

The Odyssey of an Ileostomy: A Journey of Challenges and Resilience

Marie Shella De Robles BSPH MD DPBS FRACS

This thesis is submitted in requirements for the Degree of Master of Philosophy.

Faculty of Medicine and Health

University of Sydney

2025

STATEMENT OF ORIGINALITY

The research documented in this thesis is entirely original and was completed solely by the author as a postgraduate student of the Faculty of Medicine, University of Sydney. This work was supervised by A/Professor Christopher J. Young of the University of Sydney. I certify that this thesis has not been submitted, either wholly or in part, for any other academic award. All assistance received and sources consulted in the preparation of this thesis have been fully acknowledged.

Signed

Marie Shella DE ROBLES
February 2025

ACKNOWLEDGEMENTS

This thesis is dedicated to all who have embarked on the odyssey of living with an ileostomy—a journey marked by profound challenges, resilience, and adaptation.

To my patients and their families, your courage has been the cornerstone of this work.

To my supervisor, A/Professor Christopher J. Young, whose unwavering guidance, wisdom, and mentorship have been instrumental in both shaping this research and fostering my growth as a clinician.

I am also thankful to my mentors and colleagues for their collaboration and insightful contributions during long hours of clinical work, research discussions, and the ongoing pursuit of improved patient care.

A special thank you is due to my husband, James, whose steadfast love, encouragement, and support have sustained me through every challenge.

I owe a heartfelt debt of gratitude to my family and friends, who have stood by me with patience, understanding, and unconditional support.

Above all, this thesis is dedicated to everyone who has faced the reality of an ileostomy—those who have struggled, adapted, and discovered strength amidst change. Your resilience inspires me, and it is my sincere hope that this research, in some small way, contributes to advancing care, improving quality of life, and ensuring that no one walks this path alone.

This work is not merely an academic endeavour but a tribute to the endurance, courage, and unwavering spirit of those navigating the complexities of life with an ileostomy. May we continue to push boundaries, seek understanding, and foster compassionate care for all who embark on this odyssey.

ABSTRACT

Introduction: Undergoing an ileostomy is a significant life transition, presenting medical, psychological, and social adjustments for patients. This thesis examines the multifaceted experience of patients undergoing ileostomy formation and reversal, focusing on clinical outcomes such as postoperative complications—particularly incisional hernia and renal impairment—and the often-overlooked psychosocial impact on patients and their caregivers. Using Homer's *Odyssey* as a framework, this research explores the journey of resilience and adaptation experienced by both patients and their caregivers.

Methods: This study employed a mixed-methods approach to analyse the ileostomy experience comprehensively. A retrospective cohort study involving 224 patients with stoma undergoing reversal evaluated predictors of complications, focusing on incisional hernia. Additionally, a systematic review was conducted following PRISMA guidelines to synthesise existing evidence on renal impairment following ileostomy formation in rectal cancer surgery. Qualitative data were obtained through structured interviews and validated instruments, including the Stoma Quality of Life (SQOL) questionnaire and the Caregiver Burden Scale (CBS), to assess the long-term psychosocial impact on patients and their caregivers of having a stoma.

Results: The quantitative analysis revealed that significant complications persist after ileostomy reversal while immediate surgical outcomes have improved. Incisional hernias occurred in 5% of cases post-ileostomy reversal, with obesity emerging as a significant risk factor. Kidney dysfunction from having an ileostomy, including acute and chronic renal issues,

resulted from a combination of fluid imbalances, pre-existing health conditions, and chemotherapy treatments. Patients noted increased life satisfaction with living with an ileostomy, though this often came at the expense of higher caregiver demands, leading to moderate stress levels. These results underscore the need for multidisciplinary, patient-centred approaches integrating clinical and psychosocial care.

Conclusions: This thesis demonstrates that significant clinical challenges and profound psychosocial impact mark the ileostomy journey. However, surgical advancements have improved outcomes and issues like hernias and renal complications persist, emphasising the need for better preoperative planning and long-term follow-up. The interdependence between patient outcomes and caregiver burden also calls for comprehensive support systems and policy reforms. Further studies should enhance risk prediction, improve prevention strategies, and create tailored interventions supporting patients and caregivers. Just as Homer's *Odyssey* chronicles the resilience and transformation of its hero amidst great adversity, so too do patients and caregivers navigating the challenges of ileostomy, ultimately achieving growth and strength through their journey.

TABLE OF CONTENTS

	Page No.
Chapter 1: Embarking on the Odyssey: Unveiling the Journey of Discovery	11
A. Background and rationale	15
B. Research questions and objectives	15-16
C. Significance of the study	16
Chapter 2: Literary Voyage: Navigating the Odyssey of Knowledge and Insight	17
A. Overview of ileostomy and its historical context	18-19
B. Surgical techniques and advancements in ileostomy procedures	20-21
C. Physical and psychological impact of living with an ileostomy	21-22
D. Quality of life for spouses and caregivers of ileostomy patients	22
E. Complications after ileostomy reversal: predictors and outcomes	23
F. Renal impairment after ileostomy formation for rectal cancer surgery: occurrence and risk factors	23-24
G. Current gaps in the literature and research questions	24-25
Chapter 3: Navigating the Methodological Waters	26
A. Research design and approach	27-28
B. Data sources and sample selection	28-29
C. Variables and measurements	29-30
D. Statistical analysis methods	30-31
E. Ethical considerations	31
Chapter 4: Unravelling the Hernia Odyssey: Mapping the Prevalence and Risk Factors for Incisional Hernia After Reversal	32
A. Introduction	33-34
B. Methodology	35-36
C. Results	36-38
D. Discussion	39-41
E. Conclusion	42
Chapter 5: Voyage of the Caregiver: Charting the Quality-of-Life Seas for Caregivers of Stoma Patients	43
A. Introduction	44-46
B. Methodology	47-48
C. Results	49-53
D. Discussion	54-56
E. Conclusion	56
Chapter 6: Renal Odyssey Unveiled: Exploring the Impact of Ileostomy Creation on Renal Function - A Systematic Review	57
A. Introduction	58-59
B. Methodology	60-64
C. Results	65-68
D. Discussion	69-71
E. Conclusion	71-72

Chapter 7: Concluding the Odyssey: Synthesis, Discussion, and Implications for Future Research	73
A. Synthesis of Key Findings	74
B. Integration with Existing Literature	75
C. Implications for Clinical Practice and Policy	76
D. Future Directions	77
E. Conclusion	78
Chapter 8: Epilogue: Navigating Home - Reflecting on the Ileostomy Journey	79-82
Chapter 9: Anchoring Insights - A Compendium of References	83-88
Chapter 10: Appendices: Supplementary Voyages and Artifact	89
A. Invitation Letter for Patient Participation in a Survey on Quality of Life and Caregiver Burden Among Individuals with a Stoma	90
B. Stoma Patient Questionnaire – Assessing Quality of Life and Caregiver Impact	91
C. Stoma Quality of Life Assessment Tool	92
D. Caregiver Burden Assessment for Individuals Supporting People with Stomas	93
E. The Caregiver Burden Scale - Assessment Tool for Evaluating Caregiver Strain	94
F: Summary of Studies Included in the Systematic Review	95-98

LIST OF FIGURES

	Page No.
Figure 1. Participant Recruitment Flowchart Detailed overview of the identification and selection process from the ostomate database.	50
Figure 2. Correlation between SQOL and CBS Scores Scatterplot illustrating the relationship between Stoma Quality of Life (SQOL) and Caregiver Burden Scale (CBS) scores (Pearson $r = 0.433$, $p = 0.005$).	53
Figure 3. PRISMA Flow Diagram Comprehensive visual summary of the study selection process for the systematic review.	68

LIST OF TABLES

	Page No.
Table 1. Patient and Surgical Factors in the Development of Incisional Hernia	34
Detailed comparison of patient demographics, surgical characteristics, and postoperative outcomes associated with incisional hernia following ileostomy reversal.	
Table 2. Demographic Characteristics of Study Participants with Stomas and Their Caregivers	46
Summary of key demographic details for ostomate participants and corresponding caregiver data.	
Table 3. Demographics of Caregivers	46
Breakdown of caregiver characteristics, including age, gender, relationship to the patient, and prior experience in stoma care.	
Table 4: Newcastle-Ottawa Scale (NOS) Quality Assessment of Included Studies	58
Detailed quality assessment of each included study using the Newcastle-Ottawa Scale (NOS). Higher scores indicate studies of higher methodological quality.	

LIST OF ABBREVIATIONS

- **AKI** – Acute Kidney Injury
- **APR** – Abdomino-Perineal Resection
- **ASA** – American Society of Anesthesiologists
- **BUN** – Blood Urea Nitrogen test
- **BMI** – Body Mass Index
- **CAPOX** – Capecitabine and Oxaliplatin chemotherapy regimen
- **CKD** – Chronic Kidney Disease
- **CBS** – Caregiver Burden Scale
- **CRC** – Colorectal Cancer
- **eGFR** – Estimated Glomerular Filtration Rate
- **ESKD** – End-Stage Kidney Disease
- **HAR** – High Anterior Resection
- **LAR** – Low Anterior Resection
- **LI** – Loop Ileostomy
- **PRISMA** – Preferred Reporting Items for Systematic Reviews and Meta-Analyses
- **SCr** – Serum Creatinine
- **SQOL** – Stoma Quality of Life questionnaire
- **TME** – Total Mesorectal Excision

Chapter 1: Embarking on the Odyssey:

Unveiling the Journey of Discovery

*"Launch out on his story, Muse, daughter of Zeus,
start from where you will—sing for our time too."*

—Homer, *The Odyssey*, Book 1, lines 11–12

Living with an ileostomy is more than a surgical event—it is an odyssey. Drawing on the timeless metaphor of Odysseus’s epic journey (Homer, 1950), this chapter explores the multifaceted challenges patients encounter following the creation and eventual reversal of an ileostomy. These challenges encompass not only physical hurdles but also profound emotional, psychological, and social transformations (Mithany et al., 2023). It is essential to ground this narrative in empirical evidence, acknowledging that each step of the patient’s journey is shaped by both documented clinical outcomes and lived experience (Cohan et al., 2021; Rud et al., 2022).

The Journey Begins

The decision to undergo an ileostomy often arises from urgent, life-threatening conditions. Much like Odysseus, who was compelled to leave his home under dire circumstances, patients are forced to confront a sudden, life-altering reality. Severe conditions—such as colorectal cancer, inflammatory bowel disease, or diverticulitis—demand immediate action, instilling a mix of anxiety, uncertainty, and hope (Cohan et al., 2021; Rud et al., 2022). This pivotal phase marks the onset of a transformative process where patients commit to a new way of life in pursuit of improved survival and quality of life (Mithany et al., 2023).

Obstacles and Challenges

Following ileostomy formation, individuals face physical, social, and practical challenges. Physically, patients must manage discomfort, potential complications (such as bowel obstruction or infection), and the rigours of continuous self-care (Fish et al., 2017). Socially, the impact on body image and self-esteem can be profound, affecting intimate relationships and

daily interactions (Ayaz-Alkaya, 2019; Thorpe & McArthur, 2017). Additionally, strict dietary management and constant vigilance add complexity that demands determination and resourcefulness (Tsujioka et al., 2022; Polidano et al., 2021).

The Inner Journey

Beyond the physical trials lies an ardent inner journey. The psychological impact of living with an ileostomy is life-changing. Patients often grapple with altered body image, fear of social stigma, and intimacy challenges, which can lead to isolation and emotional distress (Smith et al., 2017; Ayaz-Alkaya, 2018; Xi et al., 2022). However, the literature also highlights the capacity for resilience and personal growth. Many patients, over time, learn to reframe their experiences, developing a renewed sense of identity and inner strength that transforms their outlook on life (Jayarajah & Samaraseka, 2017; Ma et al., 2022). This inner journey, while arduous, is a critical component of overall recovery and long-term well-being.

