Understanding Odor-related Challenges for Colorectal Cancer Survivors with Ostomies: Effects on Anxiety, Body Image, and Emotional Well-being

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Abstract

Anxiety in colorectal cancer (CRC) survivors with ostomies is associated with increased mortality, disease complications, and treatment non-adherence. Ostomy odor creates anxiety, particularly in public settings. While body image disturbance (BID) affects this population, relationships between odor, BID, and anxiety remain understudied, especially regarding sensory perception interactions.

This study examines relationships among ostomy-related issues (leakage, odor, and peristomal skin complications (PSC)), BID, anxiety, and emotional well-being (EWB) in CRC survivors with ostomies.

A scoping review was conducted to identify risk factors and consequences of anxiety in CRC survivors. Cross-sectional studies (N = 130) were conducted with Stage I–III CRC survivors with ostomies recruited through online support groups. Participants completed surveys containing single-item measures of ostomy issues and validated scales for anxiety, BID, and EWB. A series of regression analyses with Baron and Kenny's mediation approach examined relationships while controlling for other anxiety risk factors identified in the scoping review.

Our scoping review identified ostomy-related issues and BID as anxiety risk factors in CRC survivors. In our cross-sectional studies, leakage predicted odor (β=0.61, $p<.001$), PSC (β=0.51, $p<.001$), and anxiety (β=0.23, $p=.003$). Adding odor to the model made leakage's effect on anxiety non-significant (β=0.11, $p=0.249$), while odor remained significant (β=0.19, $p=0.039$), showing full mediation. PSC had no anxiety association. Odor predicted BID (β=0.15, $p=.037$), anxiety (β=0.25, $p<.001$), and EWB (β=-0.32,

p<.001). BID partially mediated odor and EWB relationship but showed no significant anxiety association (β=0.15, p=.088).

This research demonstrates ostomy odor's central role in the psychosocial experiences of CRC survivors with ostomies. These findings enhance our understanding of how olfactory experiences affect psychological outcomes through cross-modal sensory integration.

Keywords: ostomy, colorectal cancer, odor, body image, anxiety

Preface

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CHAPTER 1
INTRODUCTION

Background

Colorectal cancer (CRC) is a commonly diagnosed cancer globally, ranking as the third most common in the United States (Siegel et al., 2023). The American Cancer Society (2024) estimates that in 2024, 106,590 colon and 46,220 rectal cancer cases will be diagnosed in the US. Despite advances in early detection and treatment that have improved survival rates, many survivors face significant challenges related to disease and treatment effects, particularly those with ostomies. For these patients, ostomy surgery necessitates substantial lifestyle adaptations that extend beyond physical management to include significant psychosocial implications (Lim et al., 2021; Stavropoulou et al., 2021; V. Sun et al., 2013).

Anxiety constitutes a significant psychological challenge for CRC survivors with ostomies (Dellafiore et al., 2022; Farahani et al., 2022; Jayarajah et al., 2016; Peng et al., 2019), with profound implications for clinical outcomes through reduced treatment adherence, diminished quality of life, increased healthcare utilization, and elevated risks of cancer recurrence and mortality (Trudel-Fitzgerald et al., 2018; Zhu et al., 2020). Living with an ostomy presents complex challenges, with ostomy odor emerging as a particularly distressing aspect of daily management (V. Sun et al., 2013; Williams, 2008). Throughout history, social norms have stigmatized unpleasant odors, reflecting cultural attitudes about cleanliness and acceptability (Corbin, 1986). The psychological burden of managing ostomy odor manifests as heightened anxiety, especially in public settings (Annells, 2006; Black & Notter, 2021a; Saunders et al., 2021). These concerns often lead to behavioral modifications, including social withdrawal and isolation, affecting various life domains- from professional environments to personal relationships (Black & Notter,

2021a; Lim et al., 2021). Despite the significant psychosocial impact of ostomy odor, empirical quantitative research examining this phenomenon remains limited in the current literature.

Body image disturbance (BID) affects up to 78.5% of CRC survivors and is reported as the most common concern in this population, according to a recent meta-analysis (Han et al., 2020a). While research has established that changes in physical appearance and function impact body image, these dimensions are interconnected rather than separate entities (Fingeret, Hutcheson, et al., 2013; B. Rhoten, 2018; B. A. Rhoten et al., 2013; B. A. Rhoten, 2016). The relationship between olfactory stimuli and visual perception is supported by research in cross-modal correspondence, which demonstrates that odors influence cognitive processing, emotional states, and behavioral responses (Chen & Spence, 2022; Davies-Owen et al., 2024; Herz, 2009; Spence, 2021). Despite advances in olfaction research across disciplines, the application of these insights to oncology contexts remains limited. Current literature typically examines visible changes as the primary cause of BID, overlooking interactions between sensory modalities, particularly between olfactory and visual perception.

Purpose and Specific Aims

The purpose of this study is to investigate the complex relationship between ostomy-related issues (leakage, odor, and peristomal skin complications), BID, and anxiety in CRC survivors with ostomies. We aim to enhance the understanding of how odor-related concerns impact psychological well-being and identify potential intervention points to improve the quality of life in this population. The aims of this dissertation, which includes three manuscripts, and the hypotheses for empirical studies are detailed below.

Aim 1. To identify risk factors and consequences of anxiety in CRC survivors

Aim 2. To examine the structural relationships between ostomy-related issues (ostomy leakage, odor, and peristomal skin complications) and anxiety symptoms in CRC survivors with ostomies

- Hypothesis 2.1: Increased ostomy leakage, increased odor, and increased peristomal skin complications will be associated with increased anxiety, even after controlling for demographic and clinical factors
- Hypothesis 2.2: Both odor and peristomal skin complications will mediate the relationship between ostomy leakage and anxiety

Aim 3. To examine the structural relationships between ostomy odor, body image disturbance, anxiety, and emotional well-being in CRC survivors with ostomies.

- Hypothesis 3.1: Increased ostomy odor will be associated with increased body image disturbance, independent of demographic and clinical factors.

- Hypothesis 3.2: Increased ostomy odor will be associated with increased anxiety and decreased emotional well-being, even after controlling demographic and clinical factors.
- Hypothesis 3.3: Increased body image disturbance will be associated with increased anxiety and decreased emotional well-being while controlling for ostomy odor and other factors.

To address Aim 1, a scoping review was conducted. The findings from this review informed us of the selection of variables for our subsequent empirical investigations. Specifically, ostomy leakage, odor, peristomal complications, and body image disturbance were identified as potential predictors of anxiety. Additional demographic and clinical factors identified as risk factors of anxiety in the literature were included as covariates in subsequent studies for Aims 2 and 3. This methodological approach allows for the examination of the independent contributions of each factor to anxiety while controlling for potential covariates.

Theoretical Framework

This study was guided by three interconnected theoretical frameworks that provide a comprehensive foundation for understanding the complex relationships between ostomy-related complications, body image disturbance, and anxiety in colorectal cancer survivors.

Maurice Merleau-Ponty's (2011) phenomenology of perception provides the philosophical foundation for this research. His theory emphasizes that human experience is fundamentally embodied- we understand the world primarily through our bodily senses rather than abstract cognition. According to Merleau-Ponty (2011), perception involves the active engagement of the body in its environment, with one's own body existing simultaneously as both subject and object. This nature of embodied consciousness is particularly relevant for individuals with ostomies who experience profound changes in bodily function and sensory experience. In our study, we view ostomy-related olfactory changes as a critical component of altered sensory experience that fundamentally reshapes one's lived reality. Merleau-Ponty's concept of embodied consciousness challenges traditional views of body image as primarily visual, recognizing instead how integrated sensory experiences- visual, olfactory, and tactile- collectively shape one's bodily perception. This framework provides a theoretical basis for understanding how sensory disruptions, especially those related to odor, contribute to anxiety and body image disturbance in CRC survivors with ostomies. The integration of these varied sensory inputs ultimately determines how individuals perceive their bodies, suggesting that ostomy-related odors can profoundly alter one's embodied experience and relationship with the surrounding world (Merleau-Ponty, 2011).

Complementing this framework, odor-associative learning theory explains how individuals form mental connections between events and odor based on their prior experiences (Herz, Schankler, et al., 2004; Herz, 2009). Specifically, odor-associative learning elucidates how odors trigger emotional responses and influence cognition and behavior (Herz, 2009). Research demonstrates that odor-related associations are particularly potent because olfactory stimuli and emotional processing share direct neuroanatomical connections through the amygdala- a connection that no other sensory system possesses (Herz, 2009; Spence, 2021). Studies have shown that negative emotional experiences create more durable associations with odors compared to positive experiences (Davies-Owen et al., 2024; Herz, 2009), potentially explaining why ostomy odor concerns persist even after technical management solutions are implemented. This associative learning process is especially relevant in our study population, as it helps explain how repeated exposure to ostomy leakage and odor may condition survivors to experience anxiety even in anticipation of potential odor events, leading to hypervigilance, social avoidance, and complex ritualistic behaviors around ostomy management (Black & Notter, 2021a; Dalton & Maute, 2019; Saunders et al., 2021).

Finally, the concept of cross-modal correspondence provides insights into how different sensory attributes of a stimulus interact across multiple sensory modalities (Chen & Spence, 2022; Spence, 2021). This theoretical perspective helps explain how olfactory stimuli can contribute to the visual perception of self and others. For colorectal cancer survivors with ostomies, this suggests that odor-related concerns may significantly impact their body image and self-perception beyond merely physical appearance concerns.

References for Chapter 1

American Cancer Society. (2024). Cancer Facts & Figures 2024. American Cancer Society.

Annells, M. (2006). The Experience of Flatus Incontinence From a Bowel Ostomy: A Hermeneutic Phenomenology. Journal of Wound Ostomy & Continence Nursing, 33(5), 518.

Black, P., & Notter, J. (2021). Psychological issues affecting patients living with a stoma. British Journal of Nursing (Mark Allen Publishing), 30(6), S20–S32. MEDLINE. https://doi.org/10.12968/bjon.2021.30.6.S20

Chen, Y.-C., & Spence, C. (2022). Investigating the Crossmodal Influence of Odour on the Visual Perception of Facial Attractiveness and Age. https://doi.org/10.1163/22134808-bja10076

Corbin, A. (1986). The Foul and the Fragrant: Odor and the French Social Imagination. Harvard University Press.

Dalton, P., & Maute, C. (2019). Odours and incontinence: What does the nose know? Proceedings of the Institution of Mechanical Engineers, Part H: Journal of Engineering in Medicine, 233(1), 127–134. https://doi.org/10.1177/0954411918781409

Davies-Owen, J., Roberts, H., Scott, M., Thomas, A., Sen, S., Sethna, S., Roberts, C., Giesbrecht, T., & Fallon, N. (2024). Beauty is in the nose of the beholder: Fragrance modulates attractiveness, confidence and femininity ratings and neural

responses to faces of self and others. Behavioural Brain Research, 465, 114932. https://doi.org/10.1016/j.bbr.2024.114932

Dellafiore, F., Manara, D. F., Arrigoni, C., Baroni, I., Di Pasquale, C., Nania, T., Caruso, R., & Villa, G. (2022). Predictors of Adjustment to Living with an Ostomy: Results of a Cross-sectional Study. Advances in Skin & Wound Care, 35(5), 1. https://doi.org/10.1097/01.ASW.0000823980.15166.35

Farahani, M. A., Sargolzaei, M. S., Shariatpanahi, S., Dehkordi, A. H., Dalvand, P., & Heidari-Beni, F. (2022). The prevalence of anxiety and depression in patients with ostomy: A systematic review and meta-analysis. Psycho-Oncology, n/a(n/a). https://doi.org/10.1002/pon.5988

Fingeret, M. C., Hutcheson, K. A., Jensen, K., Yuan, Y., Urbauer, D., & Lewin, J. S. (2013). Associations among speech, eating, and body image concerns for surgical patients with head and neck cancer. Head & Neck, 35(3), 354–360. https://doi.org/10.1002/hed.22980

Han, C. J., Yang, G. S., & Syrjala, K. (2020). Symptom experiences in colorectal cancer survivors after cancer treatments: A systematic review and meta-analysis. Cancer Nursing, 43(3), E132–E158. https://doi.org/10.1097/NCC.0000000000000785

Herz, R. S. (2009). Aromatherapy Facts and Fictions: A Scientific Analysis of Olfactory Effects on Mood, Physiology and Behavior. International Journal of Neuroscience, 119(2), 263–290. https://doi.org/10.1080/00207450802333953

Herz, R. S., Schankler, C., & Beland, S. (2004). Olfaction, Emotion and Associative Learning: Effects on Motivated Behavior. Motivation and Emotion, 28(4), 363–383. https://doi.org/10.1007/s11031-004-2389-x

Jayarajah, U., Samarasekera, A. M., & Samarasekera, D. N. (2016). A study of postoperative anxiety and depression among patients with intestinal stomas. Sri Lanka Journal of Surgery, 34(2), 6. https://doi.org/10.4038/sljs.v34i2.8261

Lim, C. Y. S., Laidsaar-Powell, R. C., Young, J. M., Kao, S. C.-H., Zhang, Y., & Butow, P. (2021). Colorectal cancer survivorship: A systematic review and thematic synthesis of qualitative research. European Journal of Cancer Care, 30(4), e13421. MEDLINE. https://doi.org/10.1111/ecc.13421

Merleau-Ponty, M. (2011). Phenomenology of Perception. Routledge. https://doi.org/10.4324/9780203720714

Peng, Y.-N., Huang, M.-L., & Kao, C.-H. (2019). Prevalence of Depression and Anxiety in Colorectal Cancer Patients: A Literature Review. International Journal of Environmental Research and Public Health, 16(3), Article 3. https://doi.org/10.3390/ijerph16030411

Rhoten, B. (2018). Theoretical Foundations of Body Image. In Body Image Care for Cancer Patients: Principles and Practice (p. 400). Oxford University Press.

Rhoten, B. A. (2016). Body image disturbance in adults treated for cancer – a concept analysis. Journal of Advanced Nursing, 72(5), 1001–1011. https://doi.org/10.1111/jan.12892

Rhoten, B. A., Murphy, B., & Ridner, S. H. (2013). Body image in patients with head and neck cancer: A review of the literature. Oral Oncology, 49(8), 753–760. https://doi.org/10.1016/j.oraloncology.2013.04.005

Saunders, C. H., Goldwag, J. L., Read, J. T., Durand, M.-A., Elwyn, G., & Ivatury, S. J. (2021). "Because Everybody is so Different": A qualitative analysis of the lived experiences and information needs of rectal cancer survivors. BMJ Open, 11(5), e043245. https://doi.org/10.1136/bmjopen-2020-043245

Siegel, R. L., Wagle, N. S., Cercek, A., Smith, R. A., & Jemal, A. (2023). Colorectal cancer statistics, 2023. CA: A Cancer Journal for Clinicians, 73(3), 233–254. https://doi.org/10.3322/caac.21772

Spence, C. (2021). The scent of attraction and the smell of success: Crossmodal influences on person perception. Cognitive Research: Principles and Implications, 6(1), 46. https://doi.org/10.1186/s41235-021-00311-3

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), 8512. https://doi.org/10.3390/ijerph18168512

Sun, V., Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J., Baldwin, C. M., & Krouse, R. S. (2013). Surviving Colorectal Cancer: Long-term, Persistent Ostomy-Specific Concerns and Adaptations.

Journal of Wound Ostomy & Continence Nursing, 40(1), 61. https://doi.org/10.1097/WON.0b013e3182750143

Trudel-Fitzgerald, C., Tworoger, S. S., Poole, E. M., Zhang, X., Giovannucci, E. L., Meyerhardt, J. A., & Kubzansky, L. D. (2018). Psychological symptoms and subsequent healthy lifestyle after a colorectal cancer diagnosis. Health Psychology, 37(3), 207–217. https://doi.org/10.1037/hea0000571

Williams, J. (2008). Flatus, odour and the ostomist: Coping strategies and interventions. British Journal of Nursing, 17(Sup1), S10–S14. https://doi.org/10.12968/bjon.2008.17.Sup1.28144

Zhu, L., Tong, Y. X., Xu, X. S., Xiao, A. T., Zhang, Y. J., & Zhang, S. (2020). High level of unmet needs and anxiety are associated with delayed initiation of adjuvant chemotherapy for colorectal cancer patients. Supportive Care in Cancer, 28(11), 5299–5306. CINAHL with Full Text. https://doi.org/10.1007/s00520-020-05333-z

CHAPTER 2

Manuscript 1 (published): Factors associated with anxiety in colorectal cancer survivors: a scoping review

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Factors associated with anxiety in colorectal cancer survivors: a scoping review

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Abstract

Purpose Anxiety is one of the most common psychological issues among colorectal cancer (CRC) survivors. It can interact with physical symptoms, impacting cancer progression, survival, and quality of life. This scoping review aims to explore the factors associated with anxiety in patients with CRC and the instruments used to measure anxiety.

Methods Using Arksey and O'Malley's (2005) framework for the scoping review, studies investigating anxiety in CRC patients published in CINAHL, PubMed, PsycINFO, and Scopus between 2013 and 2024 were included.

Results We analyzed fifty-one studies for this review. The review identified several risk factors and consequences of anxiety in CRC patients. The risk factors were classified into six domains using Niedzwiedz et al.'s (2019) framework: individual characteristics, social/ contextual factors, prior psychological factors, psychological responses to diagnosis and treatment, characteristics of cancer, and treatment. The consequences of anxiety were classified into three categories: global health status/quality of life, functions, and symptoms/problems. The most frequently used tool was the Hospital Anxiety and Depression Scale, with International Classification of Diseases codes being the second most used.

Conclusions This scoping review highlighted the intricate interaction between biological and psychosocial aspects in the lives of CRC survivors. It also identified unique factors associated with anxiety among these individuals. However, the review found some

inconsistencies in the results related to anxiety-related factors, potentially due to differences in study populations, designs, measurement tools, and analysis methods.

Implications for Cancer Survivors This review underscores the potential for interventions targeting modifiable factors to prevent or reduce anxiety and enhance the quality of life for CRC survivors.

Introduction

Colorectal cancer (CRC) is a common diagnosis, ranking as the third most common cancer in the US (Siegel et al., 2023). The American Cancer Society (2024) estimates that in 2024, there will be 106,590 colon and 46,220 rectal cancer cases diagnosed in the US, with an expected 53,010 deaths from CRC. However, due to advances in early diagnosis and treatment, CRC-related mortality rates have been gradually declining (Siegel et al., 2023). Notably, the rate of young-onset CRC, diagnosed before the age of 55, has been increasing over the past two decades for unknown reasons (American Cancer Society, 2024; Khoo et al., 2022). According to the American Cancer Society report (2024), since the mid-1990s, the incidence of CRC has risen by 1% to 2% annually in individuals under 55. As a result, a growing number of survivors are expected to live longer while dealing with the effects of their disease and treatment, such as increased levels of anxiety.

According to a recent meta-analysis, the pooled prevalence of anxiety symptoms in CRC patients was 18.9% (Zamani & Alizadeh-Tabari, 2023). Excessive anxiety in any cancer patient is concerning as it is associated with increased disease complications, treatment issues, and mortality rates. A US-based prospective cohort study involving 1228 health professionals diagnosed with CRC found that increases in anxiety symptoms correlated with a 17% higher mortality risk, even after controlling for cancer characteristics (Trudel-Fitzgerald et al., 2020). Therefore, understanding the factors associated with anxiety within the CRC population is crucial for its effective prevention and treatment.

Despite numerous recent findings in this research area, no scoping review specifically focusing on anxiety in the CRC population has been published. Some systematic (Cheng et al., 2022; Xia et al., 2024) or literature reviews (Peng et al., 2019) exist, though these address narrower research questions such as the onset (Cheng et al., 2022) or prevalence of anxiety (Peng et al., 2019), or the predictive value of anxiety on the mortality of patients with CRC (Xia et al., 2024). However, these reviews often exclude findings that would provide a broader view of this phenomenon. In addition, while the existing literature contains several comprehensive review articles on anxiety in cancer patients as a generalized group (Curran et al., 2017; Niedzwiedz et al., 2019; Pitman et al., 2018; Traeger et al., 2012; Wang et al., 2020; Yi & Syrjala, 2017), there are few that specifically address anxiety in CRC patients. Synthesizing findings on anxiety in specific types of cancer is crucial, as each cancer type exhibits unique characteristics in terms of disease progression and treatment modalities. CRC patients often experience unique anxiety-related factors that differentiate them from other cancer patients, such as social isolation resulting from bowel or ostomy problems (Carlile & McAdam, 2023; Saunders et al., 2021). The primary purpose of this scoping review is to synthesize and compile findings on the factors associated with anxiety in CRC patients. By analyzing the current literature, our goal is to identify risk factors and consequences of anxiety in CRC survivors, as well as the instruments used for assessment. Through this, we aim to pinpoint the current research gaps concerning anxiety in this population.

Methods

We followed Arksey and O'Malley's (2005) methodological framework for this scoping review. The research process was initiated with an initial article search in

November 2023, in consultation with a health sciences librarian. To ensure that our research was up to date and included the most recent information available, we conducted a final follow-up search in April 2024. We utilized four key databases for the search: CINAHL, PubMed, PsycINFO, and Scopus. Our search strategy was carefully crafted to capture a broad range of articles related to anxiety and colorectal cancer. The specific query used was: ((anxiety[Title/Abstract]) AND (colorectal[Title/Abstract] OR colon[Title/Abstract] OR bowel[Title/Abstract] OR rectal[Title/Abstract])) AND (cancer[Title/Abstract] OR neoplasm*[Title/Abstract] OR carcinoma*[Title/Abstract] OR tumor*[Title/Abstract]).We included articles with ‘colorectal cancer’ and ‘anxiety’ keywords in their title or abstract, published in English between 2013 and 2024. We limited our search to this period to collect the most current research on this issue. We excluded studies where CRC or anxiety was not the major subject (e.g., mixed results with other cancer populations or other mental health outcomes like depression), those solely evaluating specific intervention aspects (e.g., surgical technique, cognitive behavior therapy), or studies centered on colorectal cancer screening.

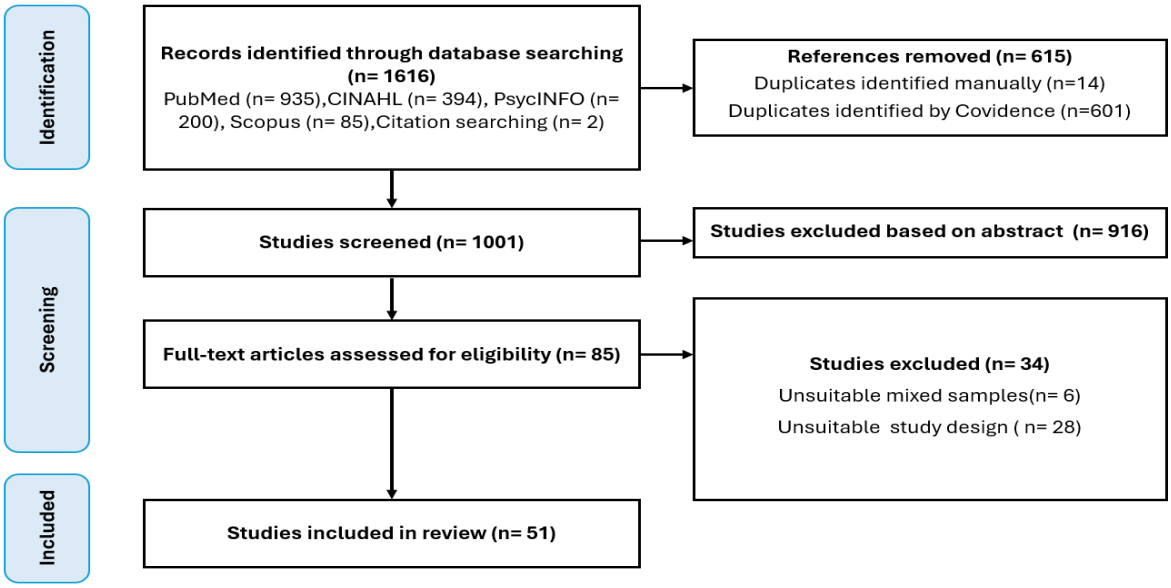
Our selection process is visualized using a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram (see Figure 1). At the initial stage of our process, a total of 1616 studies were identified as potential sources for our review. Using Covidence, we identified 601 duplicate studies to remove from our pool. We also manually identified an additional 14 duplicates, further refining our pool. After eliminating these duplicates, we were left with 1001 studies. After reviewing titles and abstracts, we excluded 916 studies that did not meet our prespecified criteria for inclusion. We then reviewed the full text of the remaining 85 studies, leading to the

exclusion of 34 additional studies. The reasons for their exclusion varied, including issues such as unsuitable mixed samples (e.g., results related to anxiety were mixed with those of other cancer populations or individuals without a cancer diagnosis) or unsuitable study design (e.g., results related to anxiety were combined with other mental illnesses such as depression, or studies where anxiety is not the focus) (Figure 1). After this comprehensive review and exclusion process, 51 studies met our specified criteria and were included in our review.

The data charting process for this scoping review involved extracting key information from each included study. The extracted data items included the authors and year of publication, study design, the country where the study was conducted, cancer site, stage of cancer at the time of the study, sample size, exclusion of participants with a mental health history, study timeframe, measures used to assess anxiety, cut-off points used in these measures, identified risk factors for anxiety, and the consequences of anxiety as reported in the study.

Figure 1.

Prisma for anxiety among colorectal cancer survivors



Results

The included articles comprise three review papers, 43 quantitative studies (including 22 cross-sectional and 21 longitudinal studies), four qualitative studies, and one mixed-method study. These studies were conducted in various countries, with the majority in the US (n=12) and China (n=10), including Brazil, Spain, the Netherlands, and Japan. The characteristics of the included studies are summarized in Table 1. In addition, this table categorizes variables into two groups: risk factors and consequences of anxiety. We consider independent variables as potential risk factors and dependent variables as potential consequences. We also consider timely sequences or mechanistic plausibility, such as gender being a risk factor of anxiety, not the other way around. The interpretation of results within the studies also significantly influences our classification process. However, it is important to note that due to the observational nature of most included studies, our ability to confidently establish a clear cause-and-effect relationship, or even directionality, between anxiety and the other variables is inherently limited.

We classified data on risk factors into six domains using Niedzwiedz et al.'s (2019) framework, designed to explain factors contributing to depression and anxiety among cancer patients. The framework considers individual characteristics, social/ contextual factors, prior psychological factors, psychological responses to diagnosis, characteristics of cancer, and treatment (Niedzwiedz et al., 2019). We modified the 'psychological responses to diagnosis' domain to 'psychological responses to diagnosis and treatment', as most psychological factors in our included studies were evaluated during or after treatment.

Table 1.

