed the design and recruitment strategy, reviewed and edited the paper.

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CONFLICT OF INTEREST STATEMENT

The authors declare they have no competing interests.

DATA AVAILABILITY STATEMENT

The dataset is not publicly available due to confidentiality and ethical reasons but could be made available from the corresponding author on reasonable request.

ETHICS STATEMENT

The study was conducted with the prior approval from the University Ethics Committee (RG3060618 – June 2018), and all participants gave informed consent, in accordance with the Declaration of Helsinki. Participants were given an information sheet prior to consenting to the study, tick box consent was used, and anonymity guaranteed, as no identifying data were collected. No incentive was given to participants to complete the survey. Contact details were provided for the chief investigator to answer any queries that participants had regarding the study. Qualtrics (Qualtrics, Provo, UT) was used to host the survey and data collection, which requires a licence and password for access to the data. The data were downloaded and securely stored on password-protected computers for analyses, in keeping with General Data Protection Regulation (UK GDPR, 2018).

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