Allies and Support

No odyssey is undertaken alone. Just as Odysseus benefitted from loyal companions and divine intervention, patients with an ileostomy rely on a support network. Healthcare professionals, support groups, and counselling services are indispensable in this process (Mithany et al., 2023; Vonk-Klaassen et al., 2016; Kittscha et al., 2024). These allies provide practical guidance—such as managing stoma care and dietary restrictions—and offer emotional support, helping to mitigate feelings of isolation and foster a sense of community. The importance of these support systems is reinforced by qualitative studies that document the positive impact of peer interactions and professional guidance on patients' quality of life (Klaassen et al., 2016; Kittscha et al., 2024).

The Return Home

For many, the prospect of ileostomy reversal represents a return to normalcy—a homecoming after a long and gruelling journey. However, despite the successful reversal, the residual impact of the ileostomy experience may endure repercussions for physical, emotional and psychological well-being (Rubinkiewicz et al., 2019; Iqbal et al., 2018). Even when reversal can restore bodily function, what was learned along the way and what transformed during the odyssey remain part of the long-term outcomes, requiring continued clinical efforts.

Adjusting to an ileostomy is a complex process involving physical challenges, emotional adaptation, and the development of resilience. Recognising the intricate interplay of these elements is essential for clinicians and researchers alike, as it underpins the development of tailored interventions and support mechanisms (Smith et al., 2017; Mithany et al., 2023). By integrating narrative insights with empirical evidence, we can better appreciate the diverse experiences of those who navigate this challenging path.

A. Background and Rationale

An ileostomy is a widely performed surgical procedure for managing conditions such as colorectal cancer, inflammatory bowel disease, and diverticulitis (Mulita & Lotfollahzadeh, 2023). Although it offers the potential to save lives and improve quality of life, the procedure introduces a host of complications and challenges. Studies suggest that understanding what leads to complications—like incisional hernias after a reversal—can help improve patient outcomes by allowing for more tailored surgical and follow-up care (Rubinkiewicz et al., 2019; Iqbal et al., 2018).

Moreover, the ramifications of an ileostomy extend beyond the patient. Spouses and caregivers, who play a crucial role in the patient's support system, often face considerable emotional and practical challenges (Jin et al., 2021; Alenzi et al., 2022). Assessing their quality of life is crucial for developing comprehensive care models that address the needs of the entire patient-caregiver dyad.

In addition, there is a growing concern regarding renal impairment following ileostomy formation. The literature reveals that the prevalence and mechanisms underlying this complication remain incompletely understood, underscoring the need for systematic reviews to inform better clinical practice (Smith et al., 2021; Omar et al., 2023; Rutegard et al., 2023; Solitano et al., 2024).

B. Research Questions and Objectives

- **Prevalence and Risk Factors:** To determine the prevalence of incisional hernia following ileostomy reversal and identify associated risk factors.
- **Quality of Life:** To assess the quality of life of spouses and caregivers of patients with an ileostomy.

- **Renal Impairment:** To conduct a systematic review evaluating the occurrence of renal impairment following ileostomy formation for rectal cancer surgery.
- **Synthesis of Findings:** To integrate findings from multiple studies and comprehensively understand ileostomy's clinical and psychosocial challenges.
- **Implications:** To discuss the clinical, policy, and research implications of these findings, thereby informing future guidelines and interventions.

C. Significance of the Study

Understanding the challenges associated with ileostomy is essential for refining surgical techniques and enhancing patient care outcomes. By identifying predictors of complications, healthcare professionals can refine preoperative assessments and postoperative care protocols, ultimately enhancing patient outcomes (Cohan et al., 2021; Rubinkiewicz et al., 2019). Furthermore, understanding the broader psychosocial impact—particularly on caregivers—can drive the development of targeted interventions and support networks, alleviating the overall burden on patients and their families (Smith et al., 2017; Mithany et al., 2023).

This study synthesises various research and multidisciplinary perspectives, contributing to a holistic understanding of the ileostomy trajectory. The insights gained will help guide evidence-based clinical practice, enhance policymaking, and guide further research.

Chapter 2: Literary Voyage: Navigating the Odyssey of Knowledge and Insight

*"Stranger, you are no fool, no short of sense;
if truly you were born and bred in Ithaca,
you must remember all the tales we tell of him."*

—Homer, *The Odyssey*, Book 3, lines 102–104

A. Overview of Ileostomy and Its Historical Context

An **ileostomy** is more than just a medical procedure; it reflects a rich linguistic evolution spanning centuries. The term's etymology stems from Greek and Latin, incorporating elements that define anatomical and procedural components (Ballantyne, 1984; Rajaretnam & Lieske, 2023).

The Greek word **eileos**, meaning "twisted", evolved into the Latin word **ileus**, which means twisted, and also refers to an intestinal obstruction, a term used by Celsus, a Roman encyclopedist in the first century CE (Sprumont, 2016; Wulff, 2004; OUP, 1968). Over time, this term laid the foundation for the modern term **ileum**, which refers explicitly to the distal portion of the small intestine. The usage of ileum in English was first recorded by Thomas Gibson in 1682, in which he highlighted the intricacies of its many convolutions and turns, describing the bowel as "**circumvolvendo**" (Gibson, 1682). The ileum's anatomical significance was fundamental to the development of ileostomy, as it became the primary site for the surgical creation of an ostomy when patients could no longer use the colon for waste elimination.

Similarly, the word **stoma**, derived from the Greek for "mouth," signifies an opening or aperture, aligning closely with the Latin **ostium**, which also denotes an opening (Green, T. M., 2015; OUP, 1968). As such, ileostomy—the term referring to a surgically created opening from the ileum—signifies creating an artificial passage for waste removal (Green, 2015; Zaeske, 1965). The emergence of stoma procedures in the medical field traces its roots as far back as 350 BC, indicating that the concept of surgically rerouting bodily fluids or waste is an ancient practice (Plasencia & Bahna, 2019; Babakhanlou et al., 2022). One of the first documented colostomy cases in the medical literature occurred in 1784 by William Cheselden. He performed a colostomy on Margaret White, a 73-year-old woman suffering from intestinal necrosis, marking a significant moment in the evolution of abdominal surgery (Cheselden, 1784). Despite the

rudimentary nature of care and the absence of specialised stoma management, this case marked an essential development in offering patients a chance at survival through stoma creation.

Historically, surgeons faced peril when creating stomas, attempting only 27 procedures between 1716 and 1839. Of these, only six were successful (Amussat, 1983; Cotlar, 2002; Hardy, 1989). Early surgeons employed hazardous techniques, including the use of aggressive laxatives, manual stool removal, and even the application of heated objects to stimulate bowel movements. A particularly notable case is that of French surgeon M. Pillore in 1776, who performed a stoma to relieve an intestinal obstruction in Mrs. Morel, a procedure that ultimately led to her death due to complications (Pillore, 1776; Cotlar, 2002). These early experiences in stoma surgery were fraught with danger, reflecting the limited understanding of the physiological needs of patients undergoing such procedures.

By the late 19th and early 20th centuries, stomas were becoming more commonplace, particularly in managing gastrointestinal malignancies and conditions requiring bowel diversion. Baum's 1879 operation for a malignant tumour, although a critical step forward, was marred by high postoperative mortality (Baum, 1879; Duret, 1793). After 1950, surgeons began widely performing ileostomy as a life-saving procedure due to advances in anaesthesia, improved surgical techniques, and the development of modern ostomy appliances, particularly for patients with inflammatory bowel disease (Orkin & Cataldo, 2007).

B. Surgical Techniques and Advancements in Ileostomy Procedures

The surgical management of ileostomies has undergone remarkable transformations over the past century. A key innovation in stoma surgery was the development of the distinction between primary and secondary maturation. In primary maturation, the ileal segment is immediately everted and sutured to the skin, forming a stoma spout that facilitates effluent discharge away from the peristomal area. Surgeons use secondary maturation when the bowel is too thick, inflamed, or friable for immediate eversion. In these situations, they create the stoma without eversion, allowing the tissue to settle and heal before final maturation (Orkin & Cataldo, 2007).

It was a landmark Bonafide work of Professor Bryan Brooke in 1952, who would have the first breakthrough in developing ileostomy procedures. He devised a method in which the ileal mucosa was everted and sewn to the skin, resulting in a protruding stoma that significantly decreased the occurrence of peristomal skin excoriation (Brooke, 1952). This technique has persisted as the gold standard approach to ileostomy creation and served as a platform on which innovations in the surgical management of patients requiring ostomies have built.

The field of ileostomy reversal has also undergone substantial research in recent decades. Studies comparing early reversal (within 14 days) versus standard reversal procedures have shown that although early closure can reduce the period of stoma dependence, it also increases the risk of postoperative complications, including wound infections and small bowel obstructions. These findings highlight the importance of a patient-centred approach to stoma reversal, emphasising the need to carefully assess individual risks and benefits (O'Sullivan et al., 2022; Podda et al., 2022). Furthermore, advancements in laparoscopic and robotic-assisted surgical techniques have significantly reduced postoperative pain, shortened hospital stays, and enhanced recovery times (Rondelli et al., 2023).

One notable advancement in ileostomy surgery is the development of the purse-string closure technique, which has demonstrated lower rates of surgical site infections compared to traditional linear closure methods (Nyandoro et al., 2023). This technique, which involves circularly suturing the bowel and skin, ensures a more secure and tension-free closure, reducing the likelihood of postoperative complications. Personalised approaches to stoma creation, which consider patient-specific factors such as body type and individual anatomical considerations, have further improved surgical outcomes and patient satisfaction (Ourô et al., 2021).

C. The Physical and Psychological Impact of Living with an Ileostomy

Living with an ileostomy brings both physical and psychological challenges that affect patients in profound ways. On a physical level, the presence of a stoma necessitates rigorous self-care routines, including the frequent changing of the ostomy bag and careful management of the peristomal skin to prevent complications such as irritation, infection, and skin breakdown (Smith et al., 2017; Ayaz-Alkaya, 2018). Complications such as skin irritation, peristomal hernias, and bowel obstructions remain significant concerns despite the advancement of modern ostomy appliances and surgical techniques (Ma et al., 2022).

Adjusting to life with an ileostomy can be an emotionally challenging experience. Many patients go through a grieving process as they try to accept the physical changes to their bodies and how those changes affect their sense of self. It is not uncommon for feelings of anxiety and depression to surface during this time. Body image often becomes a significant concern, as individuals struggle with the visibility of their stomas and the ongoing care required (Smith et al., 2017). The stoma can serve as a constant reminder of illness and dependency, which may lead some patients to feel disconnected from their former sense of identity. For some, this shift

impacts how they view their age, sexuality, and overall relationship with their body (Smith et al., 2017).

Despite these challenges, many patients can adjust their self-concept positively, finding strength and empowerment in managing their condition. Over time, many report developing resilience and adapting to a "new normal" (Xi et al., 2022). Support groups, professional counselling, and peer networks facilitate this adjustment process. These resources help patients build coping strategies, reduce isolation, and improve their well-being.

D. Quality of Life for Spouses and Caregivers of Ileostomy Patients

Ileostomy procedures affect the patient and place significant emotional and practical demands on caregivers and family members. Spouses and caregivers often experience increased levels of stress, anxiety, and depression as they adapt to the daily responsibilities associated with stoma care, including managing ostomy supplies, assisting with dietary modifications, and providing emotional support (Prieto et al., 2005; Zewude et al., 2021). This emotional and physical strain can lead to caregiver burnout, a phenomenon that is particularly concerning given the long-term nature of stoma care.

Caregivers frequently feel overwhelmed and unprepared to manage a patient's ileostomy (Zarit et al., 1980). In response, care models emphasise addressing caregivers' needs, introducing educational materials, counselling services, and peer support groups to help them cope with their challenges (Rafiei et al., 2020; Liu et al., 2023). Offering caregivers the proper resources and emotional backing helps prevent burnout and strengthens the relationship between caregivers and patients. Ultimately, this support contributes to better outcomes for everyone involved.