Included study characteristics, anxiety risk factors, consequences, and assessment instruments

Authors (Year)	Study Design	Country	Cancer site	Cancer Stage	Sample Size	Exclusion of Participants with Mental Health History	Time	Anxiety Measures	Cut-off Points	Risk Factors	Consequences
Akyol et al. (2015)	Cross-sectional	Turkey	Colon, rectum	N/A	105	N/A	N/A	HADS	Turkey version: ≥10 high anxiety	>Individual characteristics: female (+)	Global QOL (-), physical functioning, role functioning, cognitive functioning, emotional functioning, and social functioning (-), symptoms (Fatigue, Nausea/Vomiting, pain, appetite loss) (+), (Dyspnea, insomnia, constipation, diarrhea) (0), financial problems

											(+), sexual (touch, avoidance, Anorgasmia) problems (+)
Benedict et al. (2016)	Cross-sectional	US	Rectal or anal cancer	I-III	70 (females)	N/A	Post-treatment & Mean years since treatment (SD)= 4.3 (3.3)	Brief Symptom Inventory (BSI) Anxiety subscale	continuous	>Prior psychological factors: body image disturbance (+) >Characteristics of cancer: GI symptoms (e.g., feeling bloated, gas, and pain in abdomen) (+), diarrhea (0) >Cancer treatment: having ostomy (+)	N/A
Benedict et al. (2018)	Cross-sectional	US	Rectal or anal cancer	I-III	144	N/A	Post-treatment & Mean years since treatment (SD)= 4.6 (3.3)	Brief Symptom Inventory (BSI) Anxiety subscale	continuous	>Individual characteristics: female (+) >Characteristics of cancer: diarrhea (+). diarrhea→	N/A

										social function (-)	
Boehmer et al. (2021)	Cross-sectional	US	Colon, rectum	I-III	Heterosexual (n=353) and Sexual minority (n=127)	N/A	Within 5 years following CRC diagnosis	Health-related anxiety in QLQ-CR29, HADS	Health-related anxiety> dichotomized: <51 vs. ≥51 HADS> Dichotomized <8: normal ≥8: presence of anxiety	>Individual characteristics: Sexual minority (+)	N/A
Boehmer, Clark, et al. (2022)	Cross-sectional	US	Colon, rectum	I-III	Sexual minority (n=127)	N/A	Within 5 years following CRC diagnosis	Health-related anxiety in QLQ-CR29, HADS	Health-related anxiety> dichotomized: <51 vs. ≥51 HADS> continuous	>Individual characteristics: Age at diagnosis (-,0), sexual minority identity in years (-) >Social & Contextual factors: discrimination (+), employed (+), neighborhood poverty (+)	N/A

										>Psychological response to diagnosis and treatment: denial coping (+), embarrassment due to stoma or bowel movements (+) >Characteristics of cancer: dry mouth (+)	
Boehmer, Ozonoff, et al. (2022)	Cross-sectional	US	Colon, rectum	I-III	Heterosexual (n=353) and Sexual minority (n=127)	N/A	Within 5 years following CRC diagnosis	Health-related anxiety in QLQ-CR29, HADS	Health-related anxiety> dichotomized: <51 vs. ≥51 HADS> Continuous	>Individual characteristics: Sexual minority after adjusting for covariates (0), age at diagnosis (-,0), poor health (+), comorbidity (+), overweight or obese (-) >Social & Contextual	N/A

	factors: employed (+), discriminatio n experience (+), loneliness (+), education level (-), support (-) >Psychologi cal response to diagnosis and treatment: attending support group (+), active coping (+), low body image (+), weight concerns (+), resilience (-) >Characteris tics of cancer: Abd pain (+), dry mouth (+), embarrassme nt (+), flatulence (+)

										>Cancer treatment: chemo (+)	
Bonhof et al. (2019)	Cross-sectional	Netherlands	Colon, rectum	I - IV	1643	N/A	Mean years since diagnosis (SD)= 6.1 (2.8)	HADS	Continuous	>Cancer treatment: Chemotherapy-Induced Peripheral Neuropathy (+)	Fatigue (+)
Braamse et al. (2016)	Cross-sectional	Netherlands	Colon, rectum	I - IV	91	N/A	Diagnosed 3.5 to 6 years ago	Beck Anxiety Inventory	Continuous	>Individual characteristics: comorbidity (+) >Characteristics of cancer: The time since cancer diagnosis (-)	N/A
Carlile & McAdam (2023)	Qualitative	UK	Colon, rectum	I–III (Duke classification: A-C)	15	N/A	Completed curative treatment at least 6 months previously	Interview	N/A	>Psychological response to diagnosis and treatment: fear of recurrence (+) >Cancer treatment: bowel or ostomy dysfunction (+)	Social functioning (-), sexual dysfunction, dietary changes

Cheng et al. (2022)	Systematic Review and Meta-Analysis	N/A	Colon, rectum	N/A	8 cohort studies (only 6 studies assessed anxiety)	N/A	The included articles were published between 2010 and 2021	ICD-9 code (n= 7), Hospital Anxiety and Depression Scale (HADS) (n=1)	N/A	> Individual characteristics: Age at diagnosis (+/-), female (+), comorbidities (+) > Characteristics of cancer: cancer stage (+), cancer site (0: CRC diagnosis, no matter the site, is linked with increased anxiety) > Cancer treatment: radiotherapy (+), chemotherapy (+), colostomy (+)	After adjusting for age, sex, and number of comorbidities: global QOL (-), physical functioning, role functioning, cognitive functioning, emotional functioning, and social functioning (-) mortality (+)
Di Cristofaro et al. (2014)	Prospective Cohort	Italy	Colon, rectum	I - IV	116	N/A	At the time of admission and at 1 and 6 months	EORTC colorectal cancer module (CR29)	Continuous	>Cancer treatment: 1 month after surgery, complications (+)	N/A

							after surgery				
Gonzalez-Saenz de Tejada et al. (2016)	Longitudinal	Spain	Colon, rectum	N/A	972	N/A	Before surgery and 12 months afterwards	HADS	<8: Non-case ≥8: Borderline case ≥11: Probable case	N/A	After adjusting for age, location, gender, and baseline HRQoL: emotional functioning (-), physical functioning, role functioning, cognitive functioning, emotional functioning, and social functioning (0), pain (+), fatigue (+)
Gonzalez-Saenz de Tejada et al. (2017)	Longitudinal	Spain	Colon, rectum	0 - IV	947	N/A	Before surgery and 12 months afterward	HADS	Continuous	>Individual characteristics: age (-), female (+), married (0) >Social & Contextual factors: Unemployed (0), social support (-),	N/A

										>Psychological response to diagnosis and treatment: baseline HADS (-), insomnia (+) >Characteristics of cancer: cancer stage (0), location (0), physical function (-), cognitive function (-), social function (-), functionally independent (-)	
(Gray et al. (2014)	Cross-sectional	UK	Colon, rectum	N/A	496	N/A	Within 26 weeks or between 48 weeks to 2 years since CRC diagnosis	HADS	Dichotomized <8: non-case ≥8: borderline case	>Individual characteristics: smoker (+) >Social & Contextual factors: unemployed (+), living in a deprived area (+), difficulty in	N/A

carrying out domestic chores, financial difficulty (+), communication difficulty (+), living arrangement difficulty (+), isolation (+) >Prior psychological factors: Hx Anxiety or Depression (+) >Psychological response to diagnosis and treatment: negative emotional consequences (+), depression (+) >Characteristics of cancer: Nausea or vomiting (+), dyspnea

										(+), sleep disturbance (+), diarrhea (+), pain (+), # of symptoms (+), cognitive functioning (-)	
Hess et al. (2023)	Cross-sectional	US	Colon, rectum	I - IV	277 (≥60 years)	N/A	N/A	Patient-Reported Outcomes Measurement Information System (PROMIS) Anxiety Four-item Short Form	Dichotomized as Not or mild anxiety (t-score<60) vs Moderate or severe anxiety (t-score ≥60)	>Individual characteristics: age (0), female (0), race-ethnicity (0), married (0) >Social & Contextual factors: educational level (0), unemployed (0) >Characteristics of cancer: cancer stage (0)	After adjusting age, sex, race, and cancer stage: depression (+), frailty (+), physical HRQOL (-), mental HRQOL (-)
Holthuijsen et al. (2024)	Prospective Cohort	Netherlands	Colon, rectum	I-III	249	N/A	At 6 weeks, 6 months, 12 months, 24	HADS	<8: No anxiety disorder ≥8: Potential	>Characteristics of cancer: After adjusting confounder,	N/A

							months, and 60 months post-treatment		anxiety disorder	plasma 3-hydroxyanthranilic acid (-), Time after post-treatment (0)	
Howren et al. (2022)	Retrospective Cohort	Canada	Colon, rectum	N/A	54,634 (&546,340 cancer-free)	Met the case definition for anxiety before the index date	Initial (12 months after diagnosis), continuing (Between initial and end of life phase), end-of-life (12 months before cancer death)	ICD codes (9 or 10) : ICD-9: 300.0, 300.2 ICD-10: F40-F41	To meet the case definition for anxiety, ≥1 inpatient ICD code or 2 outpatient ICD codes within a 2-year period	>Individual characteristics: In participants diagnosed with CRC under the age of 50, the risk of anxiety was similar to those of cancer-free controls (0), Participants diagnosed with CRC after the age of 50 had a higher risk of anxiety than cancer-free individuals in the same age group (+), after adjusting for the	N/A

										confounding variables, age at diagnosis (0) >Characteristics of cancer Time since CRC diagnosis (b/w initial and end of life>12 months after CRC diagnosis> 12 months before cancer death)	
Hu et al. (2022)	Case-Control	China	Colon, rectum	I-III	602	Mental disease or pre-operate HADS>=8	Pre-surgery and 2 weeks post-discharge	HADS	Dichotomized: <8: Normal ≥8: Anxiety	>Individual characteristics: female (+), age (0), married (-), comorbidity (+) >Social & Contextual factors: education level (0), dissatisfaction with income (+) >Characteris	N/A

										tics of cancer: Cancer stage (0), Poor performance Status (+) >Cancer treatment: Postoperative complication (+), chemotherapy (+), permanent stoma (+)	
Huang et al. (2023)	Prospective Case-control	China	Colon, rectum	I - IV	362	Mental illness	1-2 days before and after chemo	HADS	Continuous	N/A	Cancer-related fatigue (+)
Hyphantis et al. (2016)	Prospective Cohort	Greece	Colon, rectum	I-III	84 (& 82 breast cancer, 50 unknown cancer, and 84 healthy controls)	History of psychotic illness	Baseline and after one year & Mean months since diagnosis (SD)= 15.5 (23)	Symptom Distress Check List (SCL-90-R)	Continuous	>Characteristics of cancer Time (+)	Trouble falling asleep (+), wakening up early in the morning (0)
Jakobsson et al. (2016)	Prospective Cohort	Sweden	Colon, rectum	N/A	105	N/A	Pre-surgery and up to 6 months	State-Trait Anxiety Inventory (STAI)	Continuous	>Characteristics of cancer: Time, before surgery (+)	N/A

							post-surgery			>Cancer treatment: Types of CRC surgery: rectal resection, abdominoperineal resection, and colonic resection (0) Within the groups (colonic resection reported less anxiety at discharge than before surgery)	
Jin et al. (2019)	Longitudinal	China	Rectal cancer	I - IV	67	History of mental illness	1-2 days pre-surgery (with colostomy) and pre-discharge	HADS	Continuous	>Characteristics of cancer: pre-surgery (+)	Psychosocial behavior reactions (-): impact, acknowledgment, retreat, and reconstruction
Kerckhove et al. (2021)	Cross-sectional	France	Colon, rectum	N/A	96	N/A	≤5 years from the time chemotherapy was discontin	HADS	<8: Normal ≥8: Borderline or suggestiv	>Cancer treatment: Chemotherapy-Induced Peripheral	N/A

							ued & who were treated with adjuvant oxaliplatin-based chemotherapy		e of anxiety ≥11: Indicative of anxiety	Neuropathy (+)	
Lim et al. (2022)	Mixed method (cross-sectional & semi-structured interviews)	Australia	Colon, rectum	IV	38	N/A	Between 0.5-2 years post-surgery. Mean months since treatment (SD)= 14 (5)	interview	N/A	>Psychological response to diagnosis and treatment: active confrontation (-), meaning making (-), and acceptance (-), active avoidance (-, +), passive avoidance (-, +)	N/A
Lloyd et al. (2019)	Retrospective Cohort	US	Colon, rectum	I - IV	8,961	Prior history of mental illness	At 0-2 years, >2-5 years or >5 years after CRC diagnosis	ICD-9 diagnostic codes	Clinical classifications software	>Characteristics of cancer: The time since cancer diagnosis (-) (Adj. HR): 0-2 Years (2.84), 2-5	Mortality (+), but this is a mixed result with other mental illnesses.

										Years (1.24), and +5 Years (1.3)	
Miranda et al. (2014)	Cross-sectional	Brazil	Colon, rectum	N/A	20 (& 20 healthy)	Schizoaffective disorder, bipolar disorder, or panic disorder	Within 15 to 30 days after diagnosis and admitted for tumor resection	HADS	Continuous	>Characteristics of cancer: proinflammatory cytokine levels: IL-1β (+), IL-6 (+), IL8 (+), TNF-α (+), IL-10 (-)	N/A
Miranda et al. (2017)	Cross-sectional	Brazil	Colon, rectum	N/A	80	Schizoaffective disorder, bipolar disorder, or panic disorder	Four groups (n=20 each): pre-surgery; post-resection without therapy; on chemotherapy for ~3 months; and post ~6-month chemotherapy	HADS	Continuous	>Characteristics of cancer: Fractalkine serum levels (+) at different stages of antitumor therapy	N/A
Miranda et al. (2018)	Cross-sectional	Brazil	Colon,	III	60 (& 20 healthy)	Schizoaffective disorder,	Pre-chemotherapy,	HADS	Continuous	>Characteristics of cancer:	N/A

			rectum			bipolar disorder, or panic disorder	Under chemotherapy and post-chemotherapy, n = 20 in each group			proinflammatory cytokine levels: IL-1β (+), IL-6 (+), IL8 (+), TNF-α (+), IL-10 (-) at different stages of antitumor therapy	
Mohamed et al. (2021)	Qualitative	US	Bladder, colon, or rectal	N/A	30 (& 13 caregivers)	N/A	Completed ostomy surgery Time since surgery: <1 year 20% 1-2 years 50% >2 years 30%	Interview	N/A	>Cancer treatment: Learning about stoma care by' trial and errors', need to master ostomy care, everyday challenges in the utility of stomal appliances, post-surgical morbidity, changes in body image, and difficulties resuming 'normal activities'	N/A

Mols et al. (2018)	Prospective Cohort	Netherlands	Colon, rectum	I - IV	2625 (& 315 cancer-free)	N/A	In 2010, 2011, 2012, and 2013 (data from the cancer registry) & mean years since diagnosis (SD)= 5.2 (2.8)	HADS	<8: Low ≥8: High	>Individual characteristics: cancer group (+), age (-), female (+), married (-), comorbidities (+) >Social & Contextual factors: education level (-) >Characteristics of cancer: Cancer stage (0), Time since CRC diagnosis (0) >Cancer treatment: Radiotherapy (0), Chemotherapy (0)	After adjusting for age, sex, and number of comorbidities: global QOL (-), physical functioning, role functioning, cognitive functioning, emotional functioning, and social functioning (-)
Orive et al. (2022)	Prospective Cohort	Spain	Colon, rectum	0 - IV	2531	Any severe mental conditions	Before surgery, and at 1, 2, 3, and 5 years after surgery	HADS	<8: Absence of anxiety ≥8: Possible case ≥11: Higher a	>Individual characteristics: female (+) >Psychological response to diagnosis and	Mortality (+)

									probable case	treatment: baseline anxiety level (+) >Characteristics of cancer: stage (+) >Cancer treatment: chemotherapy (+), Complications at 1year after surgery (+)	
Peng et al. (2019)	Literature Review	N/A	Colon, rectum	N/A	15 cohort studies	N/A	The included articles were published between 1967 and 2018	HADS (7) ICD-9 (2) Minnesota Multiphasic Personality Inventory (1), Brief Symptom Inventory-18 (1)	N/A	>Individual characteristics: age (+/0)	N/A
Renna et al. (2022)	Cross-sectional	US	Colon,	I - IV	88	N/A	Within 1-3 months after diagnosis	Beck Anxiety	Continuous	N/A	After adjusting stage, comorbiditi

			rectum				and before undergoing adjuvant cancer treatment	Inventory (BAI)			es, BMI, age, and sex: pain (+), fatigue (+), C-reactive protein (+)
Révész et al. (2022)	Longitudinal	Netherlands	Colon, rectum	I - IV	910 (non-drinkers = 191 vs. drinkers of alcohol =719)	N/A	At diagnosis and 3-, 6-, 12-, and 24-months post-diagnosis	HADS	Continuous & Dichotomized: <8: Low anxiety ≥8: Clinical anxiety	>Individual characteristics: Alcohol consumption (-)	N/A
Salamonsen et al. (2016)	Qualitative	Norway	Rectal	I–III	9	N/A	Diagnosed within the last 6 months and have completed primary surgical treatment	Interview	N/A	>Social & Contextual factors life course disruption	Patient-defined health care needs (emotional needs)
Saunders et al. (2021)	Qualitative	US	Rectal	I–III	15 (&, 5 caregivers, 10 physicians.)	N/A	Completed treatment	Interview	N/A	>Cancer treatment: bowel or ostomy dysfunction (leak, noise, odor, hernia)	Not eating or drinking before meeting to control urgency, carrying extra clothes,

											scanning the nearest bathroom, and fearing leaving their homes
Selvy et al. (2020)	Cross-sectional	France	Colon, rectum	N/A	406	N/A	Received adjuvant oxaliplatin-based chemotherapy within 5 years	HADS	<8: Normal ≥8: Borderline or suggestive of anxiety ≥11: Indicative of anxiety	>Cancer treatment: Chemotherapy-Induced Peripheral Neuropathy (+)	N/A
Song et al. (2020)	Cross-sectional	China	Colon, rectum	0 - IV	282	N/A	1 to 2 weeks post-surgery	HADS	≥9 possible cases of anxiety & continuous	>Psychological response to diagnosis and treatment: body image disturbance (+) >Cancer treatment: having ostomy (+) ostomy status (temporary or permanent) (0)	N/A

Soria-Utrilla et al. (2022)	Prospective Cohort	Spain	Colon, rectum	I - IV	215	N/A	Before surgery, during admission, and at 1-, 6-, and 12-months follow-up	HADS (before surgery)	≥8: possible presence of anxiety ≥11: probable presence of anxiety	After adjusting for age, sex, and cancer stage, Preoperative malnourished status (+)	After adjusting for age, sex, and cancer stage: Surgical complications (0), mortality (0)
Sun et al. (2020)	Cross-sectional	China	Colon, rectum	I - IV	434	Coexisting mental disorders, use of psychotropic drugs 7 days before the survey.	The morning before the day of surgery	Hamilton Anxiety Rating Scale	Continuous	N/A	Preoperative insomnia (+)
Tamura (2021)	Cross-sectional	Japan	Colon, rectum	I - IV	121	History of severe anxiety, depression, or mental illness.	Diagnosed at least 6 weeks ago and have completed one course of chemotherapy	HADS	Continuous	>Individual characteristics: age (0), female (0), married (0), comorbidity (0) >Social & Contextual factors: education level (0), financial difficulty (+), self-disclosure (-)	QOL (-) depression (+)

										>Psychological response to diagnosis and treatment: resilience (-) >Characteristics of cancer: poor appetite (+), poor concentration (+), pain (+), fatigue (+), metastasis (0), nausea (0), hair loss (0), peripheral neuropathy (0), Abd fullness (0), diarrhea (0)	
Trudel-Fitzgerald et al. (2018)	Prospective Cohort	US	Colon, rectum	N/A	145 (from the Nurses' Health Study)	N/A	Within 4 years following CRC diagnosis (Follow up every 4 years for 20 years after CRC	Crown-Crisp Index (CCI)	Dichotomized <4: low vs ≥4: high	N/A	Healthy lifestyles (physical activity, diet, BMI, alcohol, and tobacco consumption) (-)

							diagnosis)				
Trudel-Fitzgerald et al. (2020)	Prospective Cohort	US	Colon, rectum	0 - IV	1228 individuals from Nurses' Health Study and 504 from Health Professional	N/A	Within 4 years following CRC diagnosis. Follow-up over 28 years	8-item Crown-Crisp Index (CCI) 7-item Generalized Anxiety Disorder (GAD-7) scale or anxiolytics use	Dichotomized (y/n) clinical anxiety	>Individual characteristics: female (+), Prevalent cardiometabolic disease (+, 0)	Mortality (+)
Vallance et al. (2015)	Cross-sectional	Canada & Western Australia	Colon	I - IV	180	N/A	Mean months since diagnosis (SD) = 18.8(4.4) & not currently undergoing any adjuvant therapy.	Spielberger's State Anxiety Inventory (SAI)	Continuous	>Individual characteristics: moderate-to-vigorous intensity physical activity (-), Sedentary time (0)	N/A
van Putten et al. (2016)	Prospective Cohort	Netherlands	Colon, rectum	I-III	1375	N/A	In 2010, 2011, 2012 & Mean years	HADS	Continuous	N/A	Moderate-to-vigorous physical activity (-)

							since diagnosis (SD)= 5.3 (2.8)				
Wang et al. (2024)	Cross-sectional	China	Colon, rectum	I - IV	370	History of psychiatric illness	Patients undergoing postoperative adjuvant therapy	GAD-7	N/A	N/A	Cancer-related fatigue (0)
Xia et al. (2024)	Systematic Review and Meta-Analysis	N/A	Colon, rectum	N/A	12 cohort studies	N/A	The included articles were published between 2013 and 2023	HADS (5), Crown-Crisp Index (1), Generalized Anxiety Disorder-7 (1)	N/A	N/A	In univariate analysis (Unadjusted HR), mortality (+) In multivariate analysis (adjusted HR), mortality (0)
Xiangting et al. (2023)	Cross-sectional	China	Colon, rectum	I - IV	175	Psychiatric disorders	4 days- 6 months after ostomy	HADS	Continuous	N/A	Supportive care needs: Physiology and daily living needs (+), Psychological needs (+), Sexual needs (0), Care and

											support needs (+), Health information needs (+)
Zhang et al. (2016)	Prospective Cohort	China	Rectal cancer	I - IV	852	N/A	After the first treatment and 6 months later	HADS	<11: No case ≥11: Clinical anxiety	>Prior psychological factors: Type D personality (+)	N/A
Zhou & Sun (2021)	Longitudinal	China	Colon, rectum	I-III	302 (who underwent resection)	N/A	At discharge and then every 3 months till Month 36	HADS	Dichotomized <8: Non-case ≥8: Anxiety	Associated with 3-year anxiety risk, >Individual characteristics: female (+), married (-), smoker (-) >Social & Contextual factors unemployed (+) >Characteristics of cancer: stage (+), Time since discharge after resection surgery (+)	N/A

Zhu et al. (2020)	Longitudinal (Retrospective)	China	Colon, rectum	I - IV	135	Concurrent psychiatric disorder or other mental problems	Starting time and completion time of chemotherapy	HADS	Dichotomized <11: No ≥11: Case of anxiety	N/A	Early initiation of adjuvant chemotherapy (-)

0, Not statistically significant; +, Positive association; -, Negative association

Abbreviations: CRC, colorectal cancer; HADS, Hospital Anxiety and Depression Scale; global QoL, global health status and Quality of Life; HRQOL, health-related quality of life; N/A, not applicable

Based on data extracted from the included studies, we summarized the risk factors and consequences of anxiety in CRC survivors in Table 2. The consequences of anxiety in survivors of CRC were multifaceted and could be divided into three categories: global health status/quality of life, functions, and symptoms/problems. These categories were derived from the subcategories of the European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30), a quality-of-life instrument for cancer patients (Aaronson et al., 1993; Fayers et al., 2001). In this instrument, a high score for global health status or quality of life represents a high quality of life. A high score on a functional scale indicates a high or healthy level of functioning. Lastly, a high score for a symptom scale or item indicates a high level of symptomatology or problems. We modified ‘symptom scales/items’ to 'symptoms/problems’. If studies had outcome variables not assessed by the EORTC QLQ-C30, we categorized them according to their closest relevance with items of this instrument under each category.

Table 2.

Risk factors and consequences of anxiety in colorectal cancer survivors

Categories	Subcategories/ Factors
Risk Factors	
Individual Characteristics	Age (- (Gonzalez-Saenz de Tejada et al., 2017; Mols et al., 2018), +, 0 (Hess et al., 2023; Howren et al., 2022; Hu et al., 2022; Tamura, 2021)) (Cheng et al., 2022; Peng et al., 2019) Sex: female (+ (Akyol et al., 2015; Benedict et al., 2018; Cheng et al., 2022; Gonzalez-Saenz de Tejada et al., 2017; Hu et al., 2022; Mols et al., 2018; Orive et al., 2022; Trudel-Fitzgerald et al., 2020; Zhou & Sun, 2021), 0 (Hess et al., 2023; Tamura, 2021)), sexual minority (+ (Boehmer et al., 2021), 0 (Boehmer, Ozonoff, et al., 2022)) Ethnicity (0 (Hess et al., 2023)) Marital status: married (- (Hu et al., 2022; Mols et al., 2018; Zhou & Sun, 2021), 0 (Gonzalez-Saenz de Tejada et al., 2017; Hess et al., 2023; Tamura, 2021)) Comorbidities (+ (Boehmer, Ozonoff, et al., 2022; Braamse et al., 2016; Cheng et al., 2022; Hu et al., 2022; Mols et al., 2018; Trudel-Fitzgerald et al., 2020), 0 (Tamura, 2021; Trudel-Fitzgerald et al., 2020)) Behavioral factors: alcohol consumption (- (Révész et al., 2022)), physical activity (- (Vallance et al., 2015)), smoking (- (Zhou & Sun, 2021), + (Gray et al., 2014)), overweight or obsess (- (Boehmer, Ozonoff, et al., 2022)), malnourished (+ (Soria-Utrilla et al., 2022))

Social/Contextual Factors	Education level (- (Boehmer, Ozonoff, et al., 2022; Mols et al., 2018),0 (Hess et al., 2023; Hu et al., 2022; Tamura, 2021)) Employment status: employed (- (Gray et al., 2014; Zhou & Sun, 2021), + (Boehmer, Clark, et al., 2022; Boehmer, Ozonoff, et al., 2022), 0 (Gonzalez-Saenz de Tejada et al., 2017; Hess et al., 2023)) Financial status: financial difficulty (+ (Boehmer, Clark, et al., 2022; Gray et al., 2014; Hu et al., 2022; Tamura, 2021)) Social support: support (- (Boehmer, Ozonoff, et al., 2022; Gonzalez-Saenz de Tejada et al., 2017)), self-disclosure (- (Tamura, 2021)), discrimination (+ (Boehmer, Clark, et al., 2022; Boehmer, Ozonoff, et al., 2022)), loneliness (+ (Boehmer, Ozonoff, et al., 2022)) Disruptive life events prior to cancer diagnosis (+ (Salamonsen et al., 2016))
Prior Psychological Factors	Pre-existing psychiatric disorders: pre-existing anxiety or depression (+ (Gray et al., 2014)) Personality: type D-personality (+ (Zhang et al., 2016))
Psychological Responses to Diagnosis and Treatment	Fear of cancer recurrence (+ (Carlile & McAdam, 2023)) Baseline anxiety level (+ (Orive et al., 2022)) Depression (+ (Gray et al., 2014)) Insomnia (+ (Gonzalez-Saenz de Tejada et al., 2017)) Coping behavior: meaning-making (- (Lim et al., 2022)), acceptance (- (Lim et al., 2022)), support group (- (Lim et al., 2022), + (Boehmer, Ozonoff, et al., 2022)), active avoidance (-, +) (Lim et al., 2022), passive avoidance (-, +) (Lim et al., 2022), denial (+ (Boehmer, Clark, et al., 2022)) Resilience (- (Boehmer, Ozonoff, et al., 2022; Tamura, 2021)) Body image disturbance (+ (Benedict et al., 2016; Boehmer, Ozonoff, et al., 2022; Song et al., 2020)) Embarrassment (+ (Boehmer, Clark, et al., 2022; Boehmer, Ozonoff, et al., 2022))
Characteristics of Cancer	Stage: cancer (+ (Cheng et al., 2022)), cancer stage (+ (Cheng et al., 2022; Orive et al., 2022; Zhou & Sun, 2021),0 (Gonzalez-Saenz de Tejada et al., 2017; Hess et al., 2023; Hu et al., 2022; Mols et al., 2018)) Cancer Site (0 (Cheng et al., 2022; Gonzalez-Saenz de Tejada et al., 2017)) Time since diagnosis or treatment (- (Braamse et al., 2016; Jakobsson et al., 2016; Jin et al., 2019; Lloyd et al., 2019), + (Hyphantis et al., 2016; Zhou & Sun, 2021), 0 (Holthuijsen et al., 2024; Mols et al., 2018)) Physical symptoms: GI symptoms (+ (Benedict et al., 2016)), diarrhea (0 (Benedict et al., 2016), + (Benedict et al., 2018)), abdominal pain (+ (Boehmer, Ozonoff, et al., 2022)), flatulence (+ (Boehmer, Ozonoff, et al., 2022)), dry mouth (+ (Boehmer, Clark, et al., 2022; Boehmer, Ozonoff, et al., 2022)) Functional decline: cognitive functioning (- (Gonzalez-Saenz de Tejada et al., 2017; N. M. Gray et al., 2014)), physical functioning (-(Gonzalez-Saenz de Tejada et al., 2017)), social functioning (- (Benedict et al., 2018; Gonzalez-Saenz de Tejada et al., 2017)), performance (- (Hu et al., 2022)), functionally independent (- (Gonzalez-Saenz de Tejada et al., 2017)) Blood biomarkers: IL-1β (+ (Miranda et al., 2014, 2018)), IL-6 (+ (Miranda et al., 2014, 2018)), IL8 (+ (Miranda et al., 2014, 2018)), TNF-α (+(Miranda et al., 2014, 2018)), IL-10 (-(Miranda et al., 2014, 2018)), Fractalkine (+ (Miranda et al., 2017)), 3-hydroxyanthranilic acid (- (Holthuijsen et al., 2024))
Cancer Treatment	Treatment modality: radiotherapy (+ (Boehmer, Ozonoff, et al., 2022; Cheng et al., 2022; Hu et al., 2022; Orive et al., 2022),0 (Mols et al., 2018)), chemotherapy (+ [6, 23, 33, 46], 0 (Mols et al., 2018)), ostomy (+ (Benedict et al., 2016; Cheng et al., 2022; Song et al., 2020)), permanent ostomy (+ (Hu et al., 2022), 0 (Song et al., 2020)), resection site (0 (Jakobsson et al., 2016)) Complications(+ (Di Cristofaro et al., 2014; Hu et al., 2022; Orive et al., 2022)): chemotherapy-induced peripheral neuropathy (+ (Bonhof et al., 2019; Kerckhove et al., 2021; Selvy et al., 2020)), ostomy complications (+ (Carlile & McAdam, 2023; Mohamed et al., 2021; Saunders et al., 2021))