E. Complications After Ileostomy Reversal: Predictors and Outcomes

While ileostomy reversal is often seen as a step toward normalcy, it can carry significant risks.

One of the most serious complications is an anastomotic leak, which may occur due to factors like poor nutrition, smoking, steroid use, or pre-existing inflammatory bowel disease. If a leak develops, it can cause peritonitis, abscesses, sepsis, more extended hospital stays, and, in some cases, even death (Rubinkiewicz et al., 2019; Iqbal et al., 2018). Surgical site infections are another common issue after ileostomy reversal. These infections can slow wound healing and may require additional medical treatment (Rubinkiewicz et al., 2019).

Dehydration is a frequent reason for hospital readmission following ileostomy creation, accounting for 42% of readmissions within the first 60 days after surgery (Fish et al., 2017).

High-output stomas are a major contributor to dehydration, which lengthens hospital stays, raises healthcare costs, and diminishes the patient's quality of life (Vogel et al., 2022).

Repeated readmissions due to dehydration strain to the healthcare system and increase the challenges patients face during recovery.

F. Renal Impairment After Ileostomy Formation for Rectal Cancer Surgery: Occurrence and Risk Factors

Renal impairment is a known complication after ileostomy formation, with research showing it can affect anywhere from 5% to 30% of patients. Typically, this involves decreased kidney function—marked by lower glomerular filtration rates and higher levels of serum creatinine—which can make recovery more challenging and lead to poorer outcomes overall (Fielding et al., 2020; Li et al., 2017; Smith et al., 2021). Several factors increase the likelihood of this complication. Some are patient-related, like age, kidney problems, diabetes, high blood pressure, or heart conditions. Others stem from surgical conditions, including lengthy

procedures, low blood pressure during the operation, and heavy blood loss (Rhemouga et al., 2021).

The reasons behind this kidney dysfunction are complex. For one, hypovolemia—where the body does not have enough fluid—can reduce blood flow to the kidneys, causing damage. Additionally, the body’s inflammatory response to surgery can further strain kidney function (Okamoto et al., 2022; Yaegashi et al., 2020). These findings emphasise the need for close attention to fluid levels during and after surgery, and early intervention if any complications arise. By managing these factors carefully, reducing the risk of kidney injury and improving patient outcomes is possible (Rhemouga et al., 2021).

G. Current Gaps in the Literature and Research Questions

Despite significant advancements in ileostomy management, several critical gaps remain in the literature. Further research is needed to understand the predictors of complications following ileostomy reversal, incorporating a wide range of patient-related, surgical, and postoperative factors. Additionally, while the physical and psychological impacts of living with a stoma are well-documented, the unique challenges faced by caregivers and spouses require further exploration to develop effective support interventions. Further research is needed to understand long-term outcomes after ileostomy reversal, including recovery of function, bowel habit patterns, and mental well-being (Solitano et al., 2024).

Furthermore, the incidence and risk factors for renal impairment after ileostomy formation, particularly in rectal cancer surgery, remain insufficiently characterised, underscoring the need for large-scale cohort studies and systematic reviews to guide preventive strategies. The gaps in the literature reflect the ongoing need for a more comprehensive, nuanced understanding of the long-term care of ileostomy patients.

This chapter has explored the extensive historical evolution, significant surgical developments, and diverse challenges associated with ileostomy care. Thoroughly reviewing the current state of knowledge, it sets the stage for the chapters ahead, which will focus on specific research results and their clinical implications. These upcoming chapters aim to deepen our understanding of the intricate journey of managing ileostomies. Overall, this comprehensive review highlights the importance of continuing research and refining care approaches to meet the unique and often complex needs of individuals living with ileostomies.

Chapter 3: Navigating the Methodological Waters

*"Straight ahead and through the night we rowed on with never a pause,
taking turns at the oars."*

—Homer, *The Odyssey*, Book 10, lines 28–29

A. Research Design

This thesis employed a convergent parallel mixed-methods design, integrating retrospective quantitative analysis, a systematic review, and qualitative interviews. This methodological triangulation enabled exploration of both clinical outcomes and psychosocial dimensions of living with an ileostomy.

The quantitative arm comprised a retrospective observational cohort study evaluating surgical outcomes and complications following ileostomy formation and reversal. Hospital records were identified using procedural codes and categorised to capture relevant postoperative complications, such as anastomotic leak, wound infection, bowel obstruction, and incisional hernia. The retrospective design facilitated broad epidemiological insight across a diverse patient population, while a purposive sampling approach ensured demographic representativeness across age, sex, and surgical indication. Only patients with complete clinical records and longitudinal follow-up were included.

A systematic review was concurrently performed to synthesise existing evidence on renal impairment following ileostomy, particularly among patients undergoing surgery for rectal cancer. The review adhered to PRISMA 2020 guidelines (Page et al., 2021) and sourced publications from PubMed, Embase, and the Cochrane Library. This strengthened the study's external validity and contextualised findings within the broader literature.

The qualitative component aimed to capture the lived experiences of patients and their caregivers. Structured interviews were conducted using two validated instruments: the Stoma Quality of Life (SQOL) questionnaire (Prieto et al., 2005) and the Caregiver Burden Scale (CBS) (Zarit et al., 1980). This enabled insight into the psychological and social impacts of

stoma management, including emotional adaptation, stigma, and caregiving fatigue. Thematic analysis was conducted using the Braun and Clarke (2006) framework to identify patterns and meaning across narratives.

B. Data Sources and Sample Selection

The quantitative dataset was drawn from clinical records of a single colorectal surgeon working across both public and private sectors in the Illawarra Shoalhaven Local Health District. This included operative logbooks, consultation notes, and hospital databases spanning from November 1999 to February 2015. Patients were identified using procedural codes and included if they were adults (aged ≥ 18 years), underwent ileostomy formation and reversal, and had complete follow-up data. Those with incomplete records or concurrent active malignancy at follow-up were excluded. Although the exclusion of incomplete data may introduce some bias, this was deemed necessary to preserve analytical integrity, and missing data were non-systematic in nature.

In addition to the primary dataset, a systematic review was conducted to examine renal impairment in patients with ileostomies following rectal cancer surgery. A comprehensive search of PubMed, Embase, and the Cochrane Library was undertaken using relevant MeSH terms and keywords, including “ileostomy,” “renal impairment,” “acute kidney injury,” “chronic kidney disease,” and “rectal cancer.” Eligible studies included adult human subjects with ileostomies and reported renal outcomes. The search was limited to English-language publications. Studies were screened by title and abstract, followed by full-text review, and evaluated using the Newcastle-Ottawa Scale to assess methodological quality. A narrative synthesis was chosen due to heterogeneity in study design and outcome reporting.

For the qualitative component, participants were recruited through a regional stoma therapy registry and direct patient referral. The study included both patients living with an ileostomy and caregivers actively involved in their care. Purposeful sampling ensured a representative cohort in terms of age, gender, and caregiving relationships. Consent was implied through return of the completed questionnaire and participants were informed that their responses would be kept confidential.

C. Variables and Measurements

In the quantitative arm, a wide array of variables was captured to assess surgical outcomes and long-term complications. Demographic variables included age, sex, and body mass index. Clinical variables included American Society of Anesthesiologists (ASA) classification, operative approach (laparoscopic or open), type of stoma (loop or end ileostomy), and use of mesh or adjunctive measures. Postoperative complications such as wound infection, bowel obstruction, anastomotic leak, incisional hernia, and renal impairment were recorded. Renal function was specifically assessed through serum creatinine and estimated glomerular filtration rate (eGFR). The timing of stoma reversal and incidence of complications such as hernia recurrence were also documented. Where possible, the influence of surgical technique and patient comorbidities on complication rates was explored.

The qualitative measures included two validated tools. The Stoma Quality of Life (SQOL) questionnaire, developed by Prieto et al., assessed physical symptoms, emotional wellbeing, body image, and social engagement among patients with an ileostomy. The Caregiver Burden Scale (CBS), based on the instrument by Zarit et al., captured perceived burden, emotional stress, physical strain, and disruption of personal life among caregivers.

Open-ended responses were transcribed and analysed to elicit deeper meaning and narrative coherence. These tools were selected for their validity, reliability, and applicability to the stoma and caregiving context.

D. Statistical Analysis Methods

Quantitative data were analysed using SPSS version 23.0. Descriptive statistics were used to summarise patient demographics, operative details, and complication rates. Chi-square and independent t-tests were employed to compare outcomes across subgroups, such as open versus laparoscopic surgery or loop versus end ileostomy. Multivariate logistic regression analysis was performed to identify independent predictors of incisional hernia, with adjusted odds ratios and 95% confidence intervals reported. The threshold for statistical significance was set at $p < 0.05$. Data completeness was assessed for all variables, and cases with critical missing data were excluded. Given the retrospective nature of the study and the non-random pattern of missingness, no imputation methods were applied.

The systematic review findings were synthesised narratively, with attention to heterogeneity in patient populations, study settings, and outcome definitions. Key risk factors for renal impairment—including advanced age, diabetes, chemotherapy, dehydration, and high-output stoma—were noted across studies.

Qualitative data were analysed using thematic analysis, following the six-phase approach proposed by Braun and Clarke (2006). This included familiarisation with data, initial coding, theme development, theme review, theme definition, and report writing. Coding was conducted inductively to allow themes to emerge from the data without preconceived categories. Key themes included emotional adaptation to body image, practical challenges

with stoma care, caregiver fatigue, loss of autonomy, and the interplay between physical complications and psychological wellbeing. These findings were used to contextualise and enrich the quantitative data, contributing to a more integrated understanding of the patient and caregiver experience.

E. Ethical Considerations

Ethical approval was obtained from the Illawarra Shoalhaven Local Health District Human Research Ethics Committee (ISLHD HREC) under project number ISLHD-LNR-2024/001. All aspects of the study adhered to the National Statement on Ethical Conduct in Human Research (NHMRC, 2007, updated 2018). For the retrospective cohort analysis, all data were anonymised, stored securely, and used solely for research purposes. In the qualitative component, participants were provided with a plain language statement detailing the aims of the study, data confidentiality, and their right to withdraw at any time. Participation was entirely voluntary, and no financial incentives were offered. Consent was implied through return of the questionnaire, and participant identifiers were removed during transcription and analysis. All data were stored on password-protected systems in compliance with institutional data management policies.

Chapter 4: Unravelling the Hernia Odyssey: Mapping the Prevalence and Risk Factors for Incisional Hernia After Reversal

“Endure, my heart; you have endured worse than this.”

—Homer, The Odyssey, Book 20, line 18

A. Introduction

Temporary stomas are essential in treating complex colorectal disorders, particularly in cases where bowel segments are compromised due to conditions like colorectal cancer, inflammatory bowel disease, or diverticulitis (Mulita & Lotfollahzadeh, 2023). Stoma formation may be necessary for diverting intestinal contents away from affected areas, providing relief and allowing the underlying disease to heal (Cohan et al., 2021; Rud et al., 2022). After the acute phase subsides and the pathology is addressed, the next important step often involves stoma reversal— a complex procedure that recreates bowel continuity and closes the abdominal wall. This marks a key milestone in the patient's recovery (Rubinkiewicz et al., 2019). However, notwithstanding its familiar nature, stoma reversal is not without risks (O'Sullivan et al., 2022).

Although the principal aim of a stoma reversal is to restore normal bowel function, both short- and long-term complications may arise. Incisional hernia formation, for instance, represents an important clinical complication (Smith et al., 2016). If the abdominal wall does not heal appropriately following an operation, incisional hernias can develop, causing chronic pain, discomfort, and dysfunction, subsequently reducing the quality of life of the patient (Cotlar, 2002; Smith et al., 2016). In worst-case scenarios, they can result in bowel strangulation or obstruction and may require additional surgery (Cotlar, 2002; O'Sullivan et al., 2022).