Consequences	
Global Health Status/ Quality of Life (QOL)	Global QOL (- (Akyol et al., 2015; Cheng et al., 2022; Hess et al., 2023; Mols et al., 2018; Tamura, 2021), 0 (Gonzalez-Saenz de Tejada et al., 2016)) Mortality (+ (Cheng et al., 2022; Lloyd et al., 2019; Orive et al., 2022; Trudel-Fitzgerald et al., 2020), 0 (Soria-Utrilla et al., 2022; Xia et al., 2024))
Functioning	Physical functioning (- (Akyol et al., 2015; Cheng et al., 2022; Mols et al., 2018; Xiangting et al., 2023), 0 (Gonzalez-Saenz de Tejada et al., 2016)) Role functioning (- (Akyol et al., 2015; Cheng et al., 2022; Mols et al., 2018; Xiangting et al., 2023), 0 (Gonzalez-Saenz de Tejada et al., 2016)) Cognitive functioning (- (Akyol et al., 2015; Cheng et al., 2022; Mols et al., 2018), 0 (Gonzalez-Saenz de Tejada et al., 2016)) Social functioning (- (Akyol et al., 2015; Carlile & McAdam, 2023; Cheng et al., 2022; Mols et al., 2018; Saunders et al., 2021), 0 (Gonzalez-Saenz de Tejada et al., 2016)) Emotional functioning (- (Akyol et al., 2015; Carlile & McAdam, 2023; Cheng et al., 2022; Gonzalez-Saenz de Tejada et al., 2016; Mols et al., 2018; Saunders et al., 2021)) Sexual functioning (- (Akyol et al., 2015; Carlile & McAdam, 2023),0 (Xiangting et al., 2023)) Behavioral functioning: start adjuvant chemotherapy early (- (Zhu et al., 2020)), alcohol (+ (Trudel-Fitzgerald et al., 2018)), smoking (+ (Trudel-Fitzgerald et al., 2018)), physical activity (- (van Putten et al., 2016)), psychosocial behavioral responses (- (Jin et al., 2019))
Symptoms/ Problems	Pain (+ (Akyol et al., 2015; Bonhof et al., 2019; Gonzalez-Saenz de Tejada et al., 2016; Hess et al., 2023; Huang et al., 2023; Renna et al., 2022)), Fatigue (+ (Akyol et al., 2015; Bonhof et al., 2019; Gonzalez-Saenz de Tejada et al., 2016; Hess et al., 2023; Huang et al., 2023; Renna et al., 2022), 0(Wang et al., 2024)), Frailty (+ (Akyol et al., 2015; Bonhof et al., 2019; Gonzalez-Saenz de Tejada et al., 2016; Hess et al., 2023; Huang et al., 2023; Renna et al., 2022)), Insomnia (+ (Hyphantis et al., 2016; Sun et al., 2020), 0 (Akyol et al., 2015)), Nausea (+ (Akyol et al., 2015)), Vomiting (+ (Akyol et al., 2015)), Appetite loss (+ (Akyol et al., 2015)), Dyspnea (0 (Akyol et al., 2015)), Financial difficulty (+ (Akyol et al., 2015)), C-reactive protein (+ (Renna et al., 2022))

0, Not statistically significant; +, Positive association; -, Negative association

Risk Factors Associated with Anxiety in CRC Survivors

Individual Characteristics

While a few studies found no significant connections between the burden of comorbid health conditions and anxiety (Tamura, 2021; Trudel-Fitzgerald et al., 2020), the majority revealed that CRC survivors with more comorbid health conditions typically have higher levels of anxiety (Boehmer, Ozonoff, et al., 2022; Braamse et al., 2016; Cheng et al., 2022; Hu et al., 2022; Mols et al., 2018; Trudel-Fitzgerald et al., 2020). A prospective cohort study in the US involving 1228 health professionals suggested a link

between poorer cardiometabolic health and clinical anxiety levels in females with CRC (Trudel-Fitzgerald et al., 2020). However, this link was not observed in male participants.

Researchers have found that certain lifestyle and behavioral characteristics of CRC survivors are associated with anxiety levels. For example, alcohol consumption (Révész et al., 2022) and moderate-to-vigorous physical activity (Vallance et al., 2015) were linked to lower anxiety levels. However, studies have yielded mixed results on the connection between smoking and anxiety levels (Gray et al., 2014; Zhou & Sun, 2021). A cross-sectional study in the UK found that current smokers had higher odds of anxiety cases than those who never smoked (Gray et al., 2014). Conversely, a longitudinal study in China discovered that current smoking was an independent factor associated with a lower risk of anxiety over three years (Zhou & Sun, 2021). Additionally, a cross-sectional study found that participants who were overweight or obese had lower anxiety (Boehmer, Ozonoff, et al., 2022). A study in Spain evaluated the anxiety levels and nutritional status of CRC patients before surgery, revealing that those with high anxiety levels were more likely to be malnourished compared to others (Soria-Utrilla et al., 2022).

Social & Contextual Factors

Gray et al. (2014) measured the social difficulties of 496 CRC survivors using the Social Difficulties Inventory (SDI). Their study explored the relationship between these social factors and the levels of anxiety. The findings showed that participants with more social difficulties were more likely to have anxiety. In addition to this study, numerous others (see Table 2) have demonstrated the influence of various social/contextual factors

on anxiety among CRC survivors. For instance, employment status has mixed results: some studies found lower anxiety in employed survivors (Gray et al., 2014; Zhou & Sun, 2021), others found higher anxiety (Boehmer, Clark, et al., 2022; Boehmer, Ozonoff, et al., 2022), or no significant association (Gonzalez-Saenz de Tejada et al., 2017; Hess et al., 2023). Lower anxiety was noted in those with social support (Boehmer, Ozonoff, et al., 2022; Gonzalez-Saenz de Tejada et al., 2017) and cancer self-disclosure (Tamura, 2021). Higher anxiety was linked to discrimination or loneliness (Boehmer, Clark, et al., 2022; Boehmer, Ozonoff, et al., 2022).

A qualitative study in Norway involving nine adults recently diagnosed with stage I–III rectal cancer offered more contextualized insights into anxiety in CRC survivors (Salamonsen et al., 2016). The participants reported that grief, anxiety, and depression triggered by life events before their cancer diagnoses had significantly more disruptive effects than their cancer itself. These events included the loss of close relatives or loved ones from illness or serving as long-term caregivers for their ill loved ones for years (Salamonsen et al., 2016).

Prior Psychological Factors

Studies have found that the psychological factors of CRC survivors before their diagnosis influence their anxiety levels after diagnosis. In a UK-based cross-sectional study involving 496 CRC survivors, individuals who reported a history of anxiety or depression on a patient-reported co-morbidities questionnaire were significantly more likely to be classified as anxiety cases compared to those who reported no such history (Gray et al., 2014).

In Greece, a prospective cohort study involving 852 individuals diagnosed with rectal cancer yielded interesting findings (Zhang et al., 2016). The researchers used the 14-item Type D Personality Scale (DS14) to classify the participants' personality types. They discovered that patients identified as having a Type D personality, characterized by increased negative affectivity and social inhibition, experienced notably higher levels of anxiety at the time of diagnosis and six months later compared to those with a non-Type D personality (Zhang et al., 2016).

Psychological Response to Diagnosis and Treatment

Regardless of the cancer type, fear of recurrence is a common psychological response among survivors. Through interviews with CRC survivors who had completed treatment, Carlile and McAdam (Carlile & McAdam, 2023) reported that this fear, or the worry that something was " not right" (Carlile & McAdam, 2023, p. 100), caused anxiety among the study participants.

Several longitudinal studies have investigated the correlation between participants' baseline anxiety before CRC surgery and their anxiety levels at follow-up. In Spain, Gonzalez-Saenz de Tejada et al. (Gonzalez-Saenz de Tejada et al., 2017) assessed the anxiety levels of 947 CRC patients before surgery and one year afterward. They found that participants with higher anxiety levels prior to surgery reported a more significant decrease in anxiety levels after one year. Orive et al. (Orive et al., 2022) assessed the anxiety levels of 2531 CRC patients before surgery, and at one, two, three, and five years post-surgery. Study findings showed that participants with high anxiety levels before surgery reported high anxiety levels even after five years.

CRC survivors utilized a variety of coping strategies to handle the burden of cancer and its treatment. While many strategies helped to mitigate anxiety, some were associated with increased anxiety over the long term. For instance, meaning-making, acceptance, and participating in support groups were associated with reduced anxiety (Lim et al., 2022). However, both active and passive avoidance, as well as denial, were associated with increased anxiety in the long term (Boehmer, Clark, et al., 2022; Lim et al., 2022). Interestingly, a cross-sectional study involving 353 heterosexual and 127 sexual minority CRC survivors found that attending a cancer support group or using active coping strategies was associated with greater anxiety (Boehmer, Ozonoff, et al., 2022).

Characteristics of Cancer

Research shows mixed results regarding the relationship between the time since diagnosis or treatment and anxiety. While some studies find no significant variation in anxiety over time (Holthuijsen et al., 2024; Mols et al., 2018), others report either a decrease (Braamse et al., 2016; Jakobsson et al., 2016; Jin et al., 2019; Lloyd et al., 2019) or an increase (Hyphantis et al., 2016; Zhou & Sun, 2021) as time progresses. For instance, Howren et al. (2022) conducted a retrospective cohort study in Canada and found that CRC survivors displayed the highest anxiety rate during the continuing phase, which is between 12 months after CRC diagnosis and 12 months before cancer death. On the other hand, Lloyd et al. (2019) found the highest rates of anxiety within two years of a cancer diagnosis in their retrospective cohort study using the Utah population database. Additionally, a longitudinal study from China reported a consistent increase in anxiety rates from discharge to three months post-discharge (Zhou & Sun, 2021). In addition, a

different longitudinal study in China revealed that the anxiety level among rectal cancer patients decreased 1–2 days before hospital discharge compared to 1–2 days before surgery (Jin et al., 2019).

In Brazil, Miranda et al. (2014, 2018) published consecutive study findings examining the association between proinflammatory cytokine levels and anxiety or depression. Their study findings revealed that higher levels of IL-1β, IL-6, IL-8, or TNF-α were associated with higher levels of anxiety, while lower level of IL-10 was associated with higher levels of anxiety. Furthermore, Miranda et al. (2017) found that Fractalkine serum level was also positively associated with anxiety level. Moreover, a prospective cohort study conducted in the Netherlands found that in confounder-adjusted linear mixed models, higher concentrations of 3-hydroxyanthranilic acid were associated with lower anxiety scores (Holthuijsen et al., 2024). However, in sensitivity analyses, this association did not remain statistically significant after FDR adjustment.

Cancer Treatment

Research has revealed a significant association between CRC survivors who have undergone radiotherapy, chemotherapy (Boehmer, Ozonoff, et al., 2022; Cheng et al., 2022; Hu et al., 2022; Orive et al., 2022). or ostomy surgery (Benedict et al., 2016; Cheng et al., 2022; Song et al., 2020) and increased anxiety levels. However, Mols et al. (2018) found no significant association between radiotherapy or chemotherapy and anxiety levels in their prospective cohort study in the Netherlands. Regarding different types of ostomies, the results also vary. While Song et al. (2020) found no significant difference in anxiety levels between participants with temporary or permanent ostomies, Hu et al. (2022) found a higher risk of anxiety in participants with permanent ostomies

compared to those with temporary ones. Additionally, a prospective cohort study in Sweden found no difference in anxiety levels among participants who had a rectal resection, abdominoperineal resection, or colonic resection, although those who underwent colonic resection reported less anxiety at discharge than before surgery (Jakobsson et al., 2016). Anxiety due to ostomy-related issues was frequently reported, particularly in qualitative studies (Carlile & McAdam, 2023; Mohamed et al., 2021; Saunders et al., 2021). Participants voiced worries about potential or existing ostomy complications such as leakage, noise, odor, or hernias during interviews. These issues presented daily challenges, impeding their ability to resume normal activities (Carlile & McAdam, 2023; Mohamed et al., 2021; Saunders et al., 2021).

Several studies have examined the role of cancer treatment side effects and complications on anxiety levels. These studies found that participants who reported complications after CRC surgery experienced greater anxiety than those without complications (Di Cristofaro et al., 2014; Hu et al., 2022; Orive et al., 2022). Chemotherapy-Induced Peripheral Neuropathy (CIPN) is one of the most studied CRC treatment side effects. Participants with more severe CIPN also reported higher anxiety levels (Bonhof et al., 2019; Kerckhove et al., 2021; Selvy et al., 2020).

Consequences of Anxiety in CRC Survivors

Global Health Status / Quality of Life

In multiple studies, it has been observed that a heightened level of anxiety is closely associated with poor global health status and reduced quality of life (Akyol et al., 2015; Cheng et al., 2022; Hess et al., 2023; Mols et al., 2018; Tamura, 2021). However,

Gonzalez-Saenz de Tejada et al. (2016) found no significant correlation between these variables in their longitudinal study in Spain.

Functioning

A cross-sectional study of 175 CRC survivors with ostomies in China discovered an association between higher anxiety scores and increased supportive care needs, such as physiology and daily living needs, psychological needs, and health information needs (Xiangting et al., 2023). Although this study did not find a connection between anxiety and sexual needs, another cross-sectional study in Turkey and a qualitative study in the UK identified a link between anxiety and sexual functioning among CRC survivors (Akyol et al., 2015; Carlile & McAdam, 2023). Furthermore, qualitative studies disclosed that participants' social or emotional functioning was negatively impacted due to their ostomy (Carlile & McAdam, 2023; Saunders et al., 2021). During these interviews, participants mentioned limiting their food or drink intake before social activities due to worries about handling ostomy-related issues in public spaces.

A retrospective longitudinal study conducted in China found that participants with elevated anxiety levels were less likely to start adjuvant chemotherapy early (within 4 weeks after operations) (Zhu et al., 2020). In another prospective cohort study in the US involving healthcare providers diagnosed with CRC, it was discovered that individuals with anxiety often led unhealthy lifestyles, such as consuming alcohol or smoking (Trudel-Fitzgerald et al., 2018). Moreover, participants with high anxiety engaged in less physical activity (van Putten et al., 2016). A longitudinal study in China on 67 rectal cancer survivors undergoing colostomy surgery found that higher levels of anxiety

significantly predict lower psychosocial behavioral responses in colostomy patients (Jin et al., 2019).

Symptoms/ Problems

While Akyol et al. (2015) found no connection between anxiety and insomnia, other studies have identified a significant association (Hyphantis et al., 2016; Sun et al., 2020). For instance, Hyphantis et al. (2016) found that CRC patients with increased anxiety after one year had more difficulty falling asleep, but there was no significant change in waking up early.

Instruments Used to Assess Anxiety

In the included studies, researchers used a variety of instruments to measure the participants' anxiety levels. The most frequently used instrument was the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), a self-reported tool that allows participants to assess their own anxiety and depression levels. In contrast, some studies used International Classification of Diseases (ICD) codes (World Health Organization, 1992), which reflect anxiety disorders officially diagnosed by mental health specialists. Further information about each instrument is summarized in Table 3. Cutoff points used to determine the presence or severity of anxiety in the included studies are summarized in Table 1. In each of the three review manuscripts, we only counted the usage of individual tools once, regardless of how often they appeared. This method was used to avoid multiple counts, particularly if the original studies from our research were also included in those review manuscripts.

Table 3.

Anxiety measurement tools

Measure	Studies (n)	Interpretation of Scores (in Original Versions)	Items (n)
Hospital Anxiety and Depression Scale (HADS)-Anxiety (Zigmond & Snaith, 1983)	31	0-7: Normal 8-10: Borderline abnormal (borderline case) 11-21: Abnormal (case)	7
International Classification of Diseases (ICD) codes 9 or 10 (World Health Organization, 1992), or Anxiolytics use	4	N/A	N/A
Generalized Anxiety Disorder-7 (GAD-7) (Spitzer et al., 2006)	3	0-4: Minimal, 5-9: Mild, 10-14: Moderate, 15-21: Severe	7
Health-related anxiety in QLQ-CR29 (Whistance et al., 2009)	3	1 (not at all)- 4 (very much)	1
Brief Symptom Inventory-18 (BSI-18) Anxiety subscale (Derogatis, 1992)	3	0 (no anxiety)- 24 (high anxiety)	6
Crown-Crisp Index (CCI) (Crown & Crisp, 1966)	3	0 (no anxiety)- 16 (high anxiety)	8
Beck Anxiety Inventory (BAI) (Beck et al., 1988)	2	0-9: None, 10-18: Mild, 19-29: Moderate 30-63: Severe	21
Spielberger State-Trait Anxiety Inventory (STAI) (Spielberger, 1983) or Spielberger State Anxiety Inventory (SAI)	2	20 (absence of anxiety)- 80 (high level of anxiety)	state (20) + trait (20)
Hamilton Anxiety Rating Scale (Hamilton, 1959)	1	0–7: No or minimal 8–14: Mild anxiety 15–23: Moderate anxiety 24 or greater: Severe	14
Patient-Reported Outcomes Measurement Information System (PROMIS) Anxiety Four-item Short Form (Cella et al., 2010)	1	Raw score 4-20 T-score <55: Normal, 55–60: Mild, 60–70: Moderate, ≥70: Severe	4
Symptom Distress Checklist (SCL-90-R) (Donias et al., 1991)	1	0 (not at all)-36 (extreme)	9
Minnesota Multiphasic Personality Inventory (MMPI) (Pearson et al., 1965)	1	N/A	N/A

N/A, not applicable

Discussion

This scoping review illustrates the unique anxiety-related factors that specifically affect the CRC population, a perspective not commonly found in reviews focusing on the general cancer population. A recurring theme among included studies is the presence of anxiety associated with bowel or ostomy dysfunctions, common side effects of CRC

treatments. Qualitative studies focusing on CRC survivors, particularly those with ostomies, consistently find that individuals frequently dealing with embarrassing situations due to ostomy complications exhibit increased anxiety (Carlile & McAdam, 2023; Mohamed et al., 2021; Saunders et al., 2021). These situations commonly stem from ostomy leakage, odor, or noise in public spaces, contributing to heightened anxiety about social participation. To cope, these individuals often restrict their food and drink intake before or during social events, or continually look for restroom facilities when out (Carlile & McAdam, 2023; Saunders et al., 2021). This hyper-vigilance and resulting self-imposed dietary limitations contribute to their high anxiety levels. Ultimately, such anxiety can lead to social withdrawal, creating a vicious cycle that further intensifies anxiety (Benedict et al., 2018; Saunders et al., 2021). These findings align with studies conducted on individuals who have undergone ostomy surgery for various reasons, indicating a broad impact of this condition on mental health (Jayarajah et al., 2016; Jeppesen et al., 2022; Mitchell et al., 2007).

Our findings show that high levels of proinflammatory cytokines (IL-1, IL-6, IL-8, TNF-α), low levels of IL-10 (Miranda et al., 2014, 2018), and high fractalkine levels (defined as levels >3mg/L) (Miranda et al., 2017) are linked to increased anxiety in CRC patients. These findings support previous studies on neuroimmune interaction in the context of cancer (Liu et al., 2022; Santos & Pyter, 2018; Scheff & Saloman, 2021). Stress, tumor biology, and cancer treatments affect neurobiology through inflammation, influencing anxiety symptoms in cancer patients by linking sympathetic nerve activity and immune responses to tumor development (Santos & Pyter, 2018; Scheff & Saloman, 2021). Further, anxiety can present as biological symptoms such as pain and fatigue

(Renna et al., 2022) through these neuroimmune mechanisms, threatening the long-term health and physical functioning of CRC patients. Understanding these interactions would provide a more comprehensive view of the relationship between psychological and biological health in this population.

The HADS is a commonly used self-report questionnaire for measuring anxiety and depression in oncology and other health settings. This questionnaire was also predominantly used in our reviewed studies with the CRC population (see Table 3). However, as shown in Table 1, we observed that different articles used various cut-off points. While most studies dichotomized the subjects using a score of 8, Zhang et al. (2016) and Zhu et al. (2020) used a score of 11, and Song et al. (2020) used 9. This variation in cut-off points could potentially lead to contrasting results when comparing the anxiety rate between different groups, as opposed to conducting a correlation analysis.

Anxiety, as determined by ICD codes, and as referenced in several studies (Cheng et al., 2022; Howren et al., 2022; Lloyd et al., 2019; Peng et al., 2019), could potentially lead to inconsistencies when comparing with other studies that utilize self-report questionnaires. The ICD codes are used to indicate that an individual has been clinically diagnosed with an anxiety disorder by a healthcare professional. This is in contrast to self-reported surveys where individuals themselves report their symptoms and experiences, which may or may not align with a clinical diagnosis.

In quantitative studies, excluding those with pre-existing clinical anxiety before a CRC diagnosis or conducting a longitudinal study that compares anxiety levels at different times can help determine whether the observed anxiety is directly related to the

CRC diagnosis or its treatment. Understanding this is crucial. If anxiety is a by-product of CRC or its treatment, it can inform more targeted prevention interventions for this population. However, some cross-sectional studies we reviewed did not exclude pre-existing clinical anxiety cases before the CRC diagnosis (Akyol et al., 2015; Benedict et al., 2016, 2018; Boehmer, Clark, et al., 2022; Boehmer et al., 2021; Boehmer, Ozonoff, et al., 2022; Bonhof et al., 2019; Braamse et al., 2016; Gray et al., 2014; Hess et al., 2023; Kerckhove et al., 2021; Renna et al., 2022; Selvy et al., 2020; Song et al., 2020; Vallance et al., 2015), making it difficult to pinpoint the root source of the anxiety. This lack of clarity could potentially skew the results and interpretations.

In line with previous review studies of CRC survivors (Cheng et al., 2022; Peng et al., 2019), this scoping review presents mixed results about the association between age and anxiety levels. This could be due to differences in study populations, designs, measurement tools, and analysis methods. Boehmer, Clark, et al. (2022) and Boehmer, Ozonoff, et al. (2022) examined anxiety and health-related anxiety levels across different age groups at diagnosis. In their study of sexual minority CRC survivors (Boehmer, Clark, et al., 2022), they found higher anxiety levels and a greater likelihood of health-related anxiety in those diagnosed between 21-49 years, compared to those diagnosed at 65 years and older. However, the 50-64 years age group showed no significant differences in anxiety level or health-related anxiety compared to the oldest age group. In a separate study involving both heterosexual and sexual minority CRC survivors, Boehmer, Ozonoff, et al. (2022) found that younger individuals, specifically those in the 21-49 year age group, were more likely to experience health-related anxiety, as assessed by the single item QLQ-CR29, compared to those aged 65 years and older. However, the

association between age and anxiety, as assessed by HADS, was statistically nonsignificant in this group. This discrepancy could be due to the different aspects of anxiety each tool measures. On the other hand, Howren et al. (2022) categorized participants into three groups: young-onset CRC (diagnosed before 50 years old), average-age-onset CRC (diagnosed at 50 years or older), and cancer-free controls. They found that participants diagnosed with CRC under the age of 50 had a similar risk of anxiety to cancer-free controls in the same age group. However, those diagnosed with CRC after the age of 50 had a higher risk of anxiety than cancer-free individuals in the same age group. After adjusting for confounding effects such as current age, the differences in anxiety risk between CRC survivors diagnosed before 50 years and those diagnosed at or after 50 years were found to be statistically insignificant (Howren et al., 2022). Unlike these studies (Boehmer, Clark, et al., 2022; Boehmer, Ozonoff, et al., 2022; Howren et al., 2022), other included studies (Gonzalez-Saenz de Tejada et al., 2017; Hess et al., 2023; Hu et al., 2022; Mols et al., 2018; Tamura, 2021) utilized participants' current age at the time of the study to examine its association with anxiety levels. Some of these studies (Hess et al., 2023; Hu et al., 2022; Tamura, 2021) found no significant link between age and anxiety levels, while others (Gonzalez-Saenz de Tejada et al., 2017; Mols et al., 2018) found an association. Hess et al. (2023) only included CRC survivors who were 60 years or older (median age =68), which might have led to insignificant differences in anxiety levels across different ages. Hu et al. (2022) and Tamura (2021) compared anxiety levels between those <65 and ≥ 65, finding no significant differences in anxiety levels between the two age groups. However, Gonzalez-Saenz de Tejada et al. (2017) found that older CRC survivors reported a more significant decrease in anxiety

levels after a year of surgery. Mols et al. (2018) discovered that older participants reported lower anxiety levels, aligning with findings from studies of the general cancer population (Weiss Wiesel et al., 2015; Yi & Syrjala, 2017).

Limitations

While this review is intended to be comprehensive, it does have limitations that are largely consistent with those of a scoping review design. We used study design, timelines, mechanistic plausibility, and interpretation to categorize variables as risk factors or consequences of anxiety. However, the observational nature of most studies, along with some cross-sectional designs, limits our ability to establish cause-and-effect relationships between anxiety and other variables definitively. Consequently, some variables were classified as risk factors in some studies and as consequences of anxiety in others. In addition, our scoping review identifies and maps factors associated with anxiety in CRC patients, but it does not provide an in-depth analysis of study quality and risk of bias, as systematic reviews typically do. Instead, it offers a broad overview of existing literature, identifying research trends, gaps, and future investigation areas. As an exploratory study, this scoping review may lack the rigor of systematic reviews due to its less strict inclusion criteria. However, this approach allows for a more inclusive and extensive literature examination, capturing a broader range of studies and perspectives. Furthermore, anxiety is a multidimensional concept that shares common characteristics with other emotional states like depression. In the context of cancer, anxiety is particularly linked to the fear of cancer recurrence and the fear of death, making it hard to distinguish from other emotional conditions. This complexity is a significant limitation of our study and should be considered when interpreting the results.