Incisional hernias, being common after most forms of abdominal surgery, are an even greater risk in the field of ileostomy reversal (Smith et al., 2016). The potential for hernia formation can depend on many factors, including the health status of the patient, surgical technique, and postoperative care (O'Sullivan et al., 2022). Risk factors for developing these hernias have

included several patient-related factors including older age, higher body mass index (BMI), smoking status, diabetes, and other comorbidities (Podda et al., 2022; Climent & Biondo, 2022). Medication-related factors such as steroid use, VEGF inhibitors, and immunosuppressants have also been proposed as contributing risks. Surgical factors such as the method of fascial defect closure and suture type are also critical determinants, as some techniques are associated with a lower or higher risk of hernia development (Rondelli et al., 2023; Nyandoro et al., 2023).

Having a stoma, particularly one that can be reversed, brings with it a whole range of mechanical, biological and physiological challenges, which can render the abdomen more susceptible than usual to complications such as hernia formation (Cotlar, 2002; Climent & Biondo, 2022). Additionally, contamination of the wound during the surgical procedure and drainage of any postoperative infections can contribute to the risk of incisional hernia formation (Rubinkiewicz et al., 2019; Podda et al., 2022). Despite the advancements in surgical techniques, there is still a great debate regarding the optimal management and prevention of incisional hernias. For example, the routine use of prophylactic mesh reinforcement in stoma reversal surgery has yet to achieve consensus (Climent & Biondo, 2022; Rondelli et al., 2023).

This chapter explores the prevalence and characteristics of incisional hernias after ileostomy reversal, with attention to radiological versus clinical detection, symptomatic severity, and the proportion requiring surgical repair. By integrating novel and existing data, we hope to offer a more evidence-driven insight into the clinical management of patients undergoing ileostomy reversal. This study emphasises the identification of high-risk individuals and tailoring preventive strategies accordingly.

B. Methods

In this retrospective observational study, we examined a consecutive series of patients who underwent stoma reversal between November 1999 and February 2015. A single surgeon performed all surgeries. Detailed patient data—including demographic information (age, sex, BMI, ASA grade, comorbidities), stoma characteristics, and postoperative outcomes—were meticulously extracted from the surgeon’s private hospital operative records and consulting room files.

Exclusion criteria included incomplete follow-up, missing BMI or ASA grade data, and patients with known metastatic or recurrent cancer requiring palliative management. The decision to exclude patients with incomplete follow-up may introduce bias, although this was interrogated by comparing available demographic data between included and excluded patients, which showed no significant differences.

Ethical approval for the study was granted by the Illawarra Shoalhaven Local Health District Human Research Ethics Committee. All patient data were anonymised, and consent was waived due to the retrospective nature of the study.

The primary endpoints of the study were wound complications and the development of an incisional hernia at the stoma site. A wound complication was defined as any adverse event related to the surgical incision. An incisional hernia was identified by the presence of a palpable bulge or fascial defect, as confirmed through clinical examination or imaging studies. Where available, radiological reports were reviewed to distinguish between clinically evident and asymptomatic radiological hernias. Logistic regression analysis assessed the relationship between various factors and hernia formation.

All operations were performed under general anaesthesia, and patients were given standard prophylactic antibiotics. The surgical procedure was the external incision in the form of an ellipse around the stoma, careful bowel mobilisation, followed by anastomosis (a double stapling technique for loop stomas and circular stapler for end stomas). The fascial defect was closed with interrupted absorbable sutures, and the skin was approximated with interrupted subcuticular absorbable sutures. Drains were not placed during the procedure.

The statistical analysis was performed in SPSS version 23.0 (IBM, Armonk, NY, USA). Continuous variables are reported as means \pm standard deviations, and categorical variables are reported as frequencies and percentages. Group differences were evaluated using chi-square or Fisher's exact tests for categorical and independent Student's t-tests for continuous data. Multivariate logistic regression was used to identify independent predictors of incisional hernia. Statistical significance was set at $P < 0.05$.

C. Results

A total of 224 patients underwent ileostomy reversal during the study period. The cohort had a mean age of 57.5 years (range 19–66, SD 15.1) and a median age of 58. The majority of patients were male (55%). Colorectal cancer was the leading indication for stoma creation (56%), followed by inflammatory bowel disease (15%), severe diverticular disease (8%), traumatic bowel injury (8%), ischaemic bowel (5%), and other conditions (8%). The most common types of primary resections included low or ultralow anterior resections (63%), right hemicolectomy (15%), proctocolectomy with ileal pouch-anal anastomosis (13%), subtotal colectomy (6%), and small bowel resection (2%).

Approximately 67% of procedures were performed using an open approach, while 33% were laparoscopic. Most of the surgeries were elective (76%). The stoma types included loop ileostomy (75%), end-loop ileostomy (24%), and end ileostomy (1%). The mean interval from stoma creation to reversal was 6.1 months (range 2–69, SD 7.1). The mean operative time was 1.7 hours (range 1–8, SD 1.0), and the average hospital stay was 9.7 days (range 3–98, SD 12).

Wound complications occurred in 1% of patients, with cases managed conservatively using antibiotics and wound care. Over a mean follow-up period of 30.7 months (range 10–89, SD 15.1), 12 patients (5%) developed an incisional hernia at the stoma site, with a mean time to detection of 25.2 months (range 3–89, SD 32).

Patients who developed incisional hernias had a significantly higher mean BMI (28.1 ± 6.2 kg/m²) than those who did not (26.3 ± 6.0 kg/m², $P = 0.007$). Logistic regression analysis showed that each unit increase in BMI was associated with a 1.3-fold increase in the risk of developing an incisional hernia. Given the small number of hernia events ($n = 12$), this association should be interpreted cautiously.

No significant differences were observed in other variables such as age, ASA grade, stoma type, operative urgency, surgical access, incision type, time interval from stoma creation to reversal, operative time, or hospital stay. Table 1 provides a detailed comparison of patient demographics, surgical characteristics, and postoperative outcomes, highlighting the factors associated with the development of incisional hernia following ileostomy reversal.

Table 1 Patient and surgical factors in the development of incisional hernia

	Total (n = 224)	Hernia (n = 12)	No hernia (n = 212)	P-value
Age (years)† 0.438 Mean ± SD	57.5 ± 15.1	55.8 ± 7.3	57.6 ± 15.5	0.438
Sex†				
Male	124 (55%)	7 (3%)	117 (52%)	1.000
Female	100 (45%)	5 (2%)	95 (42%)	
BMI	28.1 ± 6.2	33.3 ± 3.1	26.3 ± 6.0	0.007
ASA				
1	100 (45%)	3 (25%)	97 (46%)	0.199
2	113 (50%)	9 (75%)	104 (49%)	
3	11 (5%)	0	11 (5%)	
Indication for ileostomy‡				
Colorectal cancer	126 (56%)	6 (3%)	120 (54%)	0.471
Inflammatory bowel disease	34 (15%)	1 (0.4%)	33 (15%)	
Severe diverticular disease	18 (8%)	2 (0.9%)	16 (7%)	
Acute obstruction	18 (8%)	1 (0.4%)	17 (8%)	
Traumatic injury	12 (5%)	2 (0.9%)	10 (5%)	
Infection/sepsis	10 (5%)	0	10 (5%)	
Ischaemic bowel	6 (3%)	0	6 (3%)	
Primary resection type‡				
LAR/ULAR	142 (63%)	10 (5%)	132 (59%)	0.473
Right hemicolectomy	34 (15%)	2 (0.9%)	32 (14%)	
Proctocolectomy with IPAA	30 (13%)	0	30 (13%)	
Subtotal colectomy	14 (6%)	0	14 (6%)	
Small bowel resection	4 (2%)	0	4 (2%)	
Type of ileostomy‡				
Loop	169 (75%)	10 (4.5%)	159 (71%)	0.787
End-loop	53 (24%)	2 (0.9%)	51 (23%)	
End	2 (1%)	0	2 (1%)	
Initial operative urgency‡				
Elective	170 (76%)	9 (4%)	161 (72%)	1.000
Emergency	54 (24%)	3 (1%)	51 (23%)	
Type of surgical access‡				
Open	151 (67%)	6 (3%)	145 (65%)	0.212
Laparoscopic	73 (33%)	6 (3%)	67 (30%)	
Incision type‡				
Peristomal	219 (98%)	11 (5%)	208 (93%)	0.243
Midline	5 (2%)	1 (0.4%)	4 (2%)	
Time from stoma construction to reversal (months)† Mean ± SD	6.1 ± 7.1	9.5 ± 18.8	5.9 ± 5.9	0.525
Operative time (hours)† Mean ± SD	1.7 ± 1.0	2.4 ± 1.8	1.7 ± 0.9	0.189
Length of hospital stay (days)† Mean ± SD	9.7 ± 12	7.9 ± 3.8	9.8 ± 12.3	0.593
Length of follow-up (months)† Mean ± SD	30.7 ± 15.1	28.0 ± 10.8	30.9 ± 15.4	0.526
Wound infection‡	2 (1%)	0	2 (1%)	1.000

†Two-tailed Fisher's exact/Pearson's chi-squared test performed for categorical variables. ‡Unpaired two-tailed t-test performed for continuous variables.

D. Discussion

Diverting ileostomy reversal is widely considered a standard part of the recovery process after treatment for complex colorectal conditions. However, our findings demonstrate that the procedure is not without significant risk, and incisional hernia formation is among the most important complications. As a result, chronic pain and functional limitations, even the need for additional surgical interventions in some cases, may occur (Cotlar, 2002; Smith et al., 2016). The rate of hernia in our study, 5%, is notably lower than the 7.4% observed in some meta-analytical series (O'Sullivan et al., 2022; Podda et al., 2022), though it remains sizeable and requires further investigation. Differences in reported hernia rates are likely due to variability in follow-up duration, surgical technique, and patient selection across studies (O'Sullivan et al., 2022; Podda et al., 2022).

A high BMI emerged as the only statistically significant predictor of incisional hernia formation in our cohort. This may support the biomechanical theory that obesity increases mechanical strain on the abdominal wall, predisposing it to fascial dehiscence and hernia formation (Smith et al., 2016). Additionally, increased subcutaneous fat may impair fascial closure and wound healing (Smith et al., 2016). According to our data, the odds of developing a hernia increased 1.3-fold for each unit increase in BMI ($P = 0.007$), suggesting that obesity should be carefully considered during perioperative planning (Podda et al., 2022). Given the small number of hernia cases ($n = 12$), these findings should be interpreted with appropriate caution and confirmed in larger studies.

Interestingly, other cofactors, including age, ASA grade, and surgical parameters such as operative time, stoma type, and surgical access (laparoscopic vs open), did not show

statistically significant associations. This contrasts with prior studies reporting associations between hernia risk and older age, diabetes, or surgical technique (O'Sullivan et al., 2022; Rondelli et al., 2023). These differences may reflect the relatively homogenous patient population in our study and the single-surgeon setting, which may have reduced confounding from technical variability.

Despite ongoing efforts to optimise fascial closure technique—including suture selection and prophylactic mesh—there is still no consensus on a preferred approach (Nyandoro et al., 2023; Rondelli et al., 2023). While some studies suggest that purse-string sutures or mesh reinforcement may reduce hernia risk, these strategies remain underutilised (Climent & Biondo, 2022). In our series, no differences in surgical closure technique were observed between patients who did or did not develop hernias, further supporting the role of patient-specific factors over technical ones.

The formation of an incisional hernia is a multifactorial process with biomechanical stress, poor tissue healing and possible contamination of the wound playing a role (Podda et al., 2022). A comprehensive, multidimensional approach to prevention is necessary due to the increased risk of hernia formation in patients with obesity and other comorbidities. This could vary between the preoperative risk stratification, optimised surgical techniques, and prophylactic measures such as mesh reinforcement, especially in high-risk patients.

Our study has several limitations, the main one being its retrospective design, which may introduce bias, particularly in relation to the classification of complications and to the follow-up data collection. Although our mean follow-up of 30.7 months reveals valuable data regarding long-term outcomes, larger prospective studies with increased follow-up periods are

needed to validate our findings and further develop methods of aftercare after ileostomy reversal to prevent incisional hernia formation (O'Sullivan et al., 2022).

Our data suggest that BMI is a potentially modifiable risk factor for incisional hernia after ileostomy reversal. Optimising perioperative care for high-risk patients and further investigating targeted interventions, such as prophylactic mesh, may reduce the burden of this complication. These findings support, but do not confirm, the role of BMI in hernia prevention and should be explored further in larger prospective trials.

E. Conclusion

This study contributes to the growing body of evidence that incisional hernia remains a significant, though potentially preventable, complication after ileostomy reversal. By identifying high BMI as a key risk factor, it underscores the importance of early preoperative optimisation in surgical planning. While our data reflect a lower hernia incidence than some reports, the burden of reintervention highlights the need for vigilance beyond the perioperative period. These findings should inform both clinical decision-making and the design of future research aimed at improving long-term outcomes in this population.

Chapter 5: Voyage of the Caregiver: Charting the Quality-of-Life

Seas for Caregivers of Stoma Patients

“Come, friends, let us consult together and consider whether we shall fly, or fight.”

—Homer, *The Odyssey*, Book 10, line 44

A. Introduction

Living with a stoma, whether temporary or permanent, immensely affects not only the individuals who undergo the surgical procedure but also their spouses and caregivers (Prieto et al., 2005; Zarit et al., 1980). Caregivers provide essential physical and emotional support and are often the cornerstone of those recovery and post-recovery efforts (Davis et al., 2021; Watson et al., 2021). Resources, especially for service users due to providing care to sick family members, are scarce, despite their substantial role, receiving inadequate attention in clinical practice and research (Folkman & Moskowitz, 2000). The increasing demand for caregiving strains caregivers, which affects their health, well-being, and quality of life (Middel et al., 2019).

Caregivers of stoma patients face various physical, psychological, and social challenges (Zewude et al., 2021; Rafiei et al., 2020). From a physical perspective, stoma care, which consists of managing the change of appliances, handling leaks, and keeping hygiene up, can be arduous and time-consuming (Bastiaans et al., 2018). Caregivers are always on high alert due to these obligations, disrupting their daily routines and commonly overly fatigued (Fakharian et al., 2022). The physical toll associated with caregiving can lead to "burnout" (Schulz & Beach, 1999), disrupting sleep and deteriorating physical health. From a psychological perspective, the chronic stress of providing care, combined with the emotional toll of seeing a loved one suffer, frequently results in anxiety, depression, and a sense of isolation (Zewude et al., 2021; Rafiei et al., 2020). In addition, the stigma surrounding stoma care may heighten the perception of embarrassment and social exclusion, increasing the emotional stress on the caregiver (Albo et al., 2007; Fudge et al., 2009).

Socially, caregiving can transform one's life dramatically. Caregivers must often modify their daily schedules, minimise their engagement in leisure activities, and sometimes change their careers (Bastawrous, 2013; Pollock et al., 2020). Several report disruptions in their social lives, with fewer opportunities to attend gatherings or maintain relationships outside the caregiving context (Bastiaans et al., 2018). Witnessing such events and the enormous emotional and time commitment required by caring for a person may leave little room for self-care, thus reducing the caregivers' quality of life (Greenwood et al., 2017). These challenges would impact caregivers and indirectly patient outcomes, as the caregiver's health is fundamental to the patient's support network (Zarit et al., 1980; Rafiei et al., 2020).

The caregiving experience is also influenced by cultural and demographic factors (Henneman et al., 2020). Most commonly, caregivers are elderly spouses with little experience coordinating complex medical care, which can exacerbate the social and physical toll (Robinson et al., 2009). Such a caregiver might have more difficulty than others in bearing the emotional burden associated with caring for someone with a chronic ailment (Silverman et al., 2020) who requires permanent, constant tender care. It underlines the urgent demand for tailored educational programs and psychosocial interventions to meet these caregivers' specific needs (Mittelman et al., 2016).

Studies have shown the significant impact caregivers' mental health has on patients' outcomes (Sherwood et al., 2008). Ageing, caregiving stress and feeling overwhelmed by one's responsibility can all contribute to anxiety and depression, leading to a vicious cycle that exacerbates caregivers' stress (Fakharian et al., 2022). We must not only meet stoma patients' physical needs but also equip caregivers with the resources required to thrive.

Being sensitive to these hardships builds the foundation necessary to create holistic, multidisciplinary care models that account for the needs of patients and their caregivers (Patton & Brock, 2019; Bastawrous, 2013). Healthcare professionals and policymakers should acknowledge caregivers' critical role in stoma patient recovery and long-term health and support them wherever possible. It is shown that strategies that include regular psychosocial evaluation and education specific to caregivers can help to relieve some of the stress they experience (Pakenham et al., 2006; Belle et al., 2006).

Through both qualitative and quantitative lenses, this chapter will examine the quality of life of family caregivers. We aim to systematically assess the impact of stoma care on caregivers using validated tools, the Stoma Quality of Life (SQOL) (Prieto et al., 2005) and the Caregiver Burden Scale (CBS) (Zarit et al., 1980). These tools are important for understanding the logistical and emotional burdens of caregiving and informing future clinical practice and policy to help support patients and caregivers (Sloan et al., 2018; Sanders et al., 2017).

By illuminating caregivers' experiences, we hope to highlight areas where support is most needed. This exploration will not only enhance caregiver care and quality of life but also hold the potential for a more holistic, patient-centred approach to stoma care that embraces the well-being of both the patient and their caregivers.

B. Methodology

Working with the stoma therapists in the Illawarra Shoalhaven District, a targeted recruitment strategy was mobilised. The aim was to recruit ostomates (stoma patients) and their primary caregivers to obtain a range of potential caregiving experiences. Potential patients were identified from a maintained directory of stoma patients; caregivers were recruited via patient referrals. All patients with a stoma who were registered with the stoma therapist within the preceding five years were considered eligible. Caregivers were defined as family members or close contacts who provided unpaid, non-professional support during the perioperative period.

All identified participants were sent recruitment materials, including a detailed cover letter (Appendix A) and a study information sheet. It comprised information on the purpose of the study, how to complete the Stoma Quality of Life (SQOL) questionnaire (Prieto et al., 2005) and the Caregiver Burden Scale (CBS) (Zarit et al., 1980). Participation was entirely voluntary, and informed consent was implied upon return of the completed questionnaires. Confidentiality and anonymity were assured.

To support data collection, pre-addressed return envelopes were provided, and questionnaires were distributed and returned over a six-month period from March to August 2024. The participants were told that their participation may help provide valuable insights into the caregiver experience for stoma patients. This topic has yet to be extensively explored in the literature.

The SQOL questionnaire evaluates relevant aspects of the quality of life regarding stoma care—such as physical abilities, psychological functioning, social functioning, and appearance—with the use of a Likert scale, in which high scores indicate a better quality of life (Prieto et al.,

2005). The tool has been validated specifically for this population to ensure it captures the multidimensional aspects of living with a stoma (Mittelman et al., 2016). The CBS assesses burden from emotional, social, financial, and practical perspectives (Zarit et al., 1980). These tools have been commonly used in these types of analysis and will allow us to compare caregiver burden across different caregiving contexts (Fakharian et al., 2022).

To provide context to the caregiver experience and to illustrate how socio-demographic factors might intersect with the caregiving burden, demographic information about the participants—including their age, gender, relationship status, level of education, employment, income, and duration of stoma—was collected. Only responses from caregivers who completed both the SQOL and CBS questionnaires were included in the analysis. Non-respondents and incomplete responses were excluded.

Data were analysed using IBM SPSS Statistics for Windows, Version 29.0 (Released 2022; Armonk, NY: IBM Corp). Descriptive statistics were used to summarise participant demographics. Inferential statistical tests, including independent samples t-tests and Pearson's correlation, were applied to explore associations between SQOL and CBS scores. Given the small sample size, findings were interpreted with caution and presented as indicative rather than definitive.

The study was approved by the Illawarra Shoalhaven Local Health District Low and Negligible Risk Research and Review Committee (Approval number: ISLHD/QA216), ensuring that all ethical considerations were met.

C. Results

A total of 349 potential participants were identified through the stoma therapist database. Following the distribution of recruitment letters over a six-month period, 109 responses were received, yielding a response rate of 31%. After excluding 13 patients with urostomies, 93 valid responses were included in the final analysis.

Of the 93 respondents, 70 participants (75%) had colostomies and 23 (25%) had ileostomies. A total of 39 ostomates (42%) reported having an active caregiver at the time of the study. Figure 1 provides a flowchart outlining the recruitment and selection process.

Figure 1. Participant Recruitment Flowchart: Identification and Selection Process from the Ostomate Database

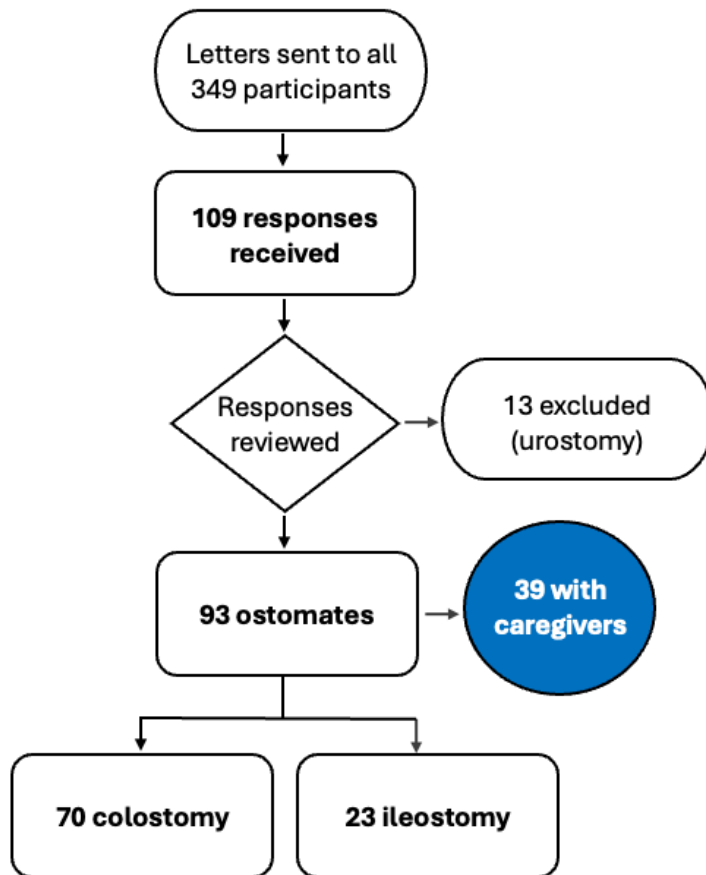


Table 2 summarises demographic characteristics and surgical factors of ostomates, while Table 3 outlines caregiver demographics. The mean age of ostomates was 73.3 years), with 44% identifying as male and 56% as female. Most participants (58%) were aged between 61 and 80 years, and 28% were over 80. Regarding education, 48% had completed secondary school, 33% had vocational training, and 12% held tertiary qualifications. The majority (89%) were retired, and 76% were Australian born. Notably, over one-third of participants had lived with their stoma for more than five years.