Recommendations for Future Research

It is crucial to identify modifiable factors related to anxiety, as these factors could be the focus of future research on targeted prevention methods. Furthermore, understanding the complex relationships between these factors can provide a holistic view, enabling the implementation of early prevention strategies. While many qualitative studies have pinpointed psychosocial issues related to ostomy complications in the CRC population, few quantitative studies have investigated this. Benedict et al. (2018) found a link between diarrhea and anxiety in survivors of rectal or anal cancer after treatment. However, it was not distinguished whether these individuals had an ostomy or not. In people with ostomies, diarrhea does not necessarily lead to ostomy leakage. Therefore, for future studies, we recommend using ostomy-specific questionnaires in quantitative research of CRC-related psychosocial outcomes. This will help investigate the correlation between ostomy complications and psychosocial problems among CRC survivors with ostomies.

Conclusions

As the survival rates for CRC increase, understanding the potential biological and psychosocial effects of CRC and its treatments becomes increasingly critical. Our review significantly contributes to this understanding by identifying various predictors and outcomes of anxiety in this group. Modifiable factors present targets for interventions aimed at reducing anxiety and enhancing quality of life. Non-modifiable risk factors help pinpoint patients at high risk for early psychological support. Moreover, these risk factors can be further examined to comprehend their interactions.

References for Chapter 2

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., Haes, J. C. J. M. de, Kaasa, S., Klee, M., Osoba, D., Razavi, D., Rofe, P. B., Schraub, S., Sneeuw, K., Sullivan, M., & Takeda, F. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A Quality-of-Life Instrument for Use in International Clinical Trials in Oncology. *JNCI: Journal of the National Cancer Institute*, *85*(5), 365–376. https://doi.org/10.1093/jnci/85.5.365

Akyol, M., Ulger, E., Alacacioglu, A., Kucukzeybek, Y., Yildiz, Y., Bayoglu, V., Gumus, Z., Yildiz, I., Salman, T., Varol, U., Ayakdas, S., & Tarhan, M. O. (2015). Sexual satisfaction, anxiety, depression and quality of life among Turkish colorectal cancer patients [Izmir Oncology Group (IZOG) study]. *Japanese Journal of Clinical Oncology*, *45*(7), 657–664. https://doi.org/10.1093/jjco/hyv051

American Cancer Society. (2024). *Cancer Facts & Figures 2024*. American Cancer Society.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology*, *56*(6), 893–897. https://doi.org/10.1037/0022-006X.56.6.893

Benedict, C., DuHamel, K., & Nelson, C. J. (2018). Reduction in social activities mediates the relationship between diarrhea and distress in rectal/anal cancer survivors. *Psycho-Oncology*, *27*(2), 691–694. https://doi.org/10.1002/pon.4486

Benedict, C., Rodriguez, V. M., Carter, J., Temple, L., Nelson, C., & DuHamel, K. (2016). Investigation of body image as a mediator of the effects of bowel and GI symptoms on psychological distress in female survivors of rectal and anal cancer. *Supportive Care in Cancer*, *24*(4), 1795–1802. https://doi.org/10.1007/s00520-015-2976-2

Boehmer, U., Clark, M. A., Winter, M., Berklein, F., & Ozonoff, A. (2022). Sexual minority–specific experiences of colorectal cancer survivors. *Health Psychology*, *41*(11), 884–892. https://doi.org/10.1037/hea0001229

Boehmer, U., Ozonoff, A., Winter, M., Berklein, F., Potter, J., Ceballos, R. M., & Clark, M. A. (2022). Anxiety and depression in colorectal cancer survivors: Are there differences by sexual orientation? *Psycho-Oncology*, *31*(3), 521–531. CINAHL with Full Text. https://doi.org/10.1002/pon.5837

Boehmer, U., Potter, J., Clark, M. A., Ozonoff, A., Winter, M., Berklein, F., Ward, K. C., & Hartshorn, K. (2021). Assessing the relationship between symptoms and health care utilization in colorectal cancer survivors of different sexual orientations. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer*, *29*(10), 5821–5830. MEDLINE. https://doi.org/10.1007/s00520-021-06157-1

Bonhof, C. S., van de Poll-Franse, L. V., Vissers, P. A. J., Wasowicz, D. K., Wegdam, J. A., Révész, D., Vreugdenhil, G., & Mols, F. (2019). Anxiety and depression mediate the association between chemotherapy-induced peripheral neuropathy and fatigue: Results from the population-based PROFILES registry. *Psycho-Oncology*, *28*(9), 1926–1933. https://doi.org/10.1002/pon.5176

Braamse, A. M. J., van Turenhout, S. T., Terhaar sive Droste, J. S., de Groot, G. H., van der Hulst, R. W. M., Klemt-Kropp, M., Kuiken, S. D., Loffeld, R. J. L. F., Uiterwaal, M. T.,

Mulder, C. J. J., & Dekker, J. (2016). Factors associated with anxiety and depressive symptoms in colorectal cancer survivors. *European Journal of Gastroenterology & Hepatology*, *28*(7), 831. https://doi.org/10.1097/MEG.0000000000000615

Carlile, A., & McAdam, T. (2023). The Long-Term and Late Effects of the Diagnosis and Treatment of Colorectal Cancer. *The Ulster Medical Journal*, *92*(2), 98–102.

Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., Amtmann, D., Bode, R., Buysse, D., Choi, S., Cook, K., DeVellis, R., DeWalt, D., Fries, J. F., Gershon, R., Hahn, E. A., Lai, J.-S., Pilkonis, P., Revicki, D., … Hays, R. (2010). Initial Adult Health Item Banks and First Wave Testing of the Patient-Reported Outcomes Measurement Information System (PROMIS™) Network: 2005–2008. *Journal of Clinical Epidemiology*, *63*(11), 1179–1194. https://doi.org/10.1016/j.jclinepi.2010.04.011

Cheng, V., Oveisi, N., McTaggart-Cowan, H., Loree, J. M., Murphy, R. A., & De Vera, M. A. (2022). Colorectal Cancer and Onset of Anxiety and Depression: A Systematic Review and Meta-Analysis. *Current Oncology*, *29*(11), Article 11. https://doi.org/10.3390/curroncol29110689

Crown, S., & Crisp, A. H. (1966). A Short Clinical Diagnostic Self-rating Scale for Psychoneurotic Patients: The Middlesex Hospital Questionnaire (M.H.Q.). *The British Journal of Psychiatry*, *112*(490), 917–923. https://doi.org/10.1192/bjp.112.490.917

Curran, L., Sharpe, L., & Butow, P. (2017). Anxiety in the context of cancer: A systematic review and development of an integrated model. *Clinical Psychology Review*, *56*, 40–54. https://doi.org/10.1016/j.cpr.2017.06.003

Derogatis, L. R. (1992). *Brief Symptom Inventory (BSI): Administration, Scoring, and Procedures Manual* (3rd ed.). NCS Pearson.

Di Cristofaro, L., Ruffolo, C., Pinto, E., Massa, M., Antoniutti, M., Cagol, M., Massani, M., Alfieri, R., Costa, A., Bassi, N., Castoro, C., & Scarpa, M. (2014). Complications after surgery for colorectal cancer affect quality of life and surgeon–patient relationship. *Colorectal Disease*, *16*(12), O407–O419. https://doi.org/10.1111/codi.12752

Donias, S., Karastergiou, A., & Manos, N. (1991). Standardization of the symptom checklist-90-R rating scale in a Greek population. *Psychiatriki*, *2*(1), 42–48.

Fayers, P., Aaronson, N. K., Bjordal, K., Groenvold, M., Curran, D., & Bottomley, A. (2001). *EORTC QLQ-C30 Scoring Manual*. European Organisation for Research and Treatment of Cancer. https://abdn.elsevierpure.com/en/publications/eortc-qlq-c30-scoring-manual

Gonzalez-Saenz de Tejada, M., Bilbao, A., Baré, M., Briones, E., Sarasqueta, C., Quintana, J. m., & Escobar, A. (2016). Association of social support, functional status, and psychological variables with changes in health-related quality of life outcomes in patients with colorectal cancer. *Psycho-Oncology*, *25*(8), 891–897. https://doi.org/10.1002/pon.4022

Gonzalez-Saenz de Tejada, M., Bilbao, A., Baré, M., Briones, E., Sarasqueta, C., Quintana, J. M., & Escobar, A. (2017). Association between social support, functional status and change in Health Related Quality of Life and changes in anxiety and depression in colorectal cancer patients. *Psycho-Oncology*, *26*(9), 1263–1269. CINAHL with Full Text. https://doi.org/10.1002/pon.4303

Gonzalez-Saenz de Tejada, M., Bilbao, A., Baré, M., Briones, E., Sarasqueta, C., Quintana, J. m., Escobar, A., & Group, C.-C. (2017). Association between social support, functional status, and change in health-related quality of life and changes in anxiety and depression in colorectal cancer patients. *Psycho-Oncology*, *26*(9), 1263–1269. https://doi.org/10.1002/pon.4303

Gray, N. M., Hall, S. J., Browne, S., Johnston, M., Lee, A. J., Macleod, U., Mitchell, E. D., Samuel, L., & Campbell, N. C. (2014). Predictors of anxiety and depression in people with colorectal cancer. *Supportive Care in Cancer*, *22*(2), 307–314. CINAHL with Full Text. https://doi.org/10.1007/s00520-013-1963-8

Hamilton, M. (1959). The assessment of anxiety states by rating. *British Journal of Medical Psychology*, *32*, 50–55. https://doi.org/10.1111/j.2044-8341.1959.tb00467.x

Hess, D. L., Fowler, M. E., Harmon, C., Giri, S., & Williams, G. R. (2023). Anxiety is Associated With Geriatric Assessment Impairments and Reduced Quality of Life Among Older Adults With Colorectal Cancer: Results From the CARE Registry. *Clinical Colorectal Cancer*, *22*(4), 383–389. https://doi.org/10.1016/j.clcc.2023.08.001

Holthuijsen, D. D. B., van Roekel, E. H., Bours, M. J. L., Ueland, P. M., Breukink, S. O., Janssen-Heijnen, M. L. G., Keulen, E. T. P., Gigic, B., Gsur, A., Meyer, K., Ose, J., Ulvik, A., Weijenberg, M. P., & Eussen, S. J. P. M. (2024). Longitudinal associations of plasma kynurenines and ratios with anxiety and depression scores in colorectal cancer survivors up to 12 months post-treatment. *Psychoneuroendocrinology*, *163*, 106981. https://doi.org/10.1016/j.psyneuen.2024.106981

Howren, A., Sayre, E. C., Cheng, V., Oveisi, N., McTaggart-Cowan, H., Peacock, S., & De Vera, M. A. (2022). Risk of Anxiety and Depression after Diagnosis of Young-Onset Colorectal Cancer: A Population-Based Cohort Study. *Current Oncology*, *29*(5), 3072-N.PAG3081. CINAHL with Full Text. https://doi.org/10.3390/curroncol29050249

Hu, Z., Zhang, H., Wang, J., Xiong, H., Liu, Y., Zhu, Y., Chang, Z., Hu, H., & Tang, Q. (2022). Nomogram to Predict the Risk of Postoperative Anxiety and Depression in Colorectal

Cancer Patients. *International Journal of General Medicine*, *15*, 4881–4895. https://doi.org/10.2147/IJGM.S350092

Huang, S.-T., Ke, X., Huang, Y.-P., Wu, Y.-X., Yu, X.-Y., Liu, H.-K., & Liu, D. (2023). A prediction model for moderate to severe cancer-related fatigue in colorectal cancer after chemotherapy: A prospective case–control study. *Supportive Care in Cancer*, *31*(7), 426. https://doi.org/10.1007/s00520-023-07892-3

Hyphantis, T., Goulia, P., Zerdes, I., Solomou, S., Andreoulakis, E., Carvalho, A. F., & Pavlidis, N. (2016). Sense of Coherence and Defense Style Predict Sleep Difficulties in Early Non-metastatic Colorectal Cancer. *Digestive Diseases and Sciences*, *61*(1), 273–282. https://doi.org/10.1007/s10620-015-3843-1

Jakobsson, J., Idvall, E., & Wann-Hansson, C. (2016). General health and state anxiety in patients recovering from colorectal cancer surgery. *Journal of Advanced Nursing (John Wiley & Sons, Inc.)*, *72*(2), 328–338. CINAHL with Full Text. https://doi.org/10.1111/jan.12841

Jayarajah, U., Samarasekera, A. M., & Samarasekera, D. N. (2016). A study of postoperative anxiety and depression among patients with intestinal stomas. *Sri Lanka Journal of Surgery*, *34*(2), 6. https://doi.org/10.4038/sljs.v34i2.8261

Jeppesen, P. B., Vestergaard, M., Boisen, E. B., & Ajslev, T. A. (2022). Impact of stoma leakage in everyday life: Data from the Ostomy Life Study 2019. *British Journal of Nursing*, *31*(6), S48–S58. https://doi.org/10.12968/bjon.2022.31.6.S48

Jin, Y., Zhang, J., Zheng, M.-C., Bu, X.-Q., & Zhang, J.-E. (2019). Psychosocial behaviour reactions, psychosocial needs, anxiety and depression among patients with rectal cancer

before and after colostomy surgery: A longitudinal study. *Journal of Clinical Nursing*, *28*(19–20), 3547–3555. https://doi.org/10.1111/jocn.14946

Kerckhove, N., Selvy, M., Lambert, C., Gonneau, C., Feydel, G., Pétorin, C., Vimal-Baguet, A., Melnikov, S., Kullab, S., Hebbar, M., Bouché, O., Slimano, F., Bourgeois, V., Lebrun-Ly, V., Thuillier, F., Mazard, T., Tavan, D., Benmammar, K. E., Monange, B., … Balayssac, D. (2021). Colorectal Cancer Survivors Suffering From Sensory Chemotherapy-Induced Peripheral Neuropathy Are Not a Homogenous Group: Secondary Analysis of Patients' Profiles With Oxaliplatin-Induced Peripheral Neuropathy. *Frontiers in Pharmacology*, *12*. https://www.frontiersin.org/articles/10.3389/fphar.2021.744085

Khoo, A. M.-G., Lau, J., Loh, X.-S., Ng, C. W.-T., Griva, K., & Tan, K.-K. (2022). Understanding the psychosocial impact of colorectal cancer on young-onset patients: A scoping review. *Cancer Medicine*, *11*(7), 1688–1700. https://doi.org/10.1002/cam4.4575

Lim, C. Y. S., Laidsaar-Powell, R. C., Young, J. M., Solomon, M., Steffens, D., Blinman, P., O'Loughlin, S., Zhang, Y., & Butow, P. (2022). Fear of Cancer Progression and Death Anxiety in Survivors of Advanced Colorectal Cancer: A Qualitative Study Exploring Coping Strategies and Quality of Life. *OMEGA - Journal of Death and Dying*, 00302228221121493. https://doi.org/10.1177/00302228221121493

Liu, M., Li, Y., & Liu, X. (2022). Serum tumor necrosis factor-α, interleukin-1β, interleukin-6, and interleukin-17 relate to anxiety and depression risks to some extent in non-small cell lung cancer survivor. *The Clinical Respiratory Journal*, *16*(2), 105–115. https://doi.org/10.1111/crj.13457

Lloyd, S., Baraghoshi, D., Tao, R., Garrido-Laguna, I., Gilcrease, G. W. I., Whisenant, J., Weis, J. R., Scaife, C., Pickron, T. B., Huang, L. C., Monroe, M. M., Abdelaziz, S., Fraser, A.

M., Smith, K. R., Deshmukh, V., Newman, M., Rowe, K. G., Snyder, J., Samadder, N. J., & Hashibe, M. (2019). Mental Health Disorders are More Common in Colorectal Cancer Survivors and Associated With Decreased Overall Survival. *American Journal of Clinical Oncology*, *42*(4), 355. https://doi.org/10.1097/COC.0000000000000529

Miranda, D. O., Anatriello, E., Azevedo, L. R., Cordeiro, J. F. C., Peria, F. M., Flória-Santos, M., & Pereira-da-Silva, G. (2018). Elevated serum levels of proinflammatory cytokines potentially correlate with depression and anxiety in colorectal cancer patients in different stages of the antitumor therapy. *Cytokine*, *104*, 72–77. https://doi.org/10.1016/j.cyto.2017.09.030

Miranda, D. O., Anatriello, E., Azevedo, L. R., Santos, J. C., Cordeiro, J. F. C., Peria, F. M., Flória-Santos, M., & Pereira-Da-Silva, G. (2017). Fractalkine (C-X3-C motif chemokine ligand 1) as a potential biomarker for depression and anxiety in colorectal cancer patients. *Biomedical Reports*, *7*(2), 188–192. https://doi.org/10.3892/br.2017.937

Miranda, D. O., Soares de Lima, T. A., Ribeiro Azevedo, L., Feres, O., Ribeiro da Rocha, J. J., & Pereira-da-Silva, G. (2014). Proinflammatory Cytokines Correlate with Depression and Anxiety in Colorectal Cancer Patients. *BioMed Research International*, *2014*, e739650. https://doi.org/10.1155/2014/739650

Mitchell, K. A., Rawl, S. M., Schmidt, C. M., Grant, M., Ko, C. Y., Baldwin, C. M., Wendel, C., & Krouse, R. S. (2007). Demographic, Clinical, and Quality of Life Variables Related to Embarrassment in Veterans Living With an Intestinal Stoma. *Journal of Wound Ostomy & Continence Nursing*, *34*(5), 524. https://doi.org/10.1097/01.WON.0000290732.15947.9e

Mohamed, N. E., Shah, Q. N., Kata, H. E., Sfakianos, J., & Given, B. (2021). Dealing With the Unthinkable: Bladder and Colorectal Cancer Patients' and Informal Caregivers' Unmet

Needs and Challenges in Life After Ostomies. *Seminars in Oncology Nursing*, *37*(1), 151111. MEDLINE. https://doi.org/10.1016/j.soncn.2020.151111

Mols, F., Schoormans, D., de Hingh, I., Oerlemans, S., & Husson, O. (2018). Symptoms of anxiety and depression among colorectal cancer survivors from the population-based, longitudinal PROFILES Registry: Prevalence, predictors, and impact on quality of life. *Cancer (0008543X)*, *124*(12), 2621–2628. CINAHL with Full Text. https://doi.org/10.1002/cncr.31369

Niedzwiedz, C. L., Knifton, L., Robb, K. A., Katikireddi, S. V., & Smith, D. J. (2019). Depression and anxiety among people living with and beyond cancer: A growing clinical and research priority. *BMC Cancer*, *19*(1), 943. https://doi.org/10.1186/s12885-019-6181-4

Orive, M., Anton-Ladislao, A., Lázaro, S., Gonzalez, N., Bare, M., Fernandez de Larrea, N., Redondo, M., Bilbao, A., Sarasqueta, C., Aguirre, U., Quintana, J. M., & for the REDISSEC-CARESS/CCR group. (2022). Anxiety, depression, health-related quality of life, and mortality among colorectal patients: 5-year follow-up. *Supportive Care in Cancer*, *30*(10), 7943–7954. https://doi.org/10.1007/s00520-022-07177-1

Pearson, J. S., Rome, H. P., Swenson, W. M., Mataya, P., & Brannick, T. L. (1965). Development of a computer system for scoring and interpretation of Minnesota Multiphasic Personality Inventories in a medical clinic. *Annals of the New York Academy of Sciences*, *126*(2), 684–695. https://doi.org/10.1111/j.1749-6632.1965.tb14315.x

Peng, Y.-N., Huang, M.-L., & Kao, C.-H. (2019). Prevalence of Depression and Anxiety in Colorectal Cancer Patients: A Literature Review. *International Journal of Environmental Research and Public Health*, *16*(3), Article 3. https://doi.org/10.3390/ijerph16030411

Pitman, A., Suleman, S., Hyde, N., & Hodgkiss, A. (2018). Depression and anxiety in patients with cancer. *BMJ*, *361*, k1415. https://doi.org/10.1136/bmj.k1415

Renna, M. E., Shrout, M. R., Madison, A. A., Alfano, C. M., Povoski, S. P., Lipari, A. M., Carson, W. E., Malarkey, W. B., Kiecolt-Glaser, J. K., Carson, W. E. 3rd, & Kiecolt-Glaser, J. K. (2022). Depression and anxiety in colorectal cancer patients: Ties to pain, fatigue, and inflammation. *Psycho-Oncology*, *31*(9), 1536–1544. CINAHL with Full Text. https://doi.org/10.1002/pon.5986

Révész, D., Bours, M. J. L., Wegdam, J. A., Keulen, E. T. P., Breukink, S. O., Slooter, G. D., Vogelaar, F. J., Weijenberg, M. P., & Mols, F. (2022). Associations between alcohol consumption and anxiety, depression, and health-related quality of life in colorectal cancer survivors. *Journal of Cancer Survivorship*, *16*(5), 988–997. CINAHL with Full Text. https://doi.org/10.1007/s11764-021-01090-y

Salamonsen, A., Kiil, M. A., Kristoffersen, A. E., Stub, T., & Berntsen, G. R. (2016). "My cancer is not my deepest concern": Life course disruption influencing patient pathways and health care needs among persons living with colorectal cancer. *Patient Preference and Adherence*, *10*, 1591–1600. https://doi.org/10.2147/PPA.S108422

Santos, J. C., & Pyter, L. M. (2018). Neuroimmunology of Behavioral Comorbidities Associated With Cancer and Cancer Treatments. *Frontiers in Immunology*, *9*. https://doi.org/10.3389/fimmu.2018.01195

Saunders, C. H., Goldwag, J. L., Read, J. T., Durand, M.-A., Elwyn, G., & Ivatury, S. J. (2021). "Because Everybody is so Different": A qualitative analysis of the lived experiences and information needs of rectal cancer survivors. *BMJ Open*, *11*(5), e043245. https://doi.org/10.1136/bmjopen-2020-043245

Scheff, N. N., & Saloman, J. L. (2021). Neuroimmunology of cancer and associated symptomology. *Immunology & Cell Biology*, *99*(9), 949–961. https://doi.org/10.1111/imcb.12496

Selvy, M., Pereira, B., Kerckhove, N., Gonneau, C., Feydel, G., Pétorin, C., Vimal-Baguet, A., Melnikov, S., Kullab, S., Hebbar, M., Bouché, O., Slimano, F., Bourgeois, V., Lebrun-Ly, V., Thuillier, F., Mazard, T., Tavan, D., Benmammar, K. E., Monange, B., … Balayssac, D. (2020). Long-Term Prevalence of Sensory Chemotherapy-Induced Peripheral Neuropathy for 5 Years after Adjuvant FOLFOX Chemotherapy to Treat Colorectal Cancer: A Multicenter Cross-Sectional Study. *Journal of Clinical Medicine*, *9*(8), Article 8. https://doi.org/10.3390/jcm9082400

Siegel, R. L., Wagle, N. S., Cercek, A., Smith, R. A., & Jemal, A. (2023). Colorectal cancer statistics, 2023. *CA: A Cancer Journal for Clinicians*, *73*(3), 233–254. https://doi.org/10.3322/caac.21772

Song, L., Han, X., Zhang, J., & Tang, L. (2020). Body image mediates the effect of stoma status on psychological distress and quality of life in patients with colorectal cancer. *Psycho-Oncology*, *29*(4), 796–802. https://doi.org/10.1002/pon.5352

Soria-Utrilla, V., Sánchez-Torralvo, F. J., González-Poveda, I., Mera-Velasco, S., Porras, N., Toval-Mata, J. A., García-Olivares, M., Ruiz-López, M., Gonzalo-Marín, M., Carrasco-Campos, J., Tapia, M. J., Santoyo-Santoyo, J., & Olveira, G. (2022). Prevalence of Anxiety and Depression Symptoms and Their Relationship with Nutritional Status and Mortality in Patients with Colorectal Cancer. *International Journal of Environmental Research and Public Health*, *19*(20), Article 20. https://doi.org/10.3390/ijerph192013548

Spielberger, C. D. (1983). *State-Trait Anxiety Inventory for Adults*. https://doi.org/10.1037/t06496-000

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. *Archives of Internal Medicine*, *166*(10), 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

Sun, G.-W., Yang, Y.-L., Yang, X.-B., Wang, Y.-Y., Cui, X.-J., Liu, Y., & Xing, C.-Z. (2020). Preoperative insomnia and its association with psychological factors, pain and anxiety in Chinese colorectal cancer patients. *Supportive Care in Cancer*, *28*(6), 2911–2919. CINAHL with Full Text. https://doi.org/10.1007/s00520-019-05151-y

Tamura, S. (2021). Factors Related to Resilience, Anxiety/Depression, and Quality of Life in Patients with Colorectal Cancer Undergoing Chemotherapy in Japan. *Asia-Pacific Journal of Oncology Nursing*, *8*(4), 393–402. CINAHL with Full Text. https://doi.org/10.4103/apjon.apjon-2099

Traeger, L., Greer, J. A., Fernandez-Robles, C., Temel, J. S., & Pirl, W. F. (2012). Evidence-Based Treatment of Anxiety in Patients With Cancer. *Journal of Clinical Oncology*, *30*(11), 1197–1205. https://doi.org/10.1200/JCO.2011.39.5632

Trudel-Fitzgerald, C., Tworoger, S. S., Poole, E. M., Zhang, X., Giovannucci, E. L., Meyerhardt, J. A., & Kubzansky, L. D. (2018). Psychological symptoms and subsequent healthy lifestyle after a colorectal cancer diagnosis. *Health Psychology*, *37*(3), 207–217. https://doi.org/10.1037/hea0000571

Trudel-Fitzgerald, C., Tworoger, S. S., Zhang, X., Giovannucci, E. L., Meyerhardt, J. A., & Kubzansky, L. D. (2020). Anxiety, Depression, and Colorectal Cancer Survival: Results

from Two Prospective Cohorts. *Journal of Clinical Medicine*, *9*(10), Article 10. https://doi.org/10.3390/jcm9103174

Vallance, J. K., Boyle, T., Courneya, K. S., & Lynch, B. M. (2015). Accelerometer-assessed physical activity and sedentary time among colon cancer survivors: Associations with psychological health outcomes. *Journal of Cancer Survivorship*, *9*(3), 404–411. https://doi.org/10.1007/s11764-014-0409-8

van Putten, M., Husson, O., Mols, F., Luyer, M. D. P., van de Poll-Franse, L. V., & Ezendam, N. P. M. (2016). Correlates of physical activity among colorectal cancer survivors: Results from the longitudinal population-based profiles registry. *Supportive Care in Cancer*, *24*(2), 573–583. https://doi.org/10.1007/s00520-015-2816-4

Wang, S., Song, Y., Zhang, H., Song, J., Guo, X., & Jiang, X. (2024). Cancer-Related Fatigue and Its Influencing Factors Among Colorectal Cancer Patients: A Generalized Linear Modeling Approach. *International Journal of General Medicine*. https://www.tandfonline.com/doi/abs/10.2147/IJGM.S447697

Wang, Y.-H., Li, J.-Q., Shi, J.-F., Que, J.-Y., Liu, J.-J., Lappin, J. M., Leung, J., Ravindran, A. V., Chen, W.-Q., Qiao, Y.-L., Shi, J., Lu, L., & Bao, Y.-P. (2020). Depression and anxiety in relation to cancer incidence and mortality: A systematic review and meta-analysis of cohort studies. *Molecular Psychiatry*, *25*(7), 1487–1499. https://doi.org/10.1038/s41380-019-0595-x

Weiss Wiesel, T. R., Nelson, C. J., Tew, W. P., Hardt, M., Mohile, S. G., Owusu, C., Klepin, H. D., Gross, C. P., Gajra, A., Lichtman, S. M., Ramani, R., Katheria, V., Zavala, L., Hurria, A., & Cancer Aging Research Group (CARG). (2015). The relationship between age,

anxiety, and depression in older adults with cancer. *Psycho-Oncology*, *24*(6), 712–717. https://doi.org/10.1002/pon.3638

Whistance, R. N., Conroy, T., Chie, W., Costantini, A., Sezer, O., Koller, M., Johnson, C. D., Pilkington, S. A., Arraras, J., Ben-Josef, E., Pullyblank, A. M., Fayers, P., & Blazeby, J. M. (2009). Clinical and psychometric validation of the EORTC QLQ-CR29 questionnaire module to assess health-related quality of life in patients with colorectal cancer. *European Journal of Cancer*, *45*(17), 3017–3026. https://doi.org/10.1016/j.ejca.2009.08.014

World Health Organization. (1992). *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. World Health Organization.

Xia, S., Zhu, Y., Luo, L., Wu, W., Ma, L., Yu, L., & Li, Y. (2024). Prognostic value of depression and anxiety on colorectal cancer-related mortality: A systematic review and meta-analysis based on univariate and multivariate data. *International Journal of Colorectal Disease*, *39*(1), 45. https://doi.org/10.1007/s00384-024-04619-6

Xiangting, Y., Meichun, Z., & Huiying, Q. (2023). Supportive care needs and related factors among colorectal cancer patients with stoma in the postoperative rehabilitation period from a bio-psycho-social perspective: A cross-sectional study. *Supportive Care in Cancer*, *31*(10), 599. https://doi.org/10.1007/s00520-023-08067-w

Yi, J. C., & Syrjala, K. L. (2017). Anxiety and Depression in Cancer Survivors. *The Medical Clinics of North America*, *101*(6), 1099–1113. https://doi.org/10.1016/j.mcna.2017.06.005

Zamani, M., & Alizadeh-Tabari, S. (2023). Anxiety and depression prevalence in digestive cancers: A systematic review and meta-analysis. *BMJ Supportive & Palliative Care*, *13*(e2), e235–e243. https://doi.org/10.1136/bmjspcare-2021-003275

Zhang, J., Fang, L., Zhang, D., Jin, Q., Wu, X., Liu, J., Zhang, C., & Dai, D. (2016). Type D personality is associated with delaying patients to medical assessment and poor quality of life among rectal cancer survivors. *International Journal of Colorectal Disease*, *31*(1), 75–85. https://doi.org/10.1007/s00384-015-2333-4

Zhou, L., & Sun, H. (2021). The longitudinal changes of anxiety and depression, their related risk factors and prognostic value in colorectal cancer survivors: A 36-month follow-up study. *Clinics and Research in Hepatology and Gastroenterology*, *45*(4), 101511. https://doi.org/10.1016/j.clinre.2020.07.016

Zhu, L., Tong, Y. X., Xu, X. S., Xiao, A. T., Zhang, Y. J., & Zhang, S. (2020). High level of unmet needs and anxiety are associated with delayed initiation of adjuvant chemotherapy for colorectal cancer patients. *Supportive Care in Cancer*, *28*(11), 5299–5306. CINAHL with Full Text. https://doi.org/10.1007/s00520-020-05333-z

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361–370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

CHAPTER 3

Manuscript 2: Ostomy Leakage, Odor, and Peristomal Skin Complications as Predictors of Anxiety Symptoms in Colorectal Cancer Survivors: A Cross-Sectional Study

Abstract

Background: Multiple factors influence anxiety among individuals with ostomies, yet the specific contributions of ostomy-related issues remain unclear. This study investigated the relationships between ostomy leakage, odor, peristomal skin complications (PSC), and anxiety symptoms in colorectal cancer (CRC) survivors with ostomies.

Methods: In this cross-sectional study, 130 CRC survivors with ostomies (Stage I-III) were recruited from online support groups. Eligible participants were adults (≥18 years) with colostomy or ileostomy, living in the community, proficient in English, and without pre-existing mood or anxiety disorders or significant sensory impairments. A series of regression analyses with Baron and Kenny's mediation model examined relationships between variables while controlling for demographic and clinical factors.

Results: A series of regression analyses revealed that ostomy leakage was a significant predictor of odor intensity (standardized regression coefficient [β] = 0.61, $p < .001$), PSC (β = 0.51, $p < .001$), and anxiety (β = 0.23, $p = .003$). In the mediation analysis, when ostomy odor was introduced into the model, the previous significant direct effect of leakage on anxiety became non-significant (β = 0.11, $p = 0.249$), while odor demonstrated a significant association with anxiety (β = 0.19, $p = 0.039$). In contrast, PSC showed no significant association with anxiety (β = -0.05, $p = 0.575$). Race and treatment status maintained significant associations with anxiety across all models, persisting even after adding ostomy-related issues.

Conclusion: Our findings suggest that ostomy odor is a main factor that explains the relationship between leakage and anxiety among CRC survivors with ostomies. These results emphasize the need for comprehensive interventions that address odor management and anxiety reduction while considering the unique challenges of diverse demographic and clinical subgroups.

Introduction

Colorectal cancer (CRC) represents a significant public health concern in the United States, ranking as the third most prevalent cancer diagnosis for both sexes. The disease's impact on mortality is substantial, ranking third among cancer-related deaths in men and fourth in women (American Cancer Society, 2024). Anxiety is one of the predominant psychological challenges among CRC survivors (Peng et al., 2019), with significant implications for patient outcomes. Research has demonstrated that anxiety is associated with reduced treatment adherence (Trudel-Fitzgerald et al., 2018; Zhu et al., 2020), accelerated disease progression (Trudel-Fitzgerald et al., 2020), elevated mortality rates (Trudel-Fitzgerald et al., 2020), and compromised quality of life (Mols et al., 2018). Multiple factors contribute to anxiety in CRC survivors, as identified in a recent scoping review (Shin et al., 2024). These include demographic variables (e.g., age, sex, marital status, comorbidities, education level, financial status) and clinical factors (e.g., cancer stage, site, time since diagnosis, treatment status). Of particular significance, evidence indicates that CRC survivors with ostomies demonstrate heightened anxiety levels compared to those without ostomies (Benedict et al., 2016; Song et al., 2020). This increased anxiety appears to be associated with specific ostomy-related challenges, including leakage, odor, and peristomal skin complications (PSC). The current study investigates the structural relationships between ostomy leakage, odor, PSC, and anxiety symptoms in CRC survivors with ostomies.

Ostomy Leakage

Leakage represents a significant concern for individuals with ostomies, affecting a substantial proportion of patients in both the immediate post-surgical period and

remaining a persistent challenge for many long-term ostomy patients (Martins et al., 2022; Ratliff, 2014; Sun et al., 2013). This complication occurs when effluent penetrates beneath the adhesive barrier that secures the ostomy appliance to the skin, potentially triggering a cascade of related complications. The immediate consequence of leakage is often unwanted odor emission, which has been associated with increased social anxiety and reduced participation in daily activities (Stavropoulou et al., 2021; Sun et al., 2020). Furthermore, prolonged exposure of peristomal skin to effluent can lead to various dermatological complications, ranging from mild irritation to severe inflammatory conditions requiring clinical intervention (Gray et al., 2011, 2013).

Literature has consistently demonstrated associations between ostomy leakage and psychological outcomes. In a recent study, Simpson et al. (2023) found that individuals experiencing frequent leakage (weekly or monthly) exhibited significantly higher rates of psychological distress compared to those reporting rare occurrences. The impact extends beyond immediate psychological effects, with evidence suggesting substantial interference with occupational and social functioning (Jeppesen et al., 2022). Furthermore, the anticipatory anxiety associated with potential leakage necessitates heightened vigilance in appliance maintenance, activity modification, and dietary management (Saunders et al., 2021; Stavropoulou et al., 2021). These findings underscore the complex relationship between ostomy leakage and anxiety in this population.

Ostomy Odor

Ostomy odor represents a significant and pervasive source of anxiety and psychological distress among individuals living with ostomies (Dalton & Maute, 2019;

Saunders et al., 2021; V. Sun et al., 2013; Williams, 2008). Research shows that concerns about uncontrolled flatulence and odor lead to substantial behavioral changes, including social withdrawal and deterioration of intimate and professional relationships (Annells, 2006; Saunders et al., 2021). In response to these concerns, many individuals develop complex, ritualistic behaviors such as compulsively checking their ostomy appliance, implementing elaborate cleaning routines, excessive use of additional ostomy supplies like tape or paste to ensure a secure seal, and maintaining hypervigilance about potential odor emission in social situations (Black & Notter, 2021b). These adaptive behaviors, though intended to manage odor-related anxiety, can themselves become sources of additional stress. The psychological impact extends beyond immediate odor management, affecting occupational performance, social engagement, intimate relationships, recreational activities, and fundamental aspects of body image and self-concept (Duluklu & Çelik, 2019; Yousef et al., 2024).

Individuals with ostomies manage odor through dietary changes (avoiding odor-producing foods), charcoal-filtered pouching systems, and commercial deodorizing products (drops, sprays, tablets), with varying effectiveness across users. Despite these management options, odor remains a predominant concern, significantly impacting quality of life and social interactions (Sun et al., 2013). While the medical community has focused on implementing direct odor-control solutions, less attention has been paid to the psychological aspects of odor perception, particularly whether individuals develop heightened sensitivity to odors from previous negative experiences with ostomy leakage. This increased olfactory awareness could be explained through odor-associative learning, as research has shown that hedonic responses to odors are primarily learned through

emotional associations rather than being innate (Herz, 2005; Herz, Beland, et al., 2004; Herz, Schankler, et al., 2004). Studies demonstrate that negative emotional experiences can create more potent and durable associations with odors compared to positive experiences, and these learned associations can significantly influence future perceptions of similar olfactory stimuli (Herz, 2005; Herz, Beland, et al., 2004; Herz, Schankler, et al., 2004). This conditioning process is particularly relevant given that both olfaction and emotion serve fundamental approach-avoidance functions, sharing direct neuroanatomical connections through the amygdala that no other sensory system possesses.

Peristomal Skin Complications

PSC represents a common challenge among individuals with ostomies, with reported incidence rates ranging from 36.3% to 73.4% (D'Ambrosio et al., 2023). Evidence suggests that PSC contributes to psychological distress in this population. Jayarajah et al. (2016) found that patients experiencing ostomy-related complications, including PSC, demonstrated elevated anxiety and depression scores compared to those without complications. The severity of PSC appears to correlate with psychological impact, as individuals with moderate PSC report greater difficulties with emotional well-being and coping compared to those with mild or no complications (Osborne et al., 2022). The psychological burden may be exacerbated by the practical challenges associated with PSC management, including frequent healthcare visits, physical discomfort, and visible skin changes.

Current Study

Despite growing qualitative evidence linking ostomy-related issues to psychological distress, the field lacks comprehensive quantitative analyses of the structural relationships between various ostomy-related issues and their psychological impacts. Moreover, existing quantitative research on ostomy-related issues has largely relied on heterogeneous study populations, including participants with ostomies resulting from diverse medical conditions such as CRC, inflammatory bowel disease, and trauma. This heterogeneity poses significant methodological challenges in distinguishing whether observed psychosocial outcomes are primarily attributable to ostomy-related issues or are influenced by condition-specific factors. Consequently, the unique psychological impacts of ostomy-related issues in CRC remain poorly understood.

The present study aims to examine the relationships between the degree of ostomy leakage, ostomy odor, PSC, and anxiety symptoms in CRC survivors with ostomies. Specifically, we investigated (1) how ostomy-related issues affect anxiety levels while controlling demographic and clinical factors and (2) whether odor intensity and PSC mediate the relationship between ostomy leakage and anxiety. We hypothesized that (1) higher levels of ostomy leakage, odor, and PSC will significantly predict increased anxiety, even after controlling demographic and clinical factors, and (2) both odor and PSC will mediate the relationship between ostomy leakage and anxiety. Understanding these relationships and potential mediating pathways could inform more targeted interventions for reducing anxiety in this population. This study contributes to both ostomy care and psychosocial oncology by advancing our understanding of the mechanisms through which ostomy-related complications influence psychological well-being in CRC survivors with ostomies.

Methods

This cross-sectional study was approved by the University of Virginia Institutional Review Board (Protocol Number: 6816).

Participants and Procedures

Participants were recruited from online support groups managed by national non-profit organizations focused on ostomy and colorectal cancer support in the United States. Inclusion criteria were: (1) age ≥18 years, (2) diagnosis of Stage I–III CRC with colostomy or ileostomy, (3) community-dwelling status (not hospitalized within previous 2 weeks), (4) English language proficiency sufficient for informed consent and survey completion, (5) no pre-existing mood or anxiety disorders prior to CRC diagnosis, and (6) absence of significant sensory impairments. Participants underwent screening against the inclusion criteria prior to survey access. Those meeting eligibility requirements provided electronic informed consent. The survey incorporated attention-check questions and Qualtrics fraud detection tools to ensure data quality. A systematic validation protocol was implemented to identify and exclude fraudulent responses (see Appendix A for details). Participants received electronic compensation for valid survey completions.

Measures

Data was collected via a Qualtrics survey panel between August and September 2024. The survey comprised three main components: demographic and clinical information, ostomy-related issues, and anxiety symptoms.

Demographic and Clinical Data. Participants provided information on age, sex, gender identity, race, marital status, anthropometric measures, education level, financial status, cancer-related factors (stage I–III, tumor location, time since diagnosis and ostomy

surgery, ostomy permanence status), treatment history (radiotherapy, chemotherapy, chemoradiotherapy), and comorbidities. These variables were selected based on previously identified risk factors for anxiety in CRC survivors (Shin et al., 2024).

Ostomy-related Issues. Leakage, odor, and peristomal skin complications were assessed using single-item measures. Each item (i.e., "Do you experience feces leakage under the baseplate?", "Do you experience embarrassing smells from your stoma bag?", and "Do you experience any skin problems around your stoma?") was rated on a 7-point Likert scale (0 = 'Not at all' to 6 = 'Very much'), with higher scores indicating greater severity.

Anxiety Symptoms. Anxiety symptoms were assessed using the Generalized Anxiety Disorder-7 (GAD-7) scale (Spitzer et al., 2006). This 7-item self-report questionnaire is recommended by the American Society of Clinical Oncology for anxiety screening in cancer patients (Andersen et al., 2014). Items assess anxiety symptom frequency over the past two weeks on a 4-point Likert scale (0 = 'Not at all' to 3 = 'Nearly every day'). Total scores range from 0-21, with established clinical cut points of 5, 10, and 15 representing mild, moderate, and severe anxiety, respectively (Spitzer et al., 2006). The GAD-7 has demonstrated excellent internal consistency ($\alpha = 0.89$-0.92) and test-retest reliability (ICC = 0.83) in validation studies (Löwe et al., 2008; Spitzer et al., 2006). In our sample, the GAD-7 showed good internal consistency ($\alpha = 0.81$) with item-total correlations ranging from 0.62 to 0.76.

Analysis

Data quality was ensured through systematic cleaning procedures. Eight cases were excluded: five due to incomplete demographic or clinical data, and three identified as age and BMI outliers to maintain normal distribution assumptions.

Statistical analyses were performed using Jamovi software version 2.3.26 (The jamovi project, 2023). To identify potential control variables, associations between anxiety and demographic and clinical factors were examined using independent t-tests for dichotomous variables, one-way analysis of variance for categorical variables with more than two groups, and Pearson correlation coefficients for continuous variables.

A series of multivariable linear regression models was performed to assess relationships between ostomy-related issues and anxiety while controlling for relevant demographic and clinical factors (distribution of the data fulfilled statistical assumptions). Potential mediating effects of ostomy odor and PSC on the relationship between ostomy leakage and anxiety were evaluated using Baron and Kenny's mediation approach. This involved conducting a series of regression analyses to establish (1) the relationship between the predictor (leakage) and potential mediators (odor, PSC), (2) the relationship between the predictor (leakage) and outcome (anxiety), and (3) the relationship between potential mediators (odor, PSC) and outcome (anxiety) while controlling demographic and clinical factors.

Results

As shown in Table 4, the study sample (N = 130) predominantly consisted of male participants (67.7%) and individuals who were married or cohabiting (68.5%). The mean age of participants was 44.3 years. The racial composition was primarily White (66.2%). Participants reported mild to moderate financial difficulties (M = 2.35, SD = 0.08; scale 1-4). Most participants had Stage 2 cancer (60%), with similar proportions of colon (48.5%) and rectal (46.9%) cancer diagnoses. The majority of participants (76.2%) received their ostomy surgery within the past year. Temporary and permanent ostomies

were nearly equally distributed (46.2% and 53.8%, respectively). At the time of the study, 45.4% were not receiving treatment, while others were undergoing radiotherapy (18.5%), chemotherapy (26.9%), or both modalities (9.2%). The mean number of comorbidities was 0.49 (SD = 0.06).

Table 4.

Characteristics of Participants (N=130)

Characteristic		N	%
Sex	Female	42	32.3 %
	Male	88	67.7%
Sexual Orientation	Heterosexual (straight)	119	91.5 %
	LGBTQ+	11	8.5%
Marital Status	Married or living with a partner	89	68.5%
	Widowed, divorced, or separated	29	22.3%
	Never been married	12	9.2 %
Race	White or Caucasian	86	66.2 %
	Black or African American	29	22.3%
	Other Races	15	11.5 %
Education	High school diploma or less	19	14.6%
	Some college/associate's degree	55	42.3%
	Bachelor's degree	43	33.1%
	Graduate/Professional degree	13	10.0%
Employment	Employed (working full-time & working part-time)	98	75.4 %
	Unemployed (unemployed, homemaker, student, retired)	32	24.6 %
Cancer Stage	Stage 1	31	23.8 %
	Stage 2	78	60 %
	Stage 3	21	16.2 %
Cancer Location	Colon	63	48.5 %
	Rectum	61	46.9 %
	Both	6	4.6 %
Ostomy Status	Temporary	60	46.2 %
	Permanent	70	53.8 %
Current Treatment	On Radiotherapy	24	18.5 %
	On Chemotherapy	35	26.9%
	On Both (Radio & Chemo)	12	9.2 %
	No (currently not on any)	59	45.4%
Time since Ostomy	Less than 1 year	99	76.2%
	1 year or more	31	23.9%
Characteristic	**Range, Mean (SD)**		
Age	22- 67, 44.3 (.94)		
BMI	16.8- 30.4, 23.6 (.25)		
Financial Difficulty	1(no difficulty)- 4(severe difficulty), 2.35 (.08)		
Number of comorbidities	0- 3, 0.49 (.06)		
Main Variables	**Range, Mean (SD)**		
Ostomy Leakage	0-6, 2.24 (0.13)		
Ostomy Odor	0-6, 2.65 (0.13)		

PSC	0-6, 2.32 (0.13)
Anxiety	0-17, 7.89 (0.35)

T-test, ANOVA, and Pearson correlation analyses revealed significant associations between demographic/clinical variables and main variables (see Appendix B for details). Males reported significantly higher ostomy odor intensity (M = 2.85, SD = 1.51) than females (M = 2.21, SD = 1.3; t (128) = −2.36, p = .02). Additionally, there was a positive correlation between financial difficulty and odor (r = .25, p = .004). PSC varied significantly by race (F (2,36.7) = 3.39, p = .044), with white participants reporting higher PSC (M = 2.53, SD = 1.42) than black participants (M = 1.97, SD = 1.55) and other races (M = 1.8, SD = 1.08). PSC also positively correlated with financial difficulty (r = .18, p = .036). In addition, the analysis revealed significant correlations between anxiety and demographic factors: higher anxiety levels were associated with older age (r = .18, p = .04) and greater financial difficulties (r = .24, p = .007). Anxiety levels also varied significantly by race (F (2,36) = 6.07, p = .005). The Games-Howell post-hoc test revealed that participants of other races reported the highest levels of anxiety (M = 10.87, SD = 3.5), followed by White (M = 7.6, SD = 4.03) and Black participants (M = 7.21, SD = 3.47). Additionally, participants with higher education levels experienced greater anxiety (F (3,43.8) = 10.2, p <.001). Among clinical factors, participants with temporary ostomies experienced higher anxiety (M = 9.15, SD = 4.08) than those with permanent ostomies (M = 6.81, SD = 3.58; t (128) = 3.48, p < .001). Treatment status also significantly influenced anxiety levels (F(3, 40.6) = 20.5, p < .001), with post-hoc results showing that participants without either chemotherapy or radiotherapy reported the lowest anxiety level (M = 5.42, SD = 3.29) compared to those who were on radiotherapy (M = 9.38, SD = 3.64), on chemotherapy (M = 10.23, SD = 3.18), and on both (M =

10.25, SD = 2.96). To account for these relationships, these variables were incorporated as covariates in subsequent analyses to isolate the specific effects of ostomy-related issues on anxiety.

Pearson correlation analyses revealed significant positive correlations among ostomy-related factors. Strong correlations were found between ostomy leakage and odor ($r = 0.645$, $p < .001$), leakage and PSC ($r = 0.535$, $p < .001$), and odor and PSC ($r = 0.595$, $p < .001$). When examining anxiety, only ostomy odor showed a weak but significant correlation ($r = 0.189$, $p = .032$). Neither leakage ($r = 0.127$, $p = .151$) nor PSC ($r = 0.09$, $p = .308$) showed statistically significant correlations with anxiety levels.

Table 5 presents the regression analyses examining the effects of ostomy leakage on odor severity and PSC severity, controlling for relevant demographic and clinical variables that showed significant differences in the above group analyses. For odor severity, ostomy leakage is a significant predictor of odor severity (standardized regression coefficient [β] = 0.61, $p < .001$) with higher leakage predicting higher odor severity while controlling for sex and financial difficulty. This means that a one standard deviation increase in leakage corresponds to a 0.61 standard deviation increase in odor severity. Similarly, ostomy leakage is a significant predictor of PSC severity ($\beta = 0.51$, $p < .001$) with higher leakage predicting higher PSC severity while controlling for race and financial difficulty. The β coefficient of 0.51 indicates that a one standard deviation increase in leakage leads to a 0.51 standard deviation increase in PSC severity, showing a moderately strong positive relationship.

Table 5.

Regression Analyses Examining Effects of Ostomy Leakage on Odor and Peristomal Skin Complications (N=130)

Predictors	Odor	PSC
	β (*p*)	β (*p*)
Male (versus Female)	0.15 (0.295)	.
Financial difficulty	0.07 (0.3)	0.05 (0.522)
Black or African American (versus White)	.	-0.39* (0.033)
Other Races (versus White)	.	-0.19 (0.42)
Ostomy Leakage	0.61 *** (< .001)	0.51*** (< .001)

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Table 6 presents regression analysis results on the effects of ostomy-related factors on anxiety levels, while controlling for demographic and clinical variables. In the model that controlled for race, ostomy status, treatment, age, education, and financial difficulty, ostomy leakage was a significant predictor of anxiety (β = 0.23, p = 0.003). When ostomy odor was added to the model, odor significantly predicted anxiety (β = 0.19, p = 0.039), while leakage became non-significant (β = 0.11, p = 0.249). Adding PSC to the model neither substantially changed the effects of leakage and odor on anxiety, nor showed a significant association with anxiety (β = -0.05, p = 0.575).

Table 6.

Regression Analyses for Variables Predicting Anxiety Levels (N=130)

Predictor of Anxiety	Model including leakage		Model additionally including odor		Model additionally including PSC	
	β	p	β	p	β	p
White (versus Other Races)	-0.8***	< .001	-0.81***	< .001	-0.80***	< .001
Black or African American (versus Other Races)	-0.97***	< .001	-0.98***	< .001	-0.99***	< .001
Some college/associate's degree (versus High school diploma or less)	0.18	0.405	0.23	0.29	0.26	0.252
Bachelor's degree (versus High school diploma or less)	0.19	0.444	0.24	0.327	0.26	0.29
Graduate/Professional degree (versus High school diploma or less)	0.01	0.975	0.09	0.779	0.14	0.682
permanent (versus temporary)	-0.2	0.198	-0.15	0.324	-0.16	0.309

On Radiotherapy (versus No)	0.69**	0.002	0.73**	0.001	0.712**	0.002
On Chemotherapy (versus No)	0.93***	<.001	0.9***	<.001	0.888***	< .001
On Both (versus No)	0.92***	<.001	0.97***	<.001	0.949***	< .001
Age	-0.14	0.086	-0.13	0.108	-0.13	0.104
Financial Difficulty	-0.14	0.071	-0.15	0.048	-0.15	0.055
Ostomy Leakage	0.23**	0.003	0.11	0.249	0.12	0.214
Ostomy Odor	.	.	0.19*	0.039	0.21*	0.034
PSC	.	.	.	.	-0.05	0.575

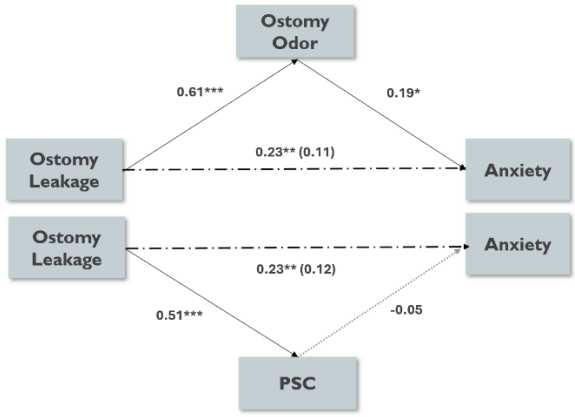
Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Across all regression models, race and treatment status showed consistent, statistically significant effects on anxiety levels. These effects remained stable even after accounting for various ostomy-related issues, indicating that these demographic and clinical factors independently influence participants' anxiety experiences.

Following Baron and Kenny's approach, mediation analyses suggest that odor may fully mediate the relationship between ostomy leakage and anxiety (see Figure 2). Specifically, ostomy leakage showed a significant direct effect on anxiety (Model including leakage, Table 6). However, when odor was introduced into the model, this direct effect of leakage on anxiety became non-significant, while odor demonstrated a significant relationship with anxiety. This suggests that the direct effect of leakage on anxiety could be attributed to odor. In contrast, while PSC was significantly associated with leakage, it did not demonstrate a significant mediating effect on the relationship between leakage and anxiety. Although leakage initially showed a significant relationship with anxiety, the addition of PSC to the model did not significantly contribute to explaining anxiety levels.

Figure 2.

Mediating effect of ostomy odor in the relationship between ostomy leakage and anxiety



Note. ( ) Direct effect after accounting for mediated effect, * p < .05, ** p < .01, *** p < .001

Discussion

This study investigated the relationship between ostomy-related issues and anxiety in CRC survivors with ostomies. Our findings suggest that ostomy odor may mediate the relationship between leakage and anxiety, while PSC, despite its association with leakage, does not serve as a mediator. Additionally, demographic and clinical factors played significant roles, with race and treatment status showing consistent, statistically significant effects on anxiety levels that remained stable even after accounting for ostomy-related issues.

Our analysis of ostomy leakage and anxiety aligns with previous research across ostomy populations with different underlying conditions (Jeppesen et al., 2022; Simpson et al., 2023). A key methodological strength was our precise definition of leakage as fecal matter under the baseplate, addressing inconsistencies in leakage interpretation between patients and healthcare providers noted in previous research. A large-scale study of 54,614 ostomy patients across 17 countries found that many individuals do not consider

effluent near the ostomy as leakage (Down et al., 2021), indicating that earlier studies may have underreported its occurrence.