Table 2: Demographic Characteristics of Study Participants with Stomas and Their Caregivers

	Total n=93
Mean Age (years)	73.3
Sex	
Male	50
Female	43
Type of Stoma	
Ileostomy	23 (25%)
Colostomy	70 (75%)
Education Level	
Secondary	48%
Vocational	33%
Tertiary	12%
Unclear	7%
Caregiver Present?	
Yes	39 (42%)
No	54 (58%)

Table 3: Demographics of Caregivers

	Total n=39
Mean Age (years)	71.5
Sex	
Male	20
Female	19
Type of Stoma	
Ileostomy	9
Colostomy	30
Relationship to Patient	
Spouse	82%
Others	18%
Prior experience with Stoma	
Yes	13%
No	87%

Among caregivers, the average age was 71.5 years, with an approximately even gender distribution (51% male, 49% female). The vast majority (82%) were spouses of the ostomate, and 97% lived in the same household. Only 13% reported prior experience with stoma care.

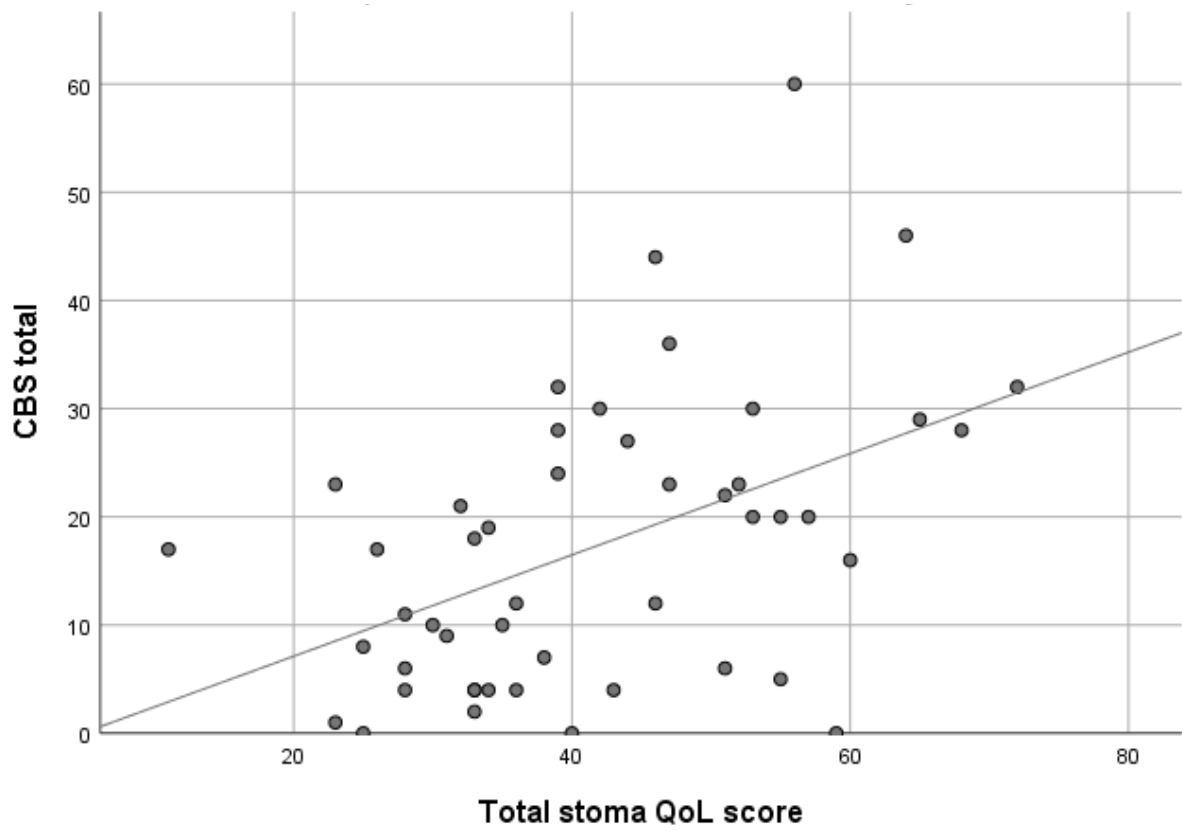
The mean Stoma Quality of Life (SQOL) score for all ostomates was 43.7 (out of a maximum possible score). There were no statistically significant differences in SQOL between those with ileostomies and colostomies (mean: 40.5 vs. 44.8, $p = 0.106$), or between ostomates with and without caregivers (40.6 vs. 46.0, $p = 0.415$). Among ostomates who had caregivers, SQOL scores did not significantly differ by stoma type (ileostomy: 39.2 vs. colostomy: 41.6, $p = 0.531$).

Caregiver Burden Scale (CBS) results indicated that 62% of caregivers reported minimal burden, 33% reported mild to moderate burden, and 5% reported moderate to severe burden. There was no statistically significant difference in caregiver burden between those supporting ileostomy versus colostomy patients (mean CBS scores: 15.3 vs. 16.9, $p = 0.932$).

Pearson's correlation analysis demonstrated a moderate positive correlation between SQOL and CBS scores ($r = 0.433$, $p = 0.005$), suggesting that higher ostomate quality of life was associated with increased caregiver burden.

Figure 2. Correlation Between Stoma Quality of Life (SQOL) and Caregiver Burden Scale (CBS)

Scores (Pearson correlation coefficient = 0.433, p=0.005).



D. Discussion

This study aimed to explore the lived experience of stoma patients and their caregivers in the Illawarra Shoalhaven region, with a particular focus on quality of life and caregiver burden following stoma formation. To our knowledge, this is one of the first Australian studies to examine this intersection systematically using validated tools.

The mean Stoma Quality of Life (SQOL) score in this cohort was 43.7, aligning with previously reported ranges for stoma patients internationally (Prieto et al., 2005; Mittelman et al., 2016). Patients with colostomies reported slightly higher SQOL than those with ileostomies, although this difference was not statistically significant. This finding may reflect differences in output consistency, appliance changes, or peristomal skin issues more frequently reported by ileostomates (Brown & Randle, 2005). However, given the limited sample size, no definitive conclusions can be drawn regarding stoma type and quality of life.

Interestingly, the presence of a caregiver did not significantly influence SQOL scores. This challenges assumptions that caregiver support directly correlates with improved patient outcomes. It may suggest that while caregivers offer important emotional and practical assistance, patients' individual coping strategies and adaptation play a substantial role in perceived quality of life.

The Caregiver Burden Scale (CBS) scores revealed that most caregivers experienced minimal to mild burden, with only a small proportion reporting moderate to severe burden. These findings are consistent with prior literature suggesting that caregiving for stoma patients is often manageable in the long term, especially when the patient is functionally independent (Fakharian et al., 2022; Grant et al., 2013). Nonetheless, 38% of caregivers reported some degree of emotional or practical strain, particularly those without prior caregiving experience or those living in the same household.

A noteworthy and somewhat counterintuitive finding was the moderate positive correlation between SQOL and CBS scores. This suggests that caregivers of patients with better quality of life may paradoxically experience greater burden. One potential explanation is that patients with high expectations of activity and social reintegration may require ongoing logistical and emotional support, increasing caregiver demands even when the stoma itself is well managed. Alternatively, caregivers may be more proactive or vigilant in cases where the patient appears to be doing well, thereby amplifying their own sense of responsibility. This underscores the complexity of caregiving dynamics and cautions against assuming a linear or inverse relationship between patient wellbeing and caregiver stress.

Demographically, most caregivers were spouses, retired, and living in the same household—an expected finding in a predominantly older ostomate population. The lack of previous stoma care experience among most caregivers highlights the need for structured education and follow-up.

This study also reaffirms the multidimensional challenges of life with a stoma. While physical adaptation is critical, psychological factors—such as anxiety about odour, noise, or visibility—continue to influence body image and social confidence, as reflected in SQOL item responses. A major strength of this study is the use of validated tools (SQOL and CBS), combined with a broad sample drawn from a real-world hospital registry over a defined period. Additionally, the inclusion of both patient and caregiver perspectives adds depth to the analysis.

Limitations include the moderate sample size and regional scope, which may affect generalisability. Self-selection bias may also be present, as individuals with strong opinions or more time available may have been more likely to respond. Moreover, this was a cross-sectional survey, so longitudinal changes in burden or adaptation over time could not be assessed.

These findings suggest that while many patients and caregivers adapt well to life with a stoma, a substantial minority experience ongoing psychological and practical challenges. Routine psychosocial screening, caregiver education, and support groups may help mitigate some of this burden.

E. Conclusion

This study offers valuable insight into the caregiving experience in the context of stoma care. While many caregivers report low levels of burden, a significant minority experience strain—sometimes paradoxically greater when patients report higher quality of life. These findings underscore the complexity of caregiver dynamics and the importance of a tailored, multidimensional approach to support (Mittelman et al., 2016; Fakharian et al., 2022).

There is a clear need for targeted interventions such as structured education, digital support platforms, and access to psychosocial services, which may alleviate caregiver burden and improve overall outcomes (Zarit et al., 1980). Future research should investigate the long-term impact of such interventions, ideally through longitudinal or interventional studies (Middel et al., 2019).

Supporting caregivers is not only vital for their own wellbeing but may also contribute to improved adaptation and outcomes for the patients they support (Bastiaans et al., 2018). Holistic care models that incorporate caregiver needs into routine clinical pathways are essential for optimising long-term recovery and quality of life in stoma patients.

Chapter 6: Renal Odyssey Unveiled: Exploring the Impact of Ileostomy Creation on Renal Function - A Systematic Review

*“A man who has been through bitter experiences and travelled far enjoys even his sufferings
after a time.”*

—Homer, The Odyssey, Book 15, line 400

A. Introduction

Renal impairment is an important yet under-recognised complication for patients undergoing ileostomy formation. Although renal dysfunction has traditionally been associated with the immediate postoperative period, it is now increasingly understood as a chronic concern, with implications that may extend well beyond the initial recovery phase—affecting quality of life, long-term morbidity, and healthcare costs (Fielding et al., 2020; Li et al., 2017).

Ileostomy formation, whether temporary or permanent, diverts small bowel contents directly to the abdominal wall, bypassing the colon. This anatomical and physiological change alters normal fluid and electrolyte regulation, predisposing patients to dehydration and electrolyte imbalances—key contributors to acute kidney injury (AKI) and, in some cases, progression to chronic kidney disease (CKD) (Yang et al., 2021; Okamoto et al., 2022).

The colon normally absorbs concentrated gastrointestinal contents, particularly water and electrolytes. In the absence of colonic absorption, patients with an ileostomy are at heightened risk of volume depletion, hypokalaemia, and acid-base disturbances (Yaegashi et al., 2020; Rhemouga et al., 2021). These derangements place additional stress on renal function, particularly in patients with underlying comorbidities such as diabetes mellitus, hypertension, and cardiovascular disease, which are common in those undergoing colorectal surgery (Fielding et al., 2020).

Furthermore, external factors such as adjuvant chemotherapy, often used in rectal cancer management, may exacerbate renal dysfunction due to the nephrotoxicity of certain chemotherapeutic agents (Okamoto et al., 2022; Yang et al., 2021).

While several population-based and institutional studies have examined this association, existing literature is fragmented, lacking a comprehensive synthesis of incidence

rates, risk factors, and clinical outcomes. This systematic review was undertaken to address that gap, with the aim of consolidating current evidence and identifying modifiable contributors to renal impairment following ileostomy formation (Page et al., 2021).

By aggregating data across multiple studies, this review seeks to clarify the prevalence and risk factors of postoperative renal dysfunction, identify vulnerable subgroups, and offer a clearer understanding of the pathophysiological mechanisms involved (Li et al., 2017). The findings also aim to inform evidence-based perioperative strategies for prevention, early recognition, and management of renal complications.

Ultimately, better recognition and management of renal risk after ileostomy may not only reduce long-term morbidity but also enhance the cost-effectiveness and sustainability of colorectal cancer care (Okamoto et al., 2022; Yang et al., 2021).

B. Methods

This systematic review examined the impact of ileostomy formation on renal function in patients undergoing rectal cancer surgery. Given the complex physiological and clinical interactions involved, the review aimed to determine the incidence of renal impairment, identify associated risk factors, and inform potential strategies for clinical optimisation.

Search Strategy and Data Sources

A comprehensive literature search was performed using three major biomedical databases: PubMed, Embase, and the Cochrane Library, selected for their broad coverage of clinical and epidemiological studies. The search included studies published up to January 2024, using combinations of the following terms:

"ileostomy"

"rectal cancer"

"renal impairment"

"acute kidney injury"

"chronic kidney disease"

Boolean operators (AND/OR) were used to refine the search strategy. Only original studies were considered. Review articles, case reports, meta-analyses, and studies with overlapping data were excluded to preserve the independence and integrity of the dataset.

Inclusion and Exclusion Criteria

Studies were included if they met the following criteria:

- Study design: Observational cohort studies, case-control studies, or other relevant comparative studies.
- Population: Adult patients (≥ 18 years) who underwent ileostomy formation as part of rectal cancer surgery.
- Outcome measures: Studies reporting renal impairment following ileostomy creation, including changes in renal function markers (e.g., serum creatinine, eGFR) or diagnoses of AKI or CKD.
- Language: Studies published in English.

Studies were excluded if:

- Renal impairment was not defined or reported
- They were narrative reviews, systematic reviews, meta-analyses, or case reports
- The data overlapped with another included study

Data Extraction

Two independent reviewers (MSDR and KMS) extracted data using a predefined data collection sheet. Discrepancies were resolved by consensus. The following data were collected:

- **Study characteristics:** Authors, publication year, study design, sample size
- **Patient demographics:** Age, sex, comorbidities (e.g., diabetes, hypertension), surgical details

- **Renal outcomes:** Pre- and postoperative serum creatinine, eGFR, AKI and CKD incidence
- **Risk factors:** Surgical techniques, medical comorbidities, perioperative hydration, adjuvant chemotherapy or radiotherapy

Data were compiled into a structured format to facilitate comparison across studies.

Quality Assessment

The methodological quality of the included studies was assessed using the Newcastle-Ottawa Scale (NOS), a validated tool for evaluating non-randomised studies (Wells et al., 2014). The NOS evaluates studies across three key domains:

1. Selection: How participants were chosen for inclusion in the study.
2. Comparability: How studies controlled for potential confounders and biases.
3. Outcome: The methods used to assess renal impairment outcomes.

Each study was assigned a score based on these domains, with higher scores indicating better methodological quality. A score of 7 or higher indicates a high-quality study, while lower scores suggest a higher risk of bias. The quality assessment results were summarised in Table 4, which presents the quality ratings for each study, categorising them based on selection, comparability, and outcome assessment methods (Wells et al., 2014).

Table 4: Newcastle-Ottawa Scale (NOS) Quality Assessment of Included Studies

Detailed quality assessment of each included study using the Newcastle-Ottawa Scale (NOS). Higher scores indicate studies of higher methodological quality.

STUDY	SELECTION			COMPARABILITY	OUTCOMES			TOTAL
	Representative	External Control	Ascertainment of Exposure		Outcome not present at start of study	Assessment of Outcomes	Length of Follow-up	
Fielding et al	*	*	*	*	*	*	*	8
Li et al	*	*	*	*	*	*	-	7
Yang et al	*	*	*	*	*	*	*	8
Yaegashi et al	*	*	*	*	*	*	*	8
Okamoto et al	*	*	*	*	*	*	*	8
Smith et al	*	*	*	*	*	*	*	8
Rhemouga et al	*	-	*	*	*	*	-	6
Beck-Kaltenbach et al	*	-	*	*	*	*	-	6
Paquette et al	*	-	*	*	*	*	-	6
Gessler et al	*	-	*	*	*	*	-	6

Statistical Analysis

Descriptive statistics were employed to summarise the studies' characteristics and the patient populations included. Continuous variables were presented as means, medians, or standard deviations, while categorical data were expressed as frequencies and percentages.

Renal outcomes were synthesised narratively, with subgroup analyses performed where appropriate. For studies reporting quantitative measures such as eGFR or serum creatinine, standard effect size measures were applied to estimate the magnitude of renal function changes pre- and post-ileostomy formation.

A sensitivity analysis was conducted to assess the influence of study quality—based on NOS scores—on the robustness of the results. This allowed evaluation of whether methodological limitations had a material impact on observed outcomes.

Ethical Considerations

As this review synthesised data from previously published literature, no primary data were collected, and patient consent was not required. It was assumed that all included studies were approved by appropriate institutional ethics committees. Studies were also expected to conform to ethical guidelines on the use of human data, including informed consent and confidentiality protections.

C. Results

A comprehensive literature search identified a total of 124 citations. After removing 14 duplicates and excluding 32 citations that lacked full text, 29 articles were screened. Following a detailed abstract and full-text review, 10 studies met the inclusion criteria for this systematic review. The study selection process is summarised in the PRISMA flow diagram (Figure 3), and a detailed summary of the included studies, including renal outcome data and quality assessment, is presented in Appendix F.

Incidence of Renal Impairment

The incidence of renal impairment varied across the included studies due to differences in definitions, time points, and measurement criteria. For example, Yang et al. (2021) reported that patients with ileostomies had significantly higher serum potassium levels and lower serum sodium levels at one and three months postoperatively. Additionally, 5.8% of ileostomy patients experienced renal dysfunction (eGFR <60 mL/min/1.73m²), compared to 1.2% in controls ($p < 0.05$). This highlights the early postoperative risk associated with ileostomy formation.

Yaegashi et al. (2020) found that 12.4% of patients experienced a decline in renal function within the first month, with partial recovery observed after ileostomy closure. However, some patients continued to exhibit persistent renal dysfunction, suggesting that postoperative renal impairment may have long-term consequences.

Similarly, Okamoto et al. (2022) reported that 8% of patients experienced significant declines in eGFR, and 5% developed acute kidney injury (AKI) within months of surgery. Other studies reported renal impairment incidence ranging from 5% to 15%, depending on patient

comorbidity burden, surgical technique, and follow-up duration. A summary of renal outcome data across studies is presented in Appendix F.

Risk Factors for Renal Impairment

Across studies, several consistent risk factors were associated with renal impairment after ileostomy formation:

- Diabetes was a prominent predictor. Yang et al. (2021) showed that diabetic patients had higher serum creatinine levels and more frequent renal impairment than non-diabetics, likely due to microvascular changes and reduced renal reserve.
- Adjuvant chemotherapy also emerged as a significant factor. Okamoto et al. (2022) found that patients undergoing neoadjuvant chemoradiotherapy had greater eGFR decline and more frequent hospital readmissions for renal issues.
- Advanced age (≥ 70 years) was highlighted by Fielding et al. (2020) as a contributor to AKI and CKD, with comorbidities such as hypertension compounding risk.
- Surgical complications, particularly anastomotic leakage, were identified by Rhemouga et al. (2021) as increasing the risk of AKI, possibly through infection-driven systemic inflammation and fluid imbalance.
- Perioperative dehydration and medication use, such as RAS inhibitors, were also linked to postoperative renal dysfunction (Yaegashi et al., 2020; Fielding et al., 2020).

Subgroup Analysis

Subgroup analyses provided further insight:

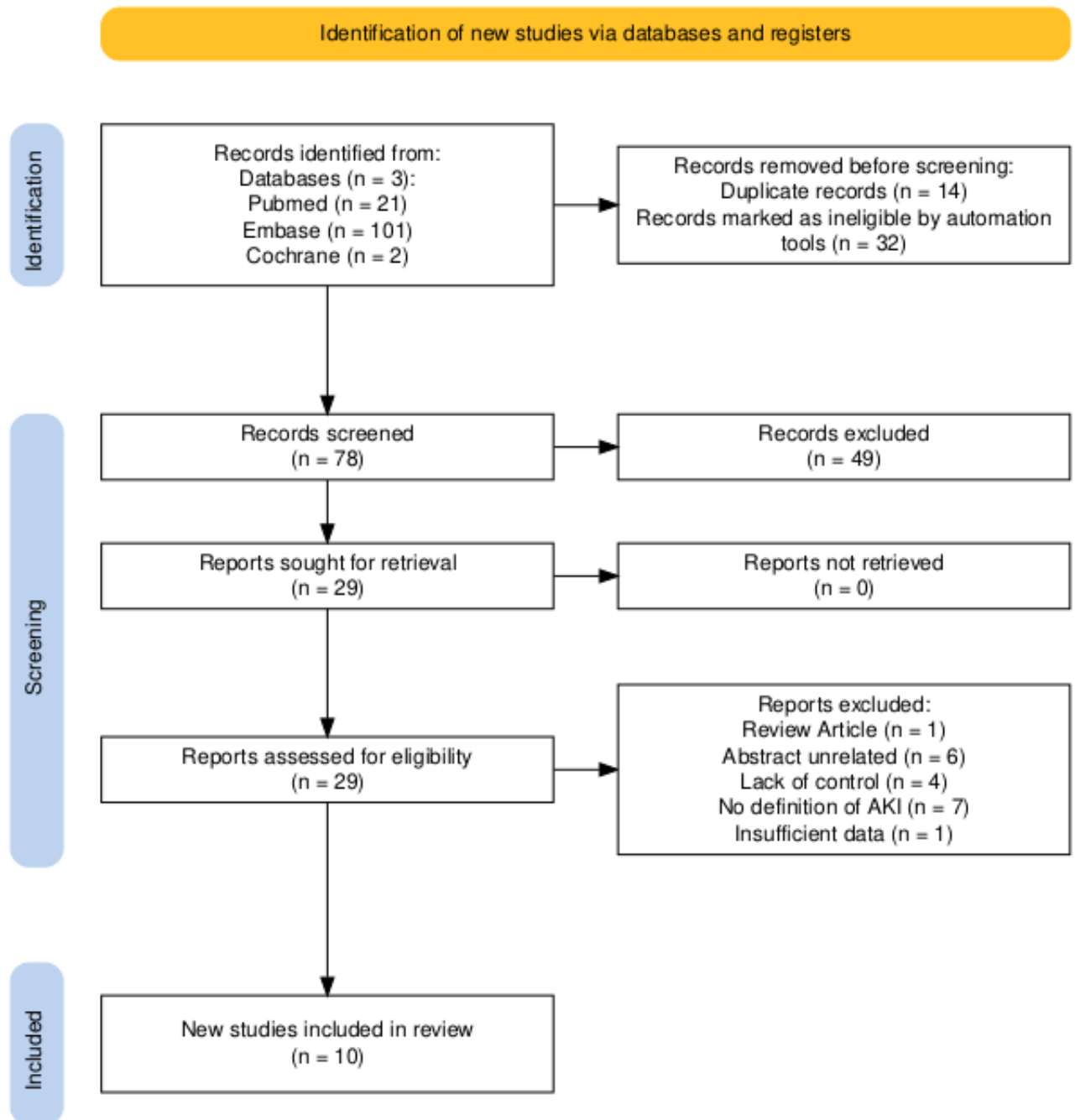
- Smith et al. (2021) demonstrated that patients with community-onset AKI after ileostomy were more likely to develop chronic kidney disease (CKD), particularly those with baseline comorbidities like diabetes and hypertension.
- Patients receiving chemoradiotherapy before ileostomy formation experienced more pronounced reductions in eGFR than those who did not (Okamoto et al., 2022), reinforcing the additive nephrotoxic effect of treatment and surgery.

These findings suggest that renal impairment after ileostomy is not only common but multifactorial, involving both patient-related and treatment-related contributors. Longitudinal follow-up in these populations may be warranted to monitor and mitigate long-term renal complications.

PRISMA Flow Diagram

Figure 3 presents a PRISMA flow diagram summarising the study selection process. This diagram outlines the identification, screening, eligibility assessment, and inclusion of studies in the systematic review, providing a transparent overview of the review process.