The identification of odor as a mediating factor between leakage and anxiety represents a significant advancement in understanding ostomy-related psychosocial challenges. This structural relationship suggests that leakage's psychological impact occurs primarily through odor-related concerns. Importantly, our multivariable regression analyses revealed that odor maintains a significant association with anxiety even after controlling for leakage (see models including odor in Table 6), highlighting the distinct psychological impact of odor. Though ostomy management differs physiologically from incontinence, both conditions share fundamental psychosocial challenges related to odor management and social stigma. Like findings in incontinence research (Dalton & Maute, 2019), our data suggest that ostomy patients often develop heightened odor sensitivity, creating a self-reinforcing cycle of anxiety and hypervigilance. This mediating relationship aligns with established research on odor-associative learning, where negative experiences with odors create lasting emotional associations that influence future perceptions (Herz, 2005; Herz, Beland, et al., 2004; Herz, Schankler, et al., 2004). These associations are reinforced through neural pathways connecting olfaction and emotion, where past negative experiences trigger anticipatory anxiety and heightened odor vigilance (Herz, 2005; Herz, Beland, et al., 2004; Herz, Schankler, et al., 2004). In the context of ostomy care, negative leakage experiences may generate emotional memory traces that heighten anxiety during subsequent similar odor encounters. This phenomenon may be particularly salient in public settings, where ostomy appliances remain concealed beneath clothing while odors present a more challenging aspect of concealment. These

findings explain common behaviors among people with ostomies, such as frequently changing their appliance, repeatedly checking it, taking excessive showers, or fasting before and during social activities (Annells, 2006; Black & Notter, 2021; Mitchell et al., 2007; Saunders et al., 2021). Rather than viewing these solely as maladaptive coping mechanisms for leakage concerns, our findings suggest these behaviors may represent attempts to manage odor-related anxiety. This indicates that interventions should target not only leakage management but also address both the physical control of odor and the psychological aspects of odor-related anxiety.

Our analysis revealed that while leakage significantly predicted PSC occurrence, consistent with literature establishing effluent exposure as a primary risk factor for PSC development (Doctor & Colibaseanu, 2016; M. Gray et al., 2011, 2013), PSC did not mediate the relationship between leakage and anxiety as hypothesized. This finding is inconsistent with previous studies showing associations between PSC and psychological distress in general ostomy populations (Jayarajah et al., 2016; Osborne et al., 2022). This divergence from prior findings may be attributed to the unique characteristics of our study population, CRC survivors, who might process and respond to physical complications differently due to their extensive experience with cancer-related challenges and medical interventions. The limited impact of PSC on anxiety may be explained by its relatively predictable and chronic clinical course when associated with prolonged leakage exposure. This predictability contrasts with the unpredictable and socially challenging nature of ostomy odor concerns. Furthermore, the distinction between PSC and odor becomes particularly relevant when considering their social dimensions. While odor represents a shared sensory experience that can affect social interactions and public

spaces, PSC remains a private physical condition that primarily impacts the individual's personal experience with their ostomy care. This fundamental difference in the social visibility and impact of these complications may help explain their differing relationships with anxiety levels.

Clinical Implications

Our findings have important clinical implications for healthcare providers managing ostomy-related complications and associated anxiety. The mediating role of odor in the relationship between leakage and anxiety suggests the need for a structured, sequential intervention approach to identify and mitigate odor. Healthcare providers should first implement evidence-based leakage prevention and management strategies, followed by targeted odor control measures. This stepwise approach should be incorporated into standardized ostomy care protocols. Furthermore, interventions should address both the physical control of odor and the psychological aspects of odor-related anxiety. Additional intervention research is needed to explore effective ways to manage the psychological aspects of odor-related anxiety, as this will provide the foundation for establishing evidence-based practice guidelines in this understudied area.

Moreover, our findings regarding demographic and clinical risk factors necessitate tailored interventions. Healthcare providers should implement enhanced psychological screening and support for individuals from minority racial groups and those undergoing concurrent cancer treatments, as these populations demonstrated elevated anxiety levels independent of ostomy management success. Implementation of such comprehensive, personalized care protocols may optimize both physical and psychological outcomes across diverse patient populations.

Limitations

Several limitations should be considered when interpreting our findings. Cross-sectional design prevents us from establishing definitive causal relationships between variables or confirming the temporal sequence of our proposed mediation effects. Although the logical sequence of our variables (e.g., leakage preceding odor, not vice versa) provides theoretical support for our findings, future longitudinal studies are needed to confirm these relationships. Our series of regression analysis approaches helped mitigate some design limitations by adjusting for potential control variables. Our study relied on self-reported measures, which may introduce reporting biases. However, self-reported data can capture participants' lived experiences and perceptions, which themselves play a role in anxiety development (Dalton & Maute, 2019; Merleau-Ponty, 2011). Recruitment through online support groups allowed us to access established national networks representing a diverse cross-section of the ostomy population. However, this approach has potentially limited participation from individuals with limited internet access or technological proficiency. The study's demographic composition presents another limitation, with restricted representation from racial groups other than white and black participants- only 11.5% of participants identified as other races. While we used statistical analysis techniques to adjust for the effects of race on anxiety, the small sample size for other racial groups may limit the generalizability of our findings across all racial and ethnic populations. Additionally, we did not control for some biological factors, particularly inflammation markers, which previous research suggests may influence anxiety in this population (Miranda et al., 2018; Oliveira Miranda et al.,

2014). Other unmeasured variables beyond the scope of our investigation may also affect anxiety levels (Shin et al., 2024).

Future Research Recommendations

Future research should employ longitudinal study designs to establish temporal relationships and validate the proposed mediation effects identified in our cross-sectional analysis. Given our finding that race and treatment status serve as fundamental determinants of anxiety independent of ostomy-related issues, future research should prioritize investigating the mechanisms through which these demographic and clinical factors influence anxiety, particularly focusing on understudied ethnic minority groups and patients undergoing active cancer treatment. Additionally, prospective studies should investigate the broader psychosocial impact of ostomy-related issues, with particular emphasis on social functioning and body image perception. These aspects have been consistently highlighted as significant concerns in qualitative research within the ostomy population but require more rigorous quantitative investigation. Furthermore, intervention studies testing targeted approaches to odor management and their subsequent effects on anxiety levels would provide valuable insights for clinical practice.

Conclusion

Our findings indicate a potential mediating effect of ostomy odor in the relationship between ostomy leakage and anxiety levels among CRC survivors with ostomies. Further, both race and treatment status emerged as fundamental determinants of anxiety, maintaining their significant influence independently of ostomy-related issues. These results emphasize the need for comprehensive interventions that address both practical odor management and underlying psychological aspects of odor-related anxiety

in CRC survivors with ostomies while considering the unique challenges of diverse demographic and clinical subgroups.

References for Chapter 3

American Cancer Society. (2024). *Cancer Facts & Figures 2024*. American Cancer Society.

Andersen, B. L., DeRubeis, R. J., Berman, B. S., Gruman, J., Champion, V. L., Massie, M. J., Holland, J. C., Partridge, A. H., Bak, K., Somerfield, M. R., & Rowland, J. H. (2014). Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation. *Journal of Clinical Oncology*, *32*(15), 1605–1619. https://doi.org/10.1200/JCO.2013.52.4611

Annells, M. (2006). The Experience of Flatus Incontinence From a Bowel Ostomy: A Hermeneutic Phenomenology. *Journal of Wound Ostomy & Continence Nursing*, *33*(5), 518.

Benedict, C., Rodriguez, V. M., Carter, J., Temple, L., Nelson, C., & DuHamel, K. (2016). Investigation of body image as a mediator of the effects of bowel and GI symptoms on psychological distress in female survivors of rectal and anal cancer. *Supportive Care in Cancer*, *24*(4), 1795–1802. https://doi.org/10.1007/s00520-015-2976-2

Black, P., & Notter, J. (2021). Psychological issues affecting patients living with a stoma. *British Journal of Nursing*, *30*(6), S20–S32. CINAHL with Full Text. https://doi.org/10.12968/bjon.2021.30.6.S20

Dalton, P., & Maute, C. (2019). Odours and incontinence: What does the nose know? *Proceedings of the Institution of Mechanical Engineers, Part H: Journal of*

Engineering in Medicine, *233*(1), 127–134. https://doi.org/10.1177/0954411918781409

D'Ambrosio, F., Pappalardo, C., Scardigno, A., Maida, A., Ricciardi, R., & Calabrò, G. E. (2023). Peristomal Skin Complications in Ileostomy and Colostomy Patients: What We Need to Know from a Public Health Perspective. *International Journal of Environmental Research and Public Health*, *20*(1), Article 1. https://doi.org/10.3390/ijerph20010079

Doctor, K., & Colibaseanu, D. T. (2016). Peristomal skin complications: Causes, effects, and treatments. *Chronic Wound Care Management and Research*, *4*, 1–6. https://doi.org/10.2147/CWCMR.S93615

Down, G., Vestergaard, M., Ajslev, T. A., Boisen, E. B., & Nielsen, L. F. (2021). Perception of leakage: Data from the Ostomy Life Study 2019. *British Journal of Nursing*, *30*(22), S4–S12. https://doi.org/10.12968/bjon.2021.30.22.S4

Duluklu, B., & Çelik, S. Ş. (2019). Effects of lavender essential oil for colorectal cancer patients with permanent colostomy on elimination of odor, quality of life, and ostomy adjustment: A randomized controlled trial. *European Journal of Oncology Nursing*, *42*, 90–96. CINAHL. https://doi.org/10.1016/j.ejon.2019.08.001

Gray, M., Black, J. M., Baharestani, M. M., Bliss, D. Z., Colwell, J. C., Goldberg, M., Kennedy-Evans, K. L., Logan, S., & Ratliff, C. R. (2011). Moisture-Associated Skin Damage: Overview and Pathophysiology. *Journal of Wound Ostomy & Continence Nursing*, *38*(3), 233–241. https://doi.org/10.1097/WON.0b013e318215f798

Gray, M., Colwell, J. C., Doughty, D., Goldberg, M., Hoeflok, J., Manson, A., McNichol, L., & Rao, S. (2013). Peristomal Moisture–Associated Skin Damage in Adults With Fecal Ostomies: A Comprehensive Review and Consensus. *Journal of Wound Ostomy & Continence Nursing*, *40*(4), 389. https://doi.org/10.1097/WON.0b013e3182944340

Herz, R. S. (2005). Odor-associative Learning and Emotion: Effects on Perception and Behavior. *Chemical Senses*, *30*(suppl_1), i250–i251. https://doi.org/10.1093/chemse/bjh209

Herz, R. S., Beland, S. L., & Hellerstein, M. (2004). Changing Odor Hedonic Perception Through Emotional Associations in Humans. *International Journal of Comparative Psychology*, *17*(4). https://doi.org/10.46867/ijcp.2004.17.04.05

Herz, R. S., Schankler, C., & Beland, S. (2004). Olfaction, Emotion and Associative Learning: Effects on Motivated Behavior. *Motivation and Emotion*, *28*(4), 363–383. https://doi.org/10.1007/s11031-004-2389-x

Jayarajah, U., Samarasekera, A. M., & Samarasekera, D. N. (2016). A study of postoperative anxiety and depression among patients with intestinal stomas. *Sri Lanka Journal of Surgery*, *34*(2), 6. https://doi.org/10.4038/sljs.v34i2.8261

Jeppesen, P. B., Vestergaard, M., Boisen, E. B., & Ajslev, T. A. (2022). Impact of stoma leakage in everyday life: Data from the Ostomy Life Study 2019. *British Journal of Nursing*, *31*(6), S48–S58. https://doi.org/10.12968/bjon.2022.31.6.S48

Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the Generalized Anxiety Disorder

Screener (GAD-7) in the general population. *Medical Care*, *46*(3), 266–274. https://doi.org/10.1097/MLR.0b013e318160d093

Martins, L., Andersen, B. D., Colwell, J., Down, G., Forest-Lalande, L., Novakova, S., Probert, R., Hedegaard, C. J., & Hansen, A. S. (2022). Challenges faced by people with a stoma: Peristomal body profile risk factors and leakage. *British Journal of Nursing*, *31*(7), 376–385. https://doi.org/10.12968/bjon.2022.31.7.376

Merleau-Ponty, M. (2011). *Phenomenology of Perception*. Routledge. https://doi.org/10.4324/9780203720714

Miranda, D. O., Anatriello, E., Azevedo, L. R., Cordeiro, J. F. C., Peria, F. M., Flória-Santos, M., & Pereira-da-Silva, G. (2018). Elevated serum levels of proinflammatory cytokines potentially correlate with depression and anxiety in colorectal cancer patients in different stages of the antitumor therapy. *Cytokine*, *104*, 72–77. https://doi.org/10.1016/j.cyto.2017.09.030

Mitchell, K. A., Rawl, S. M., Schmidt, C. M., Grant, M., Ko, C. Y., Baldwin, C. M., Wendel, C., & Krouse, R. S. (2007). Demographic, Clinical, and Quality of Life Variables Related to Embarrassment in Veterans Living With an Intestinal Stoma. *Journal of Wound Ostomy & Continence Nursing*, *34*(5), 524. https://doi.org/10.1097/01.WON.0000290732.15947.9e

Mols, F., Schoormans, D., de Hingh, I., Oerlemans, S., & Husson, O. (2018). Symptoms of anxiety and depression among colorectal cancer survivors from the population-based, longitudinal PROFILES Registry: Prevalence, predictors, and impact on quality of life. *Cancer (0008543X)*, *124*(12), 2621–2628. CINAHL with Full Text. https://doi.org/10.1002/cncr.31369

Oliveira Miranda, D., Soares de Lima, T. A., Ribeiro Azevedo, L., Feres, O., Ribeiro da Rocha, J. J., & Pereira-da-Silva, G. (2014). Proinflammatory cytokines correlate with depression and anxiety in colorectal cancer patients. *BioMed Research International*, *2014*, 739650–739650. CINAHL with Full Text. https://doi.org/10.1155/2014/739650

Osborne, W., White, M., Aibibula, M., Boisen, E. B., Ainsworth, R., & Vestergaard, M. (2022). Prevalence of leakage and its negative impact on quality of life in people living with a stoma in the UK. *British Journal of Nursing*, *31*(16), S24–S38. https://doi.org/10.12968/bjon.2022.31.16.S24

Peng, Y.-N., Huang, M.-L., & Kao, C.-H. (2019). Prevalence of Depression and Anxiety in Colorectal Cancer Patients: A Literature Review. *International Journal of Environmental Research and Public Health*, *16*(3), Article 3. https://doi.org/10.3390/ijerph16030411

Ratliff, C. R. (2014). Factors Related to Ostomy Leakage in the Community Setting. *Journal of Wound Ostomy & Continence Nursing*, *41*(3), 249–253. https://doi.org/10.1097/WON.0000000000000017

Saunders, C. H., Goldwag, J. L., Read, J. T., Durand, M.-A., Elwyn, G., & Ivatury, S. J. (2021). "Because Everybody is so Different": A qualitative analysis of the lived experiences and information needs of rectal cancer survivors. *BMJ Open*, *11*(5), e043245. https://doi.org/10.1136/bmjopen-2020-043245

Shin, J., Gibson, J. S., Jones, R. A., & Debnam, K. J. (2024). Factors associated with anxiety in colorectal cancer survivors: A scoping review. *Journal of Cancer Survivorship*. https://doi.org/10.1007/s11764-024-01678-0

Simpson, E., Pourshahidi, K., Davis, J., Slevin, M., Lawther, R., O'Connor, G., Porrett, T., Marley, J., & Gill, C. (2023). Living with and without an intestinal stoma: Factors that promote psychological well-being and self-care: A cross-sectional study. *Nursing Open*, *10*(12), 7811. https://doi.org/10.1002/nop2.2030

Song, L., Han, X., Zhang, J., & Tang, L. (2020). Body image mediates the effect of stoma status on psychological distress and quality of life in patients with colorectal cancer. *Psycho-Oncology*, *29*(4), 796–802. https://doi.org/10.1002/pon.5352

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. *Archives of Internal Medicine*, *166*(10), 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

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), 8512. https://doi.org/10.3390/ijerph18168512

Sun, V., Bojorquez, O., Grant, M., Wendel, C. S., Weinstein, R., & Krouse, R. S. (2020). Cancer survivors' challenges with ostomy appliances and self-management: A qualitative analysis. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, *28*(4), 1551–1554. https://doi.org/10.1007/s00520-019-05156-7

Sun, V., Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J., Baldwin, C. M., & Krouse, R. S. (2013). Surviving Colorectal Cancer: Long-term, Persistent Ostomy-Specific Concerns and Adaptations.

Journal of Wound Ostomy & Continence Nursing, *40*(1), 61. https://doi.org/10.1097/WON.0b013e3182750143

The jamovi project. (2023). *Jamovi*. (Version 2.3.26) [Windows]. Retrieved from https://www.jamovi.org/

Trudel-Fitzgerald, C., Tworoger, S. S., Poole, E. M., Zhang, X., Giovannucci, E. L., Meyerhardt, J. A., & Kubzansky, L. D. (2018). Psychological symptoms and subsequent healthy lifestyle after a colorectal cancer diagnosis. *Health Psychology*, *37*(3), 207–217. https://doi.org/10.1037/hea0000571

Trudel-Fitzgerald, C., Tworoger, S. S., Zhang, X., Giovannucci, E. L., Meyerhardt, J. A., & Kubzansky, L. D. (2020). Anxiety, Depression, and Colorectal Cancer Survival: Results from Two Prospective Cohorts. *Journal of Clinical Medicine*, *9*(10), Article 10. https://doi.org/10.3390/jcm9103174

Williams, J. (2008). Flatus, odour and the ostomist: Coping strategies and interventions. *British Journal of Nursing*, *17*(Sup1), S10–S14. https://doi.org/10.12968/bjon.2008.17.Sup1.28144

Yousef, J., Al Hasanat, A., Othman, S., Alrahma, S., & Alloubani, A. (2024). Effects of lavender oil on odor elimination, ostomy adjustment and quality of life in patients with permanent colostomy: A randomized controlled trial. *European Journal of Oncology Nursing*, *68*, N.PAG-N.PAG. https://doi.org/10.1016/j.ejon.2023.102471

Zhu, L., Tong, Y. X., Xu, X. S., Xiao, A. T., Zhang, Y. J., & Zhang, S. (2020). High level of unmet needs and anxiety are associated with delayed initiation of adjuvant

chemotherapy for colorectal cancer patients. *Supportive Care in Cancer*, *28*(11), 5299–5306. CINAHL with Full Text. https://doi.org/10.1007/s00520-020-05333-z

CHAPTER 4

Manuscript 3: Associations Among Ostomy Odor, Body Image Disturbance, Anxiety, and Emotional Well-being in Colorectal Cancer Survivors with Ostomies

Abstract

Background: Ostomy odor and body image disturbance are significant concerns among colorectal cancer (CRC) survivors with ostomies. Despite growing research on the cross-modal interplay between olfactory stimuli and visual perception, the relationship between ostomy odor and body image in this population remains understudied.

Purpose: This study examined the relationships among ostomy odor, body image disturbance (BID), anxiety symptoms, and emotional well-being (EWB) in CRC survivors with ostomies.

Methods: A cross-sectional study was conducted among 130 community-dwelling colorectal cancer survivors (Stages I-III) with ostomies, recruited through national online support groups. Individuals with pre-existing mood or anxiety disorders or major sensory deficits were excluded. The survey included an ostomy odor scale (single-item, 7-point Likert scale), Body Image Scale (Hopwood et al., 2001a), GAD-7 (Spitzer et al., 2006), and FACT-G EWB subscale (D. F. Cella et al., 1993), along with demographic and clinical data. We used a series of regression analyses with Baron and Kenny's mediation model to examine relationships among variables while controlling for demographic and clinical factors.

Results: Regression analyses revealed that ostomy odor significantly predicted BID ($\beta = 0.15$, $p = .037$), anxiety ($\beta = 0.25$, $p < .001$), and EWB ($\beta = -0.32$, $p < .001$). When BID was added to the models, both ostomy odor ($\beta = -0.27$, $p = .002$) and BID ($\beta = -0.18$, $p = .043$) emerged as significant predictors of EWB, while for anxiety, ostomy odor remained significant ($\beta = 0.23$, $p = .002$) but BID was not ($\beta = 0.15$, $p = .088$). Mediation

analysis indicated that BID partially mediated the relationship between ostomy odor and EWB.

Conclusion: This study's findings demonstrate that BID partially mediates the relationship between ostomy odor and emotional outcomes in CRC survivors with ostomies, suggesting a cross-modal interaction between these factors.

Introduction

Colorectal cancer (CRC) is currently the third most prevalent malignancy in the United States (American Cancer Society, 2024). For many patients, ostomy surgery remains a primary treatment modality. Remarkably, the incidence of young-onset CRC, diagnosed before age 55, has shown a consistent increase over the past two decades (American Cancer Society, 2024). This trend suggests that a growing population of CRC survivors will face long-term management of their disease and treatment effects. Living with an ostomy requires significant lifestyle modifications (Lim et al., 2021; Stavropoulou et al., 2021; V. Sun et al., 2013), encompassing not only physical adaptations but also the development of comprehensive coping strategies. These strategies are essential for psychological health, particularly maintaining emotional well-being and managing anxiety symptoms. Emotional well-being (EWB), which encompasses various aspects of psychological functioning, including anxiety, can be significantly compromised by ostomy-related challenges. Among these challenges, ostomy odor and body image disturbance (BID) emerge as particularly significant concerns that can trigger anxiety symptoms and diminish overall EWB in CRC survivors (Han et al., 2020b; Shin et al., 2024; V. Sun et al., 2013; Williams, 2008).

Ostomy Odor

Living with an ostomy presents profound psychosocial challenges, with ostomy odor emerging as a particularly complex and emotionally charged aspect of daily life (Sun et al., 2013; Williams, 2008). Throughout history, social norms have strictly regulated and stigmatized unpleasant odors, reflecting deeply ingrained cultural attitudes about cleanliness and social acceptability that persist across diverse societies and time

periods (Corbin, 1986). The psychological burden of managing ostomy odor can be devastating, manifesting in multiple dimensions of distress. Many individuals experience intense anxiety, heightened self-consciousness, and overwhelming embarrassment related to odor, especially in public spaces where odor management becomes more challenging and socially consequential (Annells, 2006; Saunders et al., 2021). This constant vigilance and fear of odor detection frequently lead to significant behavioral modifications, including social withdrawal and self-imposed isolation (Lim et al., 2021). These adaptations profoundly impact various life domains, from professional environments where individuals may decline career advancement opportunities to personal relationships where they might avoid intimate connections, all stemming from deep-seated fears about uncontrollable ostomy functions. The emotional impact extends beyond immediate social situations, becoming deeply rooted in societal attitudes and personal identity formation. Individuals with ostomies frequently internalize adverse societal reactions, viewing themselves as sources of disgust and social disruption (Annells, 2006; Yuan et al., 2018). This self-perception catalyzes a cascade of psychological responses, resulting in powerful feelings of shame and stigma that can lead to long-term social exclusion, severe loss of confidence, and fundamental alterations in self-concept (Annells, 2006; Yuan et al., 2018).

Body Image Disturbance

A recent meta-analysis revealed body image distress as the predominant concern among CRC survivors, affecting 78.5% of individuals and ranking as the third most severe symptom with a score of 36.4 out of 100 (Han et al., 2020). This concern was particularly pronounced among those with past or current ostomies. The

conceptualization of BID in oncology has evolved to incorporate both visual and functional bodily changes, providing a more comprehensive framework (Fingeret, Nipomnick, et al., 2013; Rhoten, 2018; Rhoten et al., 2013; Rhoten, 2016). Research has established that alterations in physical appearance and bodily functions significantly impact body image perception, as demonstrated in studies of head and neck cancer survivors experiencing eating and speech difficulties (Fingeret, Hutcheson, et al., 2013; Rhoten, 2016). While these aspects have expanded our understanding of body image as a multifaceted construct, when considering the spectrum of sensory input categories, these two aspects demonstrate profound interconnectivity rather than existing as separate entities, as functional changes to the body frequently manifest visible components. This interconnected nature of bodily perception extends beyond just visual and functional aspects to include other sensory modalities, particularly olfactory experiences in individuals with ostomies (Annells, 2006; Yousef et al., 2024). This expansion of body image construct is crucial for understanding BID in CRC survivors with ostomies, as it acknowledges multisensory experiences beyond visual aspects that contribute to body image perception.

The relationship between olfactory stimuli and psychological responses, particularly in the context of body image, is supported by extensive research in cross-modal correspondences and aromachology (Davies-Owen et al., 2024; Herz, 2009; Herz, Beland, et al., 2004; Spence, 2021). Studies have demonstrated that odors significantly influence cognitive processing, emotional states, and behavioral responses through cross modal correspondences- natural connections between different types of sensations that are shared across individuals (Herz, 2009; Spence, 2021). Recent experimental work has

shown that scents can directly affect body image perception, with certain fragrances (like lemon) making individuals feel lighter while others (like vanilla) create sensations of heaviness (Brianza et al., 2019). This finding aligns with broader research showing that pleasant fragrances positively influence evaluations of attractiveness and confidence in pictures of others and self, while unpleasant odors have the opposite effect (Chen & Spence, 2022; Davies-Owen et al., 2024; Spence, 2021). A recent randomized controlled trial by Yousef et al. (2024) provides evidence for the impact of pleasant odors on body image and psychosocial outcomes in individuals with ostomies. The study found that lavender oil intervention significantly improved body image connected to sexuality and social involvement. Studies have also revealed that individuals often pay more attention to unpleasant odors than pleasant ones, with negative olfactory experiences having a more pronounced impact on social interactions and self-perception (Cook et al., 2018; Demattè et al., 2007; Li et al., 2007; Waskul & Vannini, 2008). The psychological impact of odor extends beyond immediate reactions, influencing both short-term emotional states and longer-term aspects of self-image and psychosocial well-being (Herz, 2009; Waskul & Vannini, 2008). This mind-body connection aligns with Merleau-Ponty's (2011) phenomenological framework, which emphasizes the embodied nature of perception and the inseparable connection between bodily experiences and psychological responses.

Current Study

Guided by Maurice Merleau-Ponty's (2011) view of the body as both object and subject, this study conceptualizes olfactory bodily changes as one component of overall sensory experience. Despite significant advances in olfaction research across neuroscience, psychology, and biotechnology, the application of these insights to medical

contexts, especially in cancer survivors, remains underdeveloped. Current literature predominantly examines the positive effects of pleasant fragrances on body image, leaving a significant knowledge gap regarding the psychosocial impact of disease- or treatment-related odors, such as those associated with ostomies. Moreover, existing ostomy research tends to examine visible bodily changes as the sole cause of BID, overlooking the cross-modal interaction between different senses, particularly between olfactory and visual perception. Furthermore, most studies have included participants with ostomies from various medical conditions, creating a heterogeneous sample that makes it difficult to separate ostomy-specific effects from those of underlying diseases. For example, emotional well-being may vary considerably between individuals with ostomies from inflammatory bowel disease versus CRC. This limitation has left gaps in our understanding of how ostomy-specific factors influence psychological outcomes.

The present study aims to examine the structural relationships between ostomy odor, BID, anxiety symptoms, and emotional well-being in CRC survivors with ostomies. We hypothesize that (1) higher levels of ostomy odor will be associated with increased BID, independent of demographic and clinical factors, (2) higher levels of ostomy odor will be associated with elevated anxiety and decreased emotional well-being, independent of demographic and clinical factors, and (3) increased BID will be associated with increased anxiety and decreased emotional well-being EWB while controlling for ostomy odor and other factors, with BID partially mediating the relationship between ostomy odor and anxiety/emotional well-being. Understanding these relationships may guide the development of targeted psychosocial interventions for this population.

Methods

This study was approved by the University of Virginia Institutional Review Board (Protocol Number: 6816).

Study Design and Participants

Our cross-sectional study focused on CRC survivors with ostomies (Stages I–III), recruited through online support networks affiliated with national organizations dedicated to ostomy and CRC support. Study eligibility criteria included: age 18 or older, colostomy or ileostomy due to Stage I–III CRC, community-dwelling in the USA (not hospitalized in the past two weeks), proficient in English for survey completion, no pre-CRC diagnosis history of mood or anxiety disorders, and no significant sensory impairments. To maintain data quality, we employed a validation strategy to detect potentially fraudulent responses, incorporating dynamic attention-check questions and consistency verifications. Participants who completed the survey successfully and met our validation standards were provided with electronic gift cards as incentives.

Measures

We conducted an online survey using Qualtrics to gather data from participants during August and September 2024. The survey included questions about ostomy odor, body image, anxiety, and emotional well-being, as well as demographic and clinical information.

Demographic and Clinical Data. The survey collected a wide range of information from participants, including but not limited to age, sex, race, cancer stage, tumor location, time elapsed since diagnosis and ostomy surgery, ostomy status such as

temporary or permanent, types of adjuvant treatments received, and presence of comorbidities.

Ostomy odor. We assessed the severity of ostomy odor using a single item. Participants answered the question, "Do you experience embarrassing smells from your stoma bag?" This item employed a 7-point Likert scale (0 = 'Not at all' to 6 = 'Very much'), with higher scores indicating more severe issues.

Body Image Disturbance. Body image disturbance was assessed using the Body Image Scale (BIS) (Hopwood et al., 2001). The BIS is a 10-item self-report measure evaluating three dimensions of cancer-related body image: affective (e.g., feelings about femininity/masculinity, attractiveness), behavior (e.g., difficulty looking at oneself naked, avoiding social interactions due to appearance), and cognitive (e.g., satisfaction with appearance or scars). Participants rate each item on a four-point Likert scale (0 = 'Not at all' to 3 = 'Very much'), with total scores ranging from 0 to 30. Higher scores indicate greater body image disturbance. The BIS has been validated for use in various medical contexts, including colorectal disease (Bullen et al., 2012; Sharpe et al., 2011; Whistance et al., 2010). It demonstrates high internal consistency (Cronbach's $\alpha = 0.93$) and good clinical validity and sensitivity to change. For this study, we modified the 10th item, replacing 'your scar' with 'your stoma' to better reflect the experiences of ostomy patients. In our study, the scale showed good internal consistency (Cronbach's alpha = 0.88).

Anxiety Symptoms. We evaluated anxiety using the Generalized Anxiety Disorder-7 (GAD-7) scale, a validated instrument comprising seven items (Spitzer et al., 2006). The GAD-7 employs a four-point Likert scale (0-3), with total scores ranging from 0 to 21. Higher scores indicate greater anxiety severity, with 5, 10, and 15 representing

mild, moderate, and severe symptoms, respectively. The American Society of Clinical Oncology recommends the GAD-7 for anxiety screening in cancer patients. In our study, the scale demonstrated good internal consistency (Cronbach's alpha = 0.81).

Emotional Well-being. The emotional well-being subscale of the Functional Assessment of Cancer Therapy-General (FACT-G) measures emotional well-being using a 5-point Likert scale (0 = 'Not at all' to 4 = 'Very much') (D. F. Cella et al., 1993). The subscale consists of 6 items assessing anxiety, sadness, coping with illness, fear of death, worry about condition worsening, and hope. Total scores range from 0 to 24, with higher scores indicating better emotional well-being. The FACT-G has demonstrated strong psychometric properties and validation across various cancer populations. We selected this measure because it evaluates emotional functioning within a comprehensive quality-of- life framework while remaining sensitive to clinical changes. For our sample, the emotional well-being subscale showed a Cronbach's alpha of 0.654.

Analysis

To enhance data quality, we implemented data cleaning procedures. This involved excluding cases with missing key demographic and clinical information (n=5) and removing outliers in age and BMI (n=3) to improve distribution normality.

We conducted statistical analysis using Jamovi 2.3.26 software (The jamovi project, 2023). We used t-tests, ANOVA, and Pearson correlations to explore relationships between cancer- and demographic-related factors and dependent variables. This process helped identify potential covariates for subsequent analyses.

To examine the associations between ostomy odor, BID, and emotional well-being, we performed a series of multivariable regression analyses (distribution of the data

fulfilled statistical assumptions). This method allowed us to control for relevant demographic and clinical factors identified in our initial analyses. Additionally, we investigated the potential mediating effects of BID on the relationship between ostomy odor and emotional well-being, using Baron and Kenny's three-step mediation model.

Results

The demographic and clinical profiles of the study participants (N = 130) are detailed in Table 7. The study sample comprised 130 CRC survivors with ostomies, predominantly male (67.7%) and heterosexual (91.5%), with a mean age of 44.3 years. Most participants were white (66.2%), employed (75.4%), and married or cohabiting (68.5%). Clinically, Stage 2 cancer was most common (60%), with cancer locations almost equally divided between the colon and rectum. Most participants (76.2%) had received their ostomy surgery within the past year. Over half had permanent ostomies (53.8%), and 45.4% were not undergoing treatment at the time of the study.

Table 7.

Characteristics of Participants (N=130)

Characteristic		N	%
Sex	Female	42	32.3 %
	Male	88	67.7%
Sexual Orientation	Heterosexual (straight)	119	91.5 %
	LGBTQ+	11	8.5%
Marital Status	Married or living with a partner	89	68.5%
	Widowed, divorced, or separated	29	22.3%
	Never been married	12	9.2 %
Race	White or Caucasian	86	66.2 %
	Black or African American	29	22.3%
	Other Races	15	11.5 %
Education	High school diploma or less	19	14.6%
	Some college/associate's degree	55	42.3%
	Bachelor's degree	43	33.1%
	Graduate/Professional degree	13	10.0%
Employment	Employed (working full-time & working part-time)	98	75.4 %
	Unemployed (unemployed, homemaker, student, retired)	32	24.6 %
Cancer Stage	Stage 1	31	23.8 %
	Stage 2	78	60 %

	Stage 3	21	16.2 %
Cancer Location	Colon	63	48.5 %
	Rectum	61	46.9 %
	Both	6	4.6 %
Ostomy Status	Temporary	60	46.2 %
	Permanent	70	53.8 %
Current Treatment	On Radiotherapy	24	18.5 %
	On Chemotherapy	35	26.9%
	On Both (Radio & Chemo)	12	9.2 %
	No (currently not on any)	59	45.4%
Time since Ostomy	Less than 1 year	99	76.2%
	1 year or more	31	23.9%
Characteristic	**Range, Mean (SD)**		
Age	22- 67, 44.3 (.94)		
BMI	16.8- 30.4, 23.6 (.25)		
Financial Difficulty	1(no difficulty)- 4(severe difficulty), 2.35 (.08)		
Number of comorbidities	0- 3, 0.49 (.06)		
Main Variables	**Range, Mean (SD)**		
Ostomy Odor	0-6, 2.65 (0.13)		
Body Image	4-29, 18.26 (0.51)		
Anxiety	0-17, 7.89 (0.35)		
Emotional Well-being	2-22, 13.07 (0.33)		

Group difference analyses (T and F tests) and Pearson correlation analyses revealed statistically significant associations between demographic/clinical variables and main variables (see Appendix C for details). Anxiety showed significant correlations with demographic factors: age ($r = 0.18$, $p = 0.04$), education ($r = -0.22$, $p = 0.012$), and financial difficulty ($r = 0.24$, $p = 0.007$). Race significantly impacted anxiety levels ($F(2,36) = 6.07$, $p = 0.005$), with Games-Howell post-hoc tests showing other races reporting highest anxiety ($M = 10.87$, $SD = 3.5$) compared to White ($M = 7.6$, $SD = 4.03$) and Black participants ($M = 7.21$, $SD = 3.47$). Temporary ostomy holders showed greater anxiety than those with permanent ostomies ($M = 9.15$ vs. 6.81, $p < .001$). Those receiving active treatment reported significantly higher anxiety than untreated participants ($M = 5.42$, $SD = 3.29$; $F(3, 20.6) = 20.5$, $p < .001$). Emotional well-being correlated significantly with age ($r=0.2$, $p=0.025$) and number of comorbidities ($r=-0.22$, $p=0.024$). Regarding BID, males reported significantly higher scores ($M=19.8$, $SD=5.69$)

than females (M=15, SD=5.69; t (128) =-4.73, *p*<.001). BID varied significantly by marital status (F (2,32.1) =6.01, *p*=.006), with Games-Howell post-hoc tests showing widowed, divorced, or separated participants reporting higher BID (M=20.6, SD=6.18) than never-married participants (M=1.97, SD=1.55). White participants reported a significantly higher BID (M=19, SD=5.62) than participants of other races excluding Black participants (M=14, SD=4.99; F (2,34.7) =6.17, *p*=0.005). Employed participants reported significantly higher BID (M=19.2, SD=5.81) than unemployed participants (M=15.5, SD=5.23). Those with permanent ostomies reported significantly higher BID (M=20.3, SD=6.09) than those with temporary ostomies (M=15.9, SD=4.66). Treatment status had a significant effect on BID (F (3,41.1) =9.87, *p*<.001). Post-hoc tests revealed that participants not receiving any treatment reported BID (M=21.2, SD=6.51) higher than those on radiotherapy (M=15.8, SD=3.39), chemotherapy (M=16.4, SD=3.62), or combined radiotherapy and chemotherapy (M=14.4, SD=5.55). BID also correlated significantly with age (r=.18, p=0.038), financial difficulty (r=.21, p=.017), and number of comorbidities (r=-.25, *p*=.004). These variables were included as covariates in subsequent analyses to isolate the specific effects of independent variables on BID and emotional well-being.

Pearson correlation analysis with main variables showed significant relationships among the variables. Ostomy odor had a significant positive correlation with BID (r = 0.231, p = .008) and anxiety (r = 0.189, p = 0.032), and a significant negative correlation with emotional well-being (r = −0.321, p < .001). Body image disturbance showed a significant negative correlation with anxiety (r = −0.219, p = 0.012) but no significant

correlation with emotional well-being (r = −0.164, p = .063). Additionally, anxiety showed a strong negative correlation with emotional well-being (r = −0.639, p < .001).

Table 8 demonstrates the relationship between ostomy odor and BID after controlling demographic and clinical factors. The results show that ostomy odor significantly predicts BID (standardized regression coefficient [β] = 0.15, *p* = .037). Greater odor severity is associated with increased BID, even when controlling for sex, employment status, education level, and number of comorbidities. Precisely, a one standard deviation increase in odor severity corresponds to a 0.15 standard deviation increase in BID.

Table 8.

Regression Analyses Examining Effects of Ostomy Odor on Body Image Disturbance (N=130)

Predictors of Body Image Disturbance	b	S.E.	t	p	β
Male (versus Female)	1.92	0.92	2.09	0.039	0.33*
Married or living with a partner (versus widowed, divorced, or separated)	-1.53	0.96	-1.59	0.115	-0.26
Never married (versus widowed, divorced, or separated)	-1.93	1.73	-1.12	0.265	-0.33
White (versus Other Races)	1.58	1.34	1.18	0.239	0.27
Black or African American (versus Other Races)	1.96	1.52	1.29	0.201	0.33
Some college/associate's degree (versus High school diploma or less)	-1.41	1.24	-1.14	0.258	-0.24
Bachelor's degree (versus High school diploma or less)	-5.18	1.29	-3.73	<.001	-0.88***
Graduate/Professional degree (versus High school diploma or less)	-4.33	1.88	-2.31	0.023	-0.74*
Unemployed (versus Employed)	-1.77	1.01	-1.75	0.084	-0.30
Permanent Ostomy (versus Temporary)	2.18	0.87	2.50	0.014	0.37*
On Radiotherapy (versus No)	-0.35	1.39	-0.25	0.801	-0.06
On Chemotherapy (versus No)	-0.98	1.26	-0.78	0.439	-0.17
On Both (versus No)	-2.18	1.49	-1.47	0.145	-0.37
Age	0.00	0.05	0.01	0.988	0.00
Financial Difficulty	0.06	0.49	0.12	0.906	0.01
Number of comorbidities	-1.78	0.66	-2.68	0.008	-0.2**
Ostomy Odor	0.60	0.28	2.11	0.037	0.15*

Note. * p < .05, ** p < .01, *** p < .001

Table 9 presents regression analyses examining predictors of anxiety across two models. The first model shows that ostomy odor significantly predicted anxiety (β = 0.25, p < .001), with each standard deviation increase in ostomy odor severity corresponding to a 0.25 standard deviation increase in anxiety. In the second model, which included body image, ostomy odor remained a significant predictor (β = 0.23, p = .002), while body image was not statistically significant (β = 0.15, p = .088). Race and treatment status (radiotherapy, chemotherapy, or both) remained significant predictors across both models.

Table 9.

Regression Analyses for Variables Predicting Anxiety (N=130)

Predictor of Anxiety	Model including Ostomy Odor					Model additionally including Body Image				
	b	S.E.	t	p	β	b	S.E.	t	p	β
White (versus Other Races)	-3.05	0.87	-3.48	< .001	-0.77***	-3.37	0.89	-3.80	< .001	-0.86***
Black or African American (versus Other Races)	-3.72	1.00	-3.69	< .001	-0.93***	-3.99	1.01	-3.95	< .001	-1.0***
Some college/associate's degree (versus High school diploma or less)	1.12	0.86	1.30	0.195	0.28	1.32	0.86	1.54	0.127	0.33
Bachelor's degree (versus High school diploma or less)	0.99	0.96	1.03	0.307	0.25	1.57	1.01	1.55	0.124	0.40
Graduate/Professional degree (versus High school diploma or less)	0.57	1.27	0.45	0.650	0.14	1.10	1.29	0.85	0.399	0.28
permanent (versus temporary)	-0.47	0.59	-0.79	0.433	-0.12	-0.73	0.61	-1.21	0.230	-0.18
On Radiotherapy (versus No)	3.08	0.86	3.56	< .001	0.77***	3.33	0.87	3.83	< .001	0.84***
On Chemotherapy (versus No)	3.67	0.83	4.44	< .001	0.92***	3.86	0.83	4.66	< .001	0.97***
On Both (versus No)	4.00	1.00	3.98	< .001	1.00***	4.39	1.02	4.30	< .001	1.10***
Age	-0.04	0.03	-1.43	0.155	-0.11	-0.04	0.03	-1.44	0.152	-0.11
Financial Difficulty	-0.61	0.33	-1.85	0.066	-0.14	-0.62	0.33	-1.88	0.062	-0.14
Ostomy Odor	0.69	0.19	3.57	< .001	0.25***	0.62	0.19	3.23	0.002	0.23**
Body Image	.	.	.	.	.	0.10	0.06	1.72	0.088	0.15

Table 10 presents stepwise regression analyses examining predictors of EWB across two models. The first model shows that ostomy odor significantly predicted EWB (β = -0.32, $p < .001$), indicating that for one standard deviation increase in ostomy odor severity, EWB decreased by 0.32 standard deviations. In the second model, when BID was added, both ostomy odor (β = -0.27, $p = .002$) and BID (β = -0.18, $p = .043$) emerged as significant predictors. Age remained a consistent positive predictor across both models (β = 0.19, $p = .030$ and β = 0.21, $p = .016$, respectively), while the number of comorbidities showed no significant effect in either model.

Table 10.

Regression Analyses for Variables Predicting Emotional Well-being (N=130)

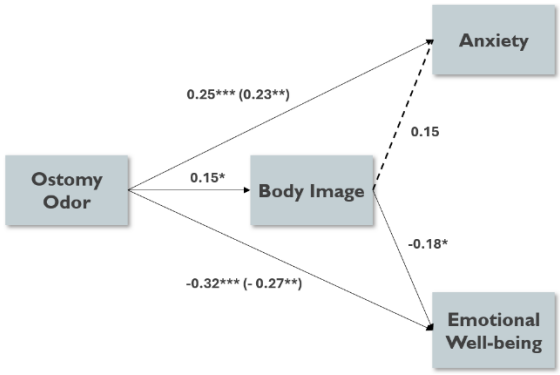
Predictors of Emotional well-being	Model including Odor					Model additionally including BID				
	b	S.E.	t	p	β	b	S.E.	t	p	β
Age	0.06	0.03	2.2	0.030	0.19*	0.07	0.03	2.43	0.016	0.21*
Number of comorbidities	-0.60	0.47	-1.26	0.210	-0.11	-0.86	0.49	-1.77	0.079	-0.16
Ostomy Odor	-0.80	0.21	-3.8	< .001	-0.32***	-0.68	0.22	-3.15	0.002	-0.27**
Body Image Disturbance	.	.	.	.	.	-0.11	0.06	-2.04	0.043	-0.18*

Note. * p < .05, ** p < .01, *** p < .001

As illustrated in Figure 3, mediation analyses using Baron and Kenny's approach showed that BID partially mediated the relationship between ostomy odor and emotional well-being but not anxiety. For anxiety outcomes, ostomy odor had a significant direct effect, while BID was not a significant predictor. In contrast, both ostomy odor and BID showed statistically significant effects on EWB when analyzed together. Ostomy odor demonstrated significant direct effects on BID, establishing the conditions for partial mediation in the relationship between ostomy odor and EWB.

Figure 3.

Mediating effect of body image disturbance in the relationship between ostomy odor and emotional well-being



Note. ( ) Direct effect after accounting for mediated effect, * p < .05, ** p < .01, *** p < .001

Discussion

This study investigated the structural relationships between ostomy odor, BID, anxiety symptoms, and EWB in CRC survivors living with ostomies. Our analysis revealed several key findings. First, BID partially mediates the relationship between ostomy odor and EWB, independent of demographic and clinical factors. While ostomy odor has a direct effect on EWB, it also exerts an indirect influence through its impact on BID. Second, although ostomy odor showed significant associations with both anxiety symptoms and BID, we found no significant relationship between BID and anxiety symptoms. This finding partially supports our initial hypothesis. The identification of a significant association between ostomy odor and BID advances our understanding of odor-related psychosocial challenges, building upon existing theoretical frameworks of olfactory-visual interactions. This finding provides empirical evidence that BID in individuals with ostomies extends beyond visual alterations alone, contributing to the broader literature on BID in oncological populations, particularly those experiencing odor-related issues due to treatment or disease.

Our findings revealed that higher levels of ostomy odor were associated with greater BID, even after controlling demographic and clinical factors. This finding aligns with established research on olfactory-visual interactions in both laboratory and clinical contexts. Chen and Spence (2022) demonstrated that unpleasant odors significantly reduced facial attractiveness ratings, with more pronounced effects occurring when odors were perceived as more intense and less pleasant. Their research highlighted that subjective perception of odor intensity was more strongly associated with outcomes than objective odor intensity. When exposed to identical odor stimuli, participants showed varying degrees of attractiveness reduction based on their subjective assessment of the odor's unpleasantness and intensity. This suggests that an individual's perception of ostomy odor may exert greater influence on body image than objective odor measurements. These findings provide a theoretical framework for understanding why ostomy odor could profoundly impact subjective body image perceptions, as olfactory influences on visual perception appear particularly significant for subjective, hedonic evaluations.

The neural mechanisms underlying these relationships were illuminated by Cook et al.'s (2015) event-related potential study, which revealed complex temporal dynamics in odor-visual integration. Their findings showed that odors can persistently influence visual self-perception even with time delays between stimuli, with pleasant and unpleasant odors activating different hemispheres during late processing stages. Cook et al.'s (2018) study further expanded on these temporal dynamics, demonstrating that unpleasant odors had stronger priming effects on facial evaluations when presented simultaneously compared to when delayed. Using an electroencephalogram (EEG), they

found enhanced activation in the late-positive-potential time range during simultaneous unpleasant odor-face presentation, suggesting an adaptive mechanism for prompt behavioral responses to potentially aversive stimuli. These neural findings collectively suggest that chronic exposure to ostomy odor likely has cumulative effects on body image perception through sustained activation of these neural pathways, with particularly strong effects during moments of conscious awareness of the odor.

Further empirical evidence for odor's impact on body image of self comes from several experimental investigations. Davies-Owen et al. (2024) found that pleasant fragrances enhanced subjective ratings of both self and other faces for attractiveness and confidence, with EEG data showing stronger effects during self-image processing. Similarly, Craig Roberts et al.(2009) demonstrated in a double-blind study that men using fragranced deodorant reported higher self-confidence and self-perceived attractiveness, with these internal perceptions manifesting in observable behavioral differences noted by external raters. In a directly relevant clinical context, Yousef et al. (2024) found that aromatherapy interventions using lavender oil led to improvements in body image outcomes among individuals with ostomies.

Our findings demonstrated that higher levels of ostomy odor predicted both increased anxiety and decreased EWB, independent of demographic and clinical factors, supporting our second hypothesis. These results align with Yousef et al.'s (2024) recent randomized controlled trial investigating lavender oil interventions for patients with permanent colostomies. In their study, participants receiving lavender oil intervention showed significant improvements in odor reduction along with corresponding improvements in anxiety levels. Our findings are also consistent with Annells' (2006)

qualitative study, which revealed that individuals with ostomies view odor as a significant threat to social acceptance and normalcy. Annells (2006) found that participants feared stigmatization not only from the visible ostomy but specifically from being “the producer of foul odor" (p.523), highlighting how odor concerns directly impact social functioning. This connects with Saunders et al.'s (2021) qualitative study, which similarly documented anxiety as a common experience among those with ostomies directly related to odor concerns. Saunders found that patients reported avoiding social interactions and experiencing anticipatory anxiety about potential odor-related embarrassment in public settings, behaviors that reflect the stigmatization fears identified by Annells (2006).

In our study participants, higher levels of BID predicted lower EWB after controlling ostomy odor and other factors, partially supporting our third hypothesis. However, we found no significant link between BID and anxiety symptoms after controlling these variables. This finding aligns with previous research, as (Bullen et al., 2012) found that BID predicted both depression and emotional well-being in colorectal surgical patients. The absence of a significant relationship between BID and anxiety in our study, however, diverges from several previous studies. (Benedict et al., 2016), examining women with rectal and anal cancer, identified significant associations between BID and anxiety in Pearson correlation analysis, although not in mediation analysis of body image between GI symptoms and anxiety. Similarly, Bullen's (2012) research demonstrated that initial BID predicted anxiety at follow-up assessment, while (Sharpe et al., 2011) established body image as a strong predictor of both initial and subsequent anxiety and distress in CRC survivors. The discrepancy between our findings and previous research may be attributed to the homogeneity of our study population. While

earlier investigations included heterogeneous samples (patients with various colorectal diseases or CRC patients both with and without ostomies), our study focused exclusively on CRC survivors with ostomies. This population-specific approach provides a more nuanced understanding of the psychosocial dynamics unique to individuals managing life with an ostomy following CRC treatment. In this population, BID may influence emotional domains differently than in the broader CRC population or individuals with non-cancer colorectal conditions. More importantly, our methodological approach incorporated comprehensive adjustments for demographic and clinical covariates (race, ostomy permanence, treatment status, age, education, and financial difficulty) in our regression analyses predicting anxiety (Table 9). This rigorous statistical control allowed us to isolate the relationship between body image and anxiety with greater precision, revealing underlying patterns that might otherwise remain obscured in less-controlled analyses. For instance, while our bivariate analysis using Pearson correlation showed a significant association between BID and anxiety, this relationship became non-significant in multivariable regression analysis after adjusting for demographic and clinical factors.

Limitations

This study has several limitations that should be considered when interpreting our findings. First, the cross-sectional design precludes causal inferences and temporal sequencing of the proposed mediation effects, though our theoretical framework guided hypothesis development and interpretation. Second, the descriptive nature of this study did not allow for the controlled laboratory conditions typical of multisensory/cross-modal research. Third, our sample lacked diversity, being predominantly white and

heterosexual, which may underrepresent experiences of racial minorities and LGBTQ+ individuals.

Future Research Recommendations

Several directions for future research emerge from this study. First, longitudinal studies should examine how relationships between ostomy odor, BID, and EWB evolve over time- particularly during critical transition periods such as immediate post-surgery recovery and long-term adaptation. Second, there is a pressing need to develop and validate body image disturbance assessment tools tailored explicitly for CRC survivors with ostomies. Current body image measures may not adequately capture the unique interplay between olfactory concerns and body perception in this population. Third, intervention research should evaluate the effectiveness of various ostomy odor management strategies on body image outcomes, incorporating both objective odor measurements (using odor detectors) and practical odor control techniques. Finally, research should extend beyond ostomy patients to investigate similar relationships in other medical contexts where patients experience illness or treatment-related bodily odors, such as incontinence or chronic wounds. This broader investigation would develop a more comprehensive understanding of how olfactory-visual interactions affect body perception and psychosocial well-being across different clinical populations.

Conclusion

This study reveals significant relationships between ostomy odor, BID, and EWB in CRC survivors with ostomies. Our findings show that ostomy odor and BID are interconnected factors affecting EWB, with BID serving as a partial mediator between ostomy odor and emotional outcomes. These insights enhance our understanding of the

complex psychosocial challenges that ostomy patients face and establish the groundwork for future research on BID in oncology populations dealing with odor-related issues.

References for Chapter 4

American Cancer Society. (2024). *Cancer Facts & Figures 2024*. American Cancer Society.

Annells, M. (2006). The Experience of Flatus Incontinence From a Bowel Ostomy: A Hermeneutic Phenomenology. *Journal of Wound Ostomy & Continence Nursing*, *33*(5), 518.

Benedict, C., Rodriguez, V. M., Carter, J., Temple, L., Nelson, C., & DuHamel, K. (2016). Investigation of body image as a mediator of the effects of bowel and GI symptoms on psychological distress in female survivors of rectal and anal cancer. *Supportive Care in Cancer*, *24*(4), 1795–1802. https://doi.org/10.1007/s00520-015-2976-2

Brianza, G., Tajadura-Jiménez, A., Maggioni, E., Pittera, D., Bianchi-Berthouze, N., & Obrist, M. (2019). As Light as Your Scent: Effects of Smell and Sound on Body Image Perception. In D. Lamas, F. Loizides, L. Nacke, H. Petrie, M. Winckler, & P. Zaphiris (Eds.), *Human-Computer Interaction – INTERACT 2019* (pp. 179–202). Springer International Publishing. https://doi.org/10.1007/978-3-030-29390-1_10

Bullen, T. L., Sharpe, L., Lawsin, C., Patel, D. C., Clarke, S., & Bokey, L. (2012). Body image as a predictor of psychopathology in surgical patients with colorectal disease. *Journal of Psychosomatic Research*, *73*(6), 459–463. https://doi.org/10.1016/j.jpsychores.2012.08.010

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S. B., Winicour, P., & Brannon, J. (1993). The Functional Assessment of

Cancer Therapy scale: Development and validation of the general measure. *Journal of Clinical Oncology*, *11*(3), 570–579. https://doi.org/10.1200/JCO.1993.11.3.570

Chen, Y.-C., & Spence, C. (2022). *Investigating the Crossmodal Influence of Odour on the Visual Perception of Facial Attractiveness and Age*. https://doi.org/10.1163/22134808-bja10076

Cook, S., Fallon, N., Wright, H., Thomas, A., Giesbrecht, T., Field, M., & Stancak, A. (2015). Pleasant and Unpleasant Odors Influence Hedonic Evaluations of Human Faces: An Event-Related Potential Study. *Frontiers in Human Neuroscience*, *9*. https://doi.org/10.3389/fnhum.2015.00661

Cook, S., Kokmotou, K., Soto, V., Wright, H., Fallon, N., Thomas, A., Giesbrecht, T., Field, M., & Stancak, A. (2018). Simultaneous odour-face presentation strengthens hedonic evaluations and event-related potential responses influenced by unpleasant odour. *Neuroscience Letters*, *672*, 22–27. https://doi.org/10.1016/j.neulet.2018.02.032

Corbin, A. (1986). *The Foul and the Fragrant: Odor and the French Social Imagination*. Harvard University Press.

Craig Roberts, S., Little, A. C., Lyndon, A., Roberts, J., Havlicek, J., & Wright, R. L. (2009). Manipulation of body odour alters men's self-confidence and judgements of their visual attractiveness by women. *International Journal of Cosmetic Science*, *31*(1), 47–54. https://doi.org/10.1111/j.1468-2494.2008.00477.x

Davies-Owen, J., Roberts, H., Scott, M., Thomas, A., Sen, S., Sethna, S., Roberts, C., Giesbrecht, T., & Fallon, N. (2024). Beauty is in the nose of the beholder:

Fragrance modulates attractiveness, confidence and femininity ratings and neural responses to faces of self and others. *Behavioural Brain Research*, *465*, 114932. https://doi.org/10.1016/j.bbr.2024.114932

Demattè, M. L., Österbauer, R., & Spence, C. (2007). Olfactory Cues Modulate Facial Attractiveness. *Chemical Senses*, *32*(6), 603–610. https://doi.org/10.1093/chemse/bjm030

Fingeret, M. C., Hutcheson, K. A., Jensen, K., Yuan, Y., Urbauer, D., & Lewin, J. S. (2013). Associations among speech, eating, and body image concerns for surgical patients with head and neck cancer. *Head & Neck*, *35*(3), 354–360. https://doi.org/10.1002/hed.22980

Fingeret, M. C., Nipomnick, S. W., Crosby, M. A., & Reece, G. P. (2013). Developing a theoretical framework to illustrate associations among patient satisfaction, body image and quality of life for women undergoing breast reconstruction. *Cancer Treatment Reviews*, *39*(6), 673–681. https://doi.org/10.1016/j.ctrv.2012.12.010

Han, C. J., Yang, G. S., & Syrjala, K. (2020). Symptom Experiences in Colorectal Cancer Survivors After Cancer Treatments: A Systematic Review and Meta-analysis. *Cancer Nursing*, *43*(3), E132. https://doi.org/10.1097/NCC.0000000000000785

Herz, R. S. (2009). Aromatherapy Facts and Fictions: A Scientific Analysis of Olfactory Effects on Mood, Physiology and Behavior. *International Journal of Neuroscience*, *119*(2), 263–290. https://doi.org/10.1080/00207450802333953

Herz, R. S., Beland, S. L., & Hellerstein, M. (2004). Changing Odor Hedonic Perception Through Emotional Associations in Humans. *International Journal of Comparative Psychology*, *17*(4). https://doi.org/10.46867/ijcp.2004.17.04.05

Hopwood, P., Fletcher, I., Lee, A., & Al Ghazal, S. (2001). A body image scale for use with cancer patients. *European Journal of Cancer*, *37*(2), 189–197. https://doi.org/10.1016/S0959-8049(00)00353-1

Li, W., Moallem, I., Paller, K. A., & Gottfried, J. A. (2007). Subliminal Smells can Guide Social Preferences. *Psychological Science*, *18*(12), 1044–1049. https://doi.org/10.1111/j.1467-9280.2007.02023.x

Lim, C. Y. S., Laidsaar-Powell, R. C., Young, J. M., Kao, S. C.-H., Zhang, Y., & Butow, P. (2021). Colorectal cancer survivorship: A systematic review and thematic synthesis of qualitative research. *European Journal of Cancer Care*, *30*(4), e13421. MEDLINE. https://doi.org/10.1111/ecc.13421

Merleau-Ponty, M. (2011). *Phenomenology of Perception*. Routledge. https://doi.org/10.4324/9780203720714

Rhoten, B. (2018). Theoretical Foundations of Body Image. In *Body Image Care for Cancer Patients: Principles and Practice* (p. 400). Oxford University Press.

Rhoten, B. A. (2016). Body image disturbance in adults treated for cancer – a concept analysis. *Journal of Advanced Nursing*, *72*(5), 1001–1011. https://doi.org/10.1111/jan.12892

Rhoten, B. A., Murphy, B., & Ridner, S. H. (2013). Body image in patients with head and neck cancer: A review of the literature. *Oral Oncology*, *49*(8), 753–760. https://doi.org/10.1016/j.oraloncology.2013.04.005

Saunders, C. H., Goldwag, J. L., Read, J. T., Durand, M.-A., Elwyn, G., & Ivatury, S. J. (2021). “Because Everybody is so Different”: A qualitative analysis of the lived

experiences and information needs of rectal cancer survivors. *BMJ Open*, *11*(5), e043245. https://doi.org/10.1136/bmjopen-2020-043245

Sharpe, L., Patel, D., & Clarke, S. (2011). The relationship between body image disturbance and distress in colorectal cancer patients with and without stomas. *Journal of Psychosomatic Research*, *70*(5), 395–402. https://doi.org/10.1016/j.jpsychores.2010.11.003

Shin, J., Gibson, J. S., Jones, R. A., & Debnam, K. J. (2024). Factors associated with anxiety in colorectal cancer survivors: A scoping review. *Journal of Cancer Survivorship*. https://doi.org/10.1007/s11764-024-01678-0

Spence, C. (2021). The scent of attraction and the smell of success: Crossmodal influences on person perception. *Cognitive Research: Principles and Implications*, *6*(1), 46. https://doi.org/10.1186/s41235-021-00311-3

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. *Archives of Internal Medicine*, *166*(10), 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

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), 8512. https://doi.org/10.3390/ijerph18168512

Sun, V., Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J., Baldwin, C. M., & Krouse, R. S. (2013). Surviving Colorectal Cancer: Long-term, Persistent Ostomy-Specific Concerns and Adaptations.

Journal of Wound Ostomy & Continence Nursing, *40*(1), 61. https://doi.org/10.1097/WON.0b013e3182750143

The jamovi project. (2023). *Jamovi*. (Version 2.3.26) [Windows]. Retrieved from https://www.jamovi.org/

Waskul, D. D., & Vannini, P. (2008). Smell, Odor, and Somatic Work: Sense-Making and Sensory Management. *Social Psychology Quarterly*, *71*(1), 53–71. https://doi.org/10.1177/019027250807100107

Williams, J. (2008). Flatus, odour and the ostomist: Coping strategies and interventions. *British Journal of Nursing*, *17*(Sup1), S10–S14. https://doi.org/10.12968/bjon.2008.17.Sup1.28144

Yousef, J., Al Hasanat, A., Othman, S., Alrahma, S., & Alloubani, A. (2024). Effects of lavender oil on odor elimination, ostomy adjustment and quality of life in patients with permanent colostomy: A randomized controlled trial. *European Journal of Oncology Nursing*, *68*, N.PAG-N.PAG. https://doi.org/10.1016/j.ejon.2023.102471

Yuan, J. M., Zhang, J. E., Zheng, M. C., & Bu, X. Q. (2018). Stigma and its influencing factors among Chinese patients with stoma. *Psycho-Oncology*, *27*(6), 1565–1571. APA PsycInfo. https://doi.org/10.1002/pon.4695

CHAPTER 5

Summary of Research Findings

Guided by Maurice Merleau-Ponty's (2011) theory on embodied consciousness, this research examined the structural relationships among ostomy-related issues (leak, odor, and peristomal skin complications), body image disturbance, and anxiety/emotional well-being in CRC survivors with ostomies.

To achieve our aim 1 (to identify risk factors and consequences of anxiety in CRC survivors), we conducted a scoping review examining 51 studies. From the identified risk factors, we included body image disturbance and ostomy-related issues as our main variables in subsequent studies while incorporating most other variables as covariates. Our review also revealed the consequences of anxiety, highlighting the critical importance of studying anxiety in this population.

To achieve our aim 2 (to examine the structural relationships between ostomy-related issues and anxiety symptoms in CRC survivors with ostomies), we conducted a cross-sectional study with 130 CRC survivors recruited through online support groups. This investigation was theoretically grounded in odor-associated learning theory, which posits that negative olfactory experiences can be conditioned with psychological responses through associative learning mechanisms (Herz, 2009; Herz, Schankler, et al., 2004). Individuals with pre-existing mood or anxiety disorders or major sensory deficits were excluded to minimize confounding variables. The study employed single-item 7-point Likert scales to measure ostomy leakage, odor, and peristomal skin complications, while the validated GAD-7 instrument was utilized to assess anxiety symptoms (Spitzer et al., 2006). Comprehensive demographic and clinical data were also collected to account for potential covariates. Statistical analysis consisted of a series of regression

analyses following Baron and Kenny's mediation model framework to systematically examine relationships among variables while controlling relevant demographic and clinical factors (Baron & Kenny, 1986). This methodological approach allowed for the examination of both direct and indirect pathways through which ostomy-related issues might influence psychological outcomes in this population.

- Hypothesis 2.1 (partially supported by our data): Our data demonstrated that increased ostomy leakage and odor are associated with increased anxiety, even after controlling demographic and clinical factors. However, unlike our hypothesis, peristomal skin complications were not statistically significantly associated with anxiety.
- Hypothesis 2.2 (partially supported by our data): Our data demonstrated that odor mediates the relationship between ostomy leakage and anxiety. However, unlike our hypothesis, peristomal skin complications did not mediate this relationship.

To achieve our aim 3 (to examine the structural relationships between ostomy odor, body image disturbance, and emotional well-being/anxiety symptoms in CRC survivors with ostomies), we conducted a study using cross-sectional data collected for Aim 2. This investigation was theoretically grounded in cross-modal correspondence theory, which posits that stimuli in one sensory modality (such as olfaction) can systematically influence perception and evaluation in another modality (such as vision) (Chen & Spence, 2022; Spence, 2021). This theoretical framework provided a robust foundation for understanding how ostomy odor might influence visual self-perception and subsequent psychological outcomes. The study employed single-item 7-point Likert scales to measure ostomy odor, along with the validated Body Image Scale (Hopwood et

al., 2001b), GAD-7 (Spitzer et al., 2006), and FACT-G emotional well-being subscale (D. F. Cella et al., 1993). Comprehensive demographic and clinical data were also collected to account for potential covariates. We utilized a series of regression analyses following Baron and Kenny's mediation model to systematically examine both direct and indirect pathways through which ostomy odor might influence body image disturbance and anxiety/ emotional well-being while controlling relevant demographic and clinical factors.

- Hypothesis 3.1 (supported by our data): Our data demonstrated that increased ostomy odor is associated with increased body image disturbance, independent of demographic and clinical factors.
- Hypothesis 3.2 (supported by our data): Our data demonstrated that increased ostomy odor is associated with increased anxiety and decreased emotional well-being.
- Hypothesis 3.3 (partially supported by our data): Our data demonstrated that increased body image disturbance is associated with increased anxiety but not with emotional well-being while controlling ostomy odor and other factors.

Collectively, these findings provide empirical support for the theoretical frameworks guiding this research (Herz, 2009; Herz, Schankler, et al., 2004; Merleau-Ponty, 2011; Spence, 2021) and significantly contribute to understanding the complex psychosocial challenges faced by CRC survivors with ostomies. Our results demonstrate that ostomy odor plays a central role in mediating relationships between ostomy leakage and anxiety while also directly influencing body image disturbance and emotional well-being. These findings highlight the multifaceted nature of ostomy-related anxiety and

underscore the importance of addressing odor concerns in clinical interventions targeting psychological well-being in this population.

Contribution to Related Field of Science

This dissertation makes significant interdisciplinary contributions to the scientific understanding of the relationships between physical symptoms, sensory experiences, and psychological processes in CRC survivors with ostomies. By integrating theories from phenomenology, cognitive psychology, and sensory science with empirical investigation, this research enhances our understanding of the unique embodied experiences in this population.

The application of Merleau-Ponty's (2011) theory of perception provides a novel theoretical framework for understanding how altered bodily states affect survivors' lived experiences. This phenomenological approach, combined with quantitative methods, offers a methodological model for future research examining the intersection of sensory perception, body image, and emotional adaptation in clinical populations, particularly those with various odor-related issues, including individuals with malodorous wounds or incontinence.

This research advances the field by establishing empirical evidence for the critical role of ostomy odor as both a direct contributor to psychological distress and as a mediator between ostomy leakage and anxiety. This finding transcends traditional clinical approaches that often treat the physical and psychological aspects of ostomy management separately. By demonstrating how olfactory experiences influence body image disturbance through cross-modal sensory integration, this work bridges previously disconnected domains of sensory science and psycho-oncology.

For nursing science specifically, this research offers evidence-based insights for developing more holistic approaches to ostomy care that address both physical

management and psychological impact. The identification of odor as a central concern provides direction for developing targeted interventions to improve quality of life in this population. Our findings in Chapter 3 revealed that odor remains significantly associated with anxiety even after controlling leakage, highlighting its distinct psychological impact. This helps explain certain behaviors frequently observed in individuals with ostomies, such as changing their appliances too frequently, repeatedly checking their appliance, taking excessive showers, or fasting before and during social activities (Annells, 2006; Black & Notter, 2021a; Mitchell et al., 2007; Saunders et al., 2021). These behaviors, while often viewed as maladaptive coping mechanisms, represent attempts to manage odor-related anxiety and can significantly impact quality of life and social functioning.

References for Chapter 5

Annells, M. (2006). The Experience of Flatus Incontinence From a Bowel Ostomy: A Hermeneutic Phenomenology. *Journal of Wound Ostomy & Continence Nursing*, *33*(5), 518.

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*(6), 1173–1182. https://doi.org/10.1037/0022-3514.51.6.1173

Black, P., & Notter, J. (2021). Psychological issues affecting patients living with a stoma. *British Journal of Nursing (Mark Allen Publishing)*, *30*(6), S20–S32. MEDLINE. https://doi.org/10.12968/bjon.2021.30.6.S20

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S. B., Winicour, P., & Brannon, J. (1993). The Functional Assessment of Cancer Therapy scale: Development and validation of the general measure. *Journal of Clinical Oncology*, *11*(3), 570–579. https://doi.org/10.1200/JCO.1993.11.3.570

Chen, Y.-C., & Spence, C. (2022). *Investigating the Crossmodal Influence of Odour on the Visual Perception of Facial Attractiveness and Age*. https://doi.org/10.1163/22134808-bja10076

Herz, R. S. (2009). Aromatherapy Facts and Fictions: A Scientific Analysis of Olfactory Effects on Mood, Physiology and Behavior. *International Journal of Neuroscience*, *119*(2), 263–290. https://doi.org/10.1080/00207450802333953

Herz, R. S., Schankler, C., & Beland, S. (2004). Olfaction, Emotion and Associative Learning: Effects on Motivated Behavior. *Motivation and Emotion*, *28*(4), 363–383. https://doi.org/10.1007/s11031-004-2389-x

Hopwood, P., Fletcher, I., Lee, A., & Al Ghazal, S. (2001). A body image scale for use with cancer patients. *European Journal of Cancer*, *37*(2), 189–197. https://doi.org/10.1016/S0959-8049(00)00353-1

Merleau-Ponty, M. (2011). *Phenomenology of Perception*. Routledge. https://doi.org/10.4324/9780203720714

Mitchell, K. A., Rawl, S. M., Schmidt, C. M., Grant, M., Ko, C. Y., Baldwin, C. M., Wendel, C., & Krouse, R. S. (2007). Demographic, Clinical, and Quality of Life Variables Related to Embarrassment in Veterans Living With an Intestinal Stoma. *Journal of Wound Ostomy & Continence Nursing*, *34*(5), 524. https://doi.org/10.1097/01.WON.0000290732.15947.9e

Saunders, C. H., Goldwag, J. L., Read, J. T., Durand, M.-A., Elwyn, G., & Ivatury, S. J. (2021). "Because Everybody is so Different": A qualitative analysis of the lived experiences and information needs of rectal cancer survivors. *BMJ Open*, *11*(5), e043245. https://doi.org/10.1136/bmjopen-2020-043245

Spence, C. (2021). The scent of attraction and the smell of success: Crossmodal influences on person perception. *Cognitive Research: Principles and Implications*, *6*(1), 46. https://doi.org/10.1186/s41235-021-00311-3

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. *Archives of Internal Medicine*, *166*(10), 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

Appendix A

Data Quality Assurance Protocol and Response Validation Process

To ensure data integrity and validity, we implemented a comprehensive verification protocol that combined automated security measures and manual validation procedures. Recruitment occurred through two established nonprofit online support groups for individuals with ostomies and/or colorectal cancer and their caregivers. These platforms required user authentication and were actively managed by webmasters. Given the limitations of online surveys, we implemented several validation processes to filter potential fraudulent responses. Below, we detail these validation processes and their outcomes throughout the pre-collection, during-collection, and post-collection phases.

Pre-Data Collection

Implementation of Qualtrics Security Features

- Captcha Verification Questions requiring respondents to complete visual challenges
- Bot detection algorithms using Google's invisible reCAPTCHA V3 technology
- Duplicate prevention through the "Prevent multiple submissions" option
- Geographic location validation (excluded responses from outside the United States)

Survey-Specific Validation Measures

- Pre-screening questionnaire with automatic survey termination for participants who did not meet inclusion criteria
- Five randomly placed attention-check questions (e.g., "Which of these is not an animal?") with automatic survey termination upon incorrect answers
- Separation of the main survey from a compensation survey that collected participants' names and email addresses. After completing the main survey, participants were redirected to the compensation survey.

During Data Collection

- Randomly updated attention-check questions and answer options
- During close monitoring, if we detected an unusual surge in responses within a short time period, we paused the survey and compared the open-ended responses. When similar response patterns were identified, we filtered out those responses.

Post-Data Collection (total completed responses=690)

- Responses with low (less than 0.5) or missing reCAPTCHA scores: removed 378
- Duplicate IP addresses: removed 5
- Suspicious email addresses (e.g., addresses that did not match provided names or contained random letter combinations): removed 52
- Completion duration (less than 5 minutes): removed 4
- Recurring patterns in open-ended questions or overall responses within a short timeframe: removed 113

Through this validation process, we excluded 552 (80%) of the initial 690 responses, yielding 138 responses that met all quality criteria. During data cleaning, we removed 5 responses from participants who selected "prefer not to say" for demographic and clinical questions. We also removed 3 responses identified as statistical outliers, resulting in a final analytical sample of 130 participants.

Appendix B

Group Differences in Ostomy Leakage, Odor, Peristomal Skin Complications, and Anxiety Levels (N = 130)

Characteristic		Ostomy Leakage				Odor				PSC				Anxiety			
		Mean	SD	t/F	*p*	Mean	SD	t/F	*p*	Mean	SD	t/F	p	Mean	SD	t/F	*p*
Sex	Female	1.81	1.37	-2.32*	0.022	2.21	1.3	-2.36*	0.02	2	1.4	-1.79	0.077	8.38	3.78	0.97	0.336
	Male	2.44	1.5			2.85	1.51			2.48	1.44			7.66	4.07		
Gender Identify	Heterosexual (straight)	2.25	1.49	0.83	0.486	2.68	1.48	0.92	0.461	2.37	1.45	0.74	0.527	7.65	3.99	4.28	0.088
	Homosexual (gay/lesbian)	1.88	1.64			2	1.41			1.88	1.25			10.25	2.87		
	Bisexual	2.67	0.58			3	1			1.67	1.53			11.33	2.89		
Marital Status	Married or living with a partner	2.26	1.44	2.93	0.07	2.69	1.47	0.2	0.822	2.29	1.49	0.31	0.739	7.99	4.07	2.32	0.116
	Widowed, divorced, or separated	2.55	1.53			2.62	1.54			2.48	1.35			6.9	3.67		
	Never been married	1.33	1.44			2.42	1.38			2.17	1.27			9.58	3.65		
Race	White or Caucasian	2.35	1.5	2.83	0.072	2.77	1.42	2.32	0.113	2.53	1.42	3.39*	0.044	7.6	4.03	6.07**	0.005
	Black or African American	2.31	1.44			2.59	1.72			1.97	1.55			7.21	3.47		
	Other Races	1.47	1.3			2.07	1.1			1.8	1.08			10.87	3.5		
Education	High school diploma or less	2.11	1.66	3.84*	0.017	2.79	1.78	1.8	0.162	1.89	1.7	2.22	0.101	4.63	2.77	10.2***	<.001
	Some college/Associate's degree	2.67	1.53			2.93	1.5			2.64	1.47			7.96	4.44		
	Bachelor's degree	1.72	1.22			2.3	1.24			2.02	1.22			8.91	3.34		
	Graduate/Professional degree	2.31	1.38			2.38	1.39			2.62	1.33			9	3		
Employment	Employed (working full-time & working part-time)	2.29	1.55	0.63	0.527	2.66	1.5	0.23	0.817	2.33	1.49	0.05	0.962	7.89	3.85	-0.02	0.982
	Unemployed (unemployed, homemaker, student, retired)	2.09	1.28			2.59	1.39			2.31	1.28			7.91	4.42		
Cancer Stage	Stage 1	2.03	1.74	1.69	0.194	2.39	1.63	1.32	0.276	2.1	1.25	0.98	0.381	6.77	4.18	2.94	0.061
	Stage 2	2.22	1.49			2.65	1.48			2.46	1.55			8.01	4.11		
	Stage 3	2.62	0.92			3	1.14			2.14	1.24			9.1	2.72		
Cancer Location	Colon	2.06	1.55	1.12	0.352	2.46	1.63	1.16	0.339	2.13	1.53	1.13	0.35	7.4	3.89	2.43	0.122
	Rectum	2.38	1.44			2.8	1.33			2.52	1.35			8.18	4.11		
	Both	2.67	1.03			3	0.89			2.33	1.21			10.17	2.86		
Ostomy Status	Temporary	2.13	1.48	0.56	0.456	2.73	1.27	0.63	0.533	2.47	1.23	1.06	0.293	9.15	4.08	3.48***	<.001
	Permanent	2.33	1.49			2.57	1.62			2.2	1.59			6.81	3.58		
Current Treatment	On Radiotherapy	2.38	1.21	0.14	0.938	2.54	1.41	0.55	0.654	2.25	1.11	0.26	0.855	9.38	3.65	20.5***	<.001
	On Chemotherapy	2.2	1.45			2.86	1.42			2.43	1.27			10.23	3.18		
	On Both (Radio & Chemo)	2.33	1.56			2.33	1.23			2	1.71			10.25	2.96		
	No (currently not on any)	2.19	1.61			2.63	1.57			2.36	1.61			5.42	3.29		
Time since Ostomy	Less than 1 year	2.24	1.53	0.05	0.957	2.7	1.46	0.7	0.483	2.35	1.44	0.43	0.668	8.13	3.92	1.23	0.223
	1 year or more	2.23	1.36			2.48	1.5			2.23	1.45			2.13	4.13		
Age		Pearson's r=0.17 , *p* =0.058				Pearson's r=0.05 , *p* =0.575				Pearson's r= 0.04, *p* = 0.666				Pearson's r= 0.18*, *p* =0.04			
BMI		Pearson's r=-0.09 , *p* =0.312				Pearson's r= - 0.09 , *p* =0.322				Pearson's r= -0.03 , *p* = 0.78				Pearson's r= -0.13 , *p* =0.137			
Financial difficulty		Pearson's r=0.28** , *p* =0.002				Pearson's r=0.25**, *p* =0.004				Pearson's r= 0.18*, *p* = 0.036				Pearson's r=0.24** , *p* =0.007			
Number of comorbidities		Pearson's r=0.05 , *p* =0.54				Pearson's r=0.14 , *p* =0.103				Pearson's r= 0.01 , *p* = 0.882				Pearson's r= 0.15 , *p* =0.096			

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Appendix C

Group Differences in Ostomy Odor, Body Image Disturbance, Anxiety Symptoms, and Emotional Well-being (N = 130)

Characteristic		Odor				Body Image				Anxiety				Emotional Well-being			
		Mean	SD	t/F	*p*	Mean	SD	t/F	*p*	Mean	SD	t/F	p	Mean	SD	t/F	*p*
Sex	Female	2.21	1.3	-2.36*	0.02	15	4.84	-4.73***	<.001	8.38	3.78	0.97	0.336	13.2	3.7	0.21	0.838
	Male	2.85	1.5			19.8	5.69			7.66	4.07			13	3.77		
Gender Identify	Heterosexual (straight)	2.68	1.5	0.92	0.461	18.5	6.02	4.38	0.069	7.65	3.99	4.28	0.088	13.1	3.84	0.34	0.73
	Homosexual (gay/lesbian)	2	1.4			15	2.83			10.25	2.87			12.8	1.98		
	Bisexual	3	1			17	2			11.33	2.89			11.7	3.21		
Marital Status	Married or living with a partner	2.69	1.5	0.2	0.822	17.9	5.78	6.01**	0.006	7.99	4.07	2.32	0.116	13.2	3.73	0.21	0.81
	Widowed, divorced, or separated	2.62	1.5			20.6	6.18			6.9	3.67			12.9	3.79		
	Never been married	2.42	1.4			15.2	3.66			9.58	3.65			12.5	3.85		
Race	White or Caucasian	2.77	1.4	2.32	0.113	19	5.62	6.17**	0.005	7.6	4.03	6.07**	0.005	13.2	3.99	0.23	0.794
	Black or African American	2.59	1.7			18.1	6.23			7.21	3.47			12.8	2.84		
	Other Races	2.07	1.1			14	4.99			10.87	3.5			12.7	3.9		
Education	High school diploma or less	2.79	1.8	1.8	0.162	23.8	5.53	20.2***	<.001	4.63	2.77	10.2***	<.001	13.9	4.63	0.34	0.796
	Some college/associate's degree	2.93	1.5			19.7	5.76			7.96	4.44			13	3.63		
	Bachelor's degree	2.3	1.2			14.9	4.13			8.91	3.34			13	3.61		
	Graduate/Professional degree	2.38	1.4			14.9	2.29			9	3			23.5	3.33		
Employment	employed (working full-time & working part-time)	2.66	1.5	0.23	0.817	19.2	5.81	3.13**	0.002	7.89	3.85	-0.02	0.982	12.9	3.51	-1.03	0.307
	unemployed (unemployed, homemaker, student, retired)	2.59	1.4			15.5	5.23			7.91	4.42			13.7	4.35		
Cancer Stage	Stage 1	2.39	1.6	1.32	0.276	18.8	6.32	1.71	0.19	6.77	4.18	2.94	0.061	13.4	3.91	0.48	0.623
	Stage 2	2.65	1.5			18.5	6.15			8.01	4.11			13.1	3.6		
	Stage 3	3	1.1			16.7	3.69			9.1	2.72			12.3	4.03		
Cancer Location	Colon	2.46	1.6	1.16	0.339	19.3	6.33	2.03	0.16	7.4	3.89	2.43	0.122	13.1	3.6	0.58	0.565
	Rectum	2.8	1.3			17.3	5.48			8.18	4.11			13	4.06		
	Both	3	0.9			17	2.76			10.17	2.86			12.7	0.52		
Ostomy Status	Temporary	2.73	1.3	0.63	0.533	15.9	4.66	-4.49***	<.001	9.15	4.08	3.48***	<.001	13.2	4.04	0.42	0.678
	Permanent	2.57	1.6			20.3	6.09			6.81	3.58			12.9	3.47		
Current Treatment	On Radiotherapy	2.54	1.4	0.55	0.654	15.8	3.39	9.87***	<.001	9.38	3.65	20.5***	<.001	12.9	3.15	2.27	0.094
	On Chemotherapy	2.86	1.4			16.4	3.62			10.23	3.18			11.9	3.03		
	On Both (Radio & Chemo)	2.33	1.2			14.4	5.55			10.25	2.96			12.8	3.33		
	No (currently not on any)	2.63	1.6			21.2	6.51			5.42	3.29			13.9	4.25		
Time since Ostomy	Less than 1 year	2.7	1.5	0.7	0.483	18.1	5.76	-0.49	0.628	8.13	3.92	1.23	0.223	12.9	3.78	-1.15	0.252
	1 year or more	2.48	1.5			18.7	6.29			2.13	4.13			13.7	3.56		
Age		Pearson's r=0.05 , *p*=0.575				Pearson's r= 0.18* , *p* = 0.038				Pearson's r= 0.18*, *p*=0.04				Pearson's r= 0.2* , *p*=0.025			
BMI		Pearson's r= - 0.09 , *p*=0.322				Pearson's r= 0.02, *p* = 0.83				Pearson's r= -0.13 , *p*=0.137				Pearson's r=0.07 , *p* = 0.429			
Financial Difficulty		Pearson's r=0.25** , *p*=0.004				Pearson's r= 0.21* , *p* = 0.017				Pearson's r=0.24** , *p*=0.007				Pearson's r= -0.04, *p* = 0.697			
Time since Ostomy		Pearson's r= - 0.05 , *p*=0.55				Pearson's r= -0.01 , *p* = 0.927				Pearson's r= -0.01 , *p*=0.262				Pearson's r= 0.02 , *p* = 0.813			
Number of Comorbidities		Pearson's r=0.14 , *p*=0.103				Pearson's r= -0.25** , *p* = 0.004				Pearson's r= 0.15 , *p*=0.096				Pearson's r= -0.2* , *p* = 0.024			

Note. * $p < .05$, ** $p < .01$, *** $p < .001$