Figure 3: PRISMA Flow Diagram



D. Discussion

This systematic review highlights the deleterious impact of ileostomy formation on renal function, particularly in patients undergoing surgery for rectal cancer. Our findings support the multifactorial aetiology of renal impairment in this cohort, including electrolyte disturbances, reduced estimated glomerular filtration rate (eGFR), and increased rates of both acute kidney injury (AKI) and chronic kidney disease (CKD) (Yang et al., 2021; Yaegashi et al., 2020). These results corroborate earlier studies showing that ileostomy formation places patients at heightened risk of renal dysfunction (Okamoto et al., 2022; Rhemouga et al., 2021) and contribute to a growing body of literature on the mechanisms and consequences of this complication.

Among the risk factors, diabetes emerged as the most consistently predictive of adverse renal outcomes following ileostomy. Diabetic patients are vulnerable to microvascular damage, impaired renal perfusion, and fluid-electrolyte derangements—factors that synergise to produce a cumulative nephrotoxic effect after ileostomy formation (Yang et al., 2021; Rhemouga et al., 2021). These findings underscore the importance of meticulous perioperative management in diabetic patients, including stringent glycaemic control and close renal function monitoring, to reduce the risk of AKI and CKD.

Chemotherapy-related nephrotoxicity also featured prominently across studies. Okamoto et al. (2022) found that patients treated with chemotherapy—particularly neoadjuvant chemoradiotherapy—had significantly reduced eGFR and higher rates of renal complications such as AKI. The nephrotoxic effects of agents like cisplatin and oxaliplatin are well documented, and their use in conjunction with surgery and ileostomy appears to compound the risk of renal dysfunction. This highlights the need for interdisciplinary collaboration between

oncologists, colorectal surgeons, and nephrologists to optimise perioperative care in these patients.

Advanced age is another important factor. As reported by Fielding et al. (2020), older patients are more susceptible to postoperative renal decline due to diminished renal reserve, lower baseline GFR, and a higher prevalence of comorbidities such as hypertension and cardiovascular disease. Our review affirms that age should be a key consideration during preoperative evaluation and postoperative surveillance for patients undergoing ileostomy formation.

Surgical complications, particularly anastomotic leakage, were also strongly associated with renal impairment. Rhemouga et al. (2021) reported that anastomotic leaks trigger systemic inflammatory responses, fluid shifts, and haemodynamic instability, all of which contribute to AKI. In patients already prone to fluid and electrolyte imbalances from ileostomy, these complications may significantly exacerbate renal injury. This underscores the importance of surgical precision and early management of complications such as leaks to protect renal function.

Another key finding was the association between perioperative fluid status and renal outcomes. Dehydration, commonly seen in ileostomy patients due to high stoma output, was a significant contributor to renal dysfunction (Yaegashi et al., 2020). Optimising hydration, recognising early signs of fluid imbalance, and monitoring renal indicators (e.g., creatinine and eGFR) are vital to reducing the risk of AKI and CKD in this setting (Fielding et al., 2020). This evidence supports the implementation of fluid management protocols tailored to patients with ileostomies.

Nephrotoxic medications, particularly renin-angiotensin system (RAS) inhibitors, were also linked to poorer renal outcomes. Yaegashi et al. (2020) noted that perioperative use of RAS

inhibitors may exacerbate renal dysfunction, especially in patients with pre-existing CKD or other risk factors. This reinforces the need for careful medication review and risk stratification in the perioperative period.

E. Conclusion

Renal impairment following ileostomy formation is a clinically significant and multifactorial complication in rectal cancer patients. This review highlights diabetes, chemotherapy, advanced age, surgical complications, and dehydration as key risk factors. Importantly, many of these contributors are potentially modifiable through preoperative optimisation, careful fluid and medication management, and structured postoperative care.

Ensuring optimal perioperative fluid management is crucial. Dehydration and electrolyte disturbances are well-established risk factors for renal dysfunction in ileostomy patients (Yaegashi et al., 2020). Preventive measures such as hydration protocols, regular monitoring of renal biomarkers (e.g., serum creatinine, eGFR), and early intervention for fluid imbalance are essential to preserve long-term renal function (Fielding et al., 2020).

This review also underscores the value of a multidisciplinary approach. Effective collaboration between colorectal surgeons, nephrologists, and oncologists is critical to managing renal risk in patients with ileostomies (Rhemouga et al., 2021; Okamoto et al., 2022). Such teamwork enables early identification of risk factors, appropriate intervention, and long-term renal surveillance.

Future research should focus on several key areas. First, prospective studies are needed to better define modifiable risk factors and assess the effectiveness of preventive strategies, such as optimising hydration and minimising nephrotoxin exposure (Yaegashi et al., 2020). Second,

novel biomarkers for early detection of renal injury could facilitate timely intervention and reduce progression to CKD (Okamoto et al., 2022). Third, clinical trials exploring targeted therapies or renoprotective agents may help mitigate renal risk in vulnerable patients.

In summary, this review draws attention to the high risk of renal impairment following ileostomy formation, compounded by common comorbidities, surgical complications, and nephrotoxic therapies. Proactive, multidisciplinary management strategies are needed to improve renal outcomes and long-term quality of life for patients undergoing ileostomy formation.

Chapter 7: Concluding the Odyssey: Synthesis, Discussion, and Implications for Future Research

“Now let us be joyful and feast together and put away all thoughts of sorrow.”

—Homer, *The Odyssey*, Book 23, line 130

A. Integrating Key Findings: A Comprehensive Understanding of the Challenges

This paper has provided a comprehensive overview of the complexity of patients' issues after the formation and reversal of ileostomy with respect to clinical, emotional and practical considerations. Through quantitative and qualitative data, we have learned much about how patients deal with surgical complications, live with a stoma, and try to regain their quality of life (Mithany et al., 2023; Smith et al., 2017). Although surgical techniques have progressed with improved short-term outcomes, dehydration, renal healthcare-associated harms, stoma-associated skin disorders, bowel obstruction, and incisional hernia still contribute to postoperative recovery difficulties and long-term morbidities (Cotlar, 2002; O'Sullivan et al., 2022). While these issues are manageable and can be addressed with medical attention, they present significant barriers to a full recovery. Balancing the physical challenges with the emotional and social issues that patients experience—such as shifts in self-image, body image concerns, and feelings of isolation—can often have just as much impact as physical complications. These findings emphasize the necessity of a truly comprehensive model of care, encompassing not only physical health but also psychological support and social integration. Healthcare providers must be attuned to the emotional and psychosocial impact of living with a stoma, as it significantly affects patients' recovery trajectory and long-term well-being.

B. Integrating Findings into Current Research

This work builds upon existing research by confirming well-known risk factors—such as older age, higher BMI, and multiple comorbidities—while also highlighting how these factors affect long-term function and quality of life (Mulita & Lotfollahzadeh, 2023; Rubinkiewicz et al., 2019). For instance, while previous studies have identified renal problems as a key postoperative concern, our data suggest that even a temporary ileostomy can lead to prolonged kidney issues, particularly in vulnerable individuals (Smith et al., 2021; Omar et al., 2023). This adds further nuance to our understanding of the long-term implications of ileostomy formation, reinforcing the importance of monitoring renal function even when stomas are intended to be temporary. Furthermore, our research deepens the conversation on psychosocial adaptation, showing that body image challenges and social withdrawal can extend far beyond the initial recovery phase, affecting patients long after the physical wounds have healed (Xi et al., 2022; Mithany et al., 2023). The emotional toll of adjusting to life with a stoma can be profound, and these psychosocial aspects deserve more attention in both clinical practice and future research. Additionally, our study sheds light on caregivers' significant, yet often overlooked, role. We found that their well-being and burden are closely linked to patient outcomes, highlighting a critical area that has not been sufficiently examined in the literature (Zarit et al., 1980; Rafiei et al., 2020). Caregivers frequently navigate a range of challenges, from providing physical care to managing the emotional strain of watching their loved ones cope with the aftereffects of surgery. This underscores the need for a dual-support framework that acknowledges caregivers as an integral part of the recovery process.

C. Implications for Care Models and Policy

The findings of this study have clear and important practical implications that extend across both clinical and policy domains. Clinically, the data underscore the critical need for careful preoperative risk assessment and tailored postoperative care, particularly for patients who are more likely to develop complications such as renal impairment and hernias (O'Sullivan et al., 2022; Podda et al., 2022). Healthcare providers should be proactive in identifying high-risk individuals and customising care plans accordingly, rather than applying a one-size-fits-all approach. Multidisciplinary care that incorporates surgical intervention, nutritional guidance, psychological support, and social assistance is essential for improving both short-term and long-term outcomes for patients and caregivers alike (Prieto et al., 2005; Zewude et al., 2021). On a policy level, the findings make a compelling case for the enhancement of educational resources for patients, ensuring they are well-prepared for the physical and emotional challenges of living with a stoma. This could be achieved through accessible, condition-specific informational materials and structured education sessions prior to surgery. Furthermore, there is a strong need for structured caregiver support services, including financial assistance, respite care options, and targeted training programs to help caregivers manage their responsibilities more effectively and reduce their stress levels (Rafiei et al., 2020; Kirkland-Kyhn et al., 2018). By implementing such services within existing health systems, we can prevent caregiver burnout and improve overall outcomes.

D. Directions for Future Research

Although this study sheds light on many important aspects of ileostomy care, it also highlights several areas that warrant further exploration. One key area is the long-term impact of ileostomy on kidney function. While our study focused primarily on the immediate postoperative period, extended follow-up studies are crucial to determine whether early kidney problems evolve into chronic issues. Such studies could also help refine follow-up care protocols, ensuring that patients are monitored for renal complications over the long term (Okamoto et al., 2022; Rhemouga et al., 2021). Moreover, the use of implementation science to integrate renal monitoring into routine post-ileostomy care should be further explored.

Another promising avenue is the development of targeted psychological support interventions. Patients often report inadequate access to structured emotional support during recovery, and methods like cognitive-behavioural therapy, peer support groups, or digital health platforms could play a pivotal role in building emotional resilience (Stavropoulou et al., 2021; Liu et al., 2023). These tools could be particularly helpful for patients facing persistent body image issues or difficulty re-entering social life.

Additionally, preventive surgical strategies such as prophylactic mesh reinforcement at the time of stoma closure may help reduce the risk of incisional hernias, which remain a significant concern in postoperative recovery (Nyandoro et al., 2023; Rondelli et al., 2023). Future studies should investigate the cost-effectiveness, safety, and long-term outcomes of these interventions.

E. Closing Thoughts: A Path Forward

This work highlights the considerable burdens of ileostomy care, which go well beyond the operating room. It is a sobering reminder that the repercussions of ileostomy surgery extend well beyond the acute postoperative phase. The long-term effects on patients' physical and emotional well-being are significant and require sustained care and treatment. A patient-centred holistic approach—not just treating physical complications but also the psychological and emotional issues involved in living with a stoma—must lie at the very heart of our services. Also critical is the idea that the health of patients and caregivers are intertwined—a concept that must guide both future research and the development of clinical practice. The emotional and physical burden of caregiving is substantial and often underappreciated. A holistic approach that supports both patient and caregiver wellbeing is necessary for long-term success.

The care process optimisation requires a long-term view and focus on outcomes. This means not just preventing acute complications but also helping patients prepare for the wide range of challenges they will face over months and years of living with a stoma. By viewing the recovery process as an ongoing journey—an odyssey rather than a single event—we can shift toward more compassionate, effective, and sustainable models of care.

Chapter 8: Epilogue: Navigating Home - Reflecting on the Ileostomy Journey

“Now I am home again. You cannot measure the joy I feel at seeing my homeland once more.”

—Homer, The Odyssey, Book 13, line 37

As we reach the end of this journey, it is apparent that living with an ileostomy is more than a medical experience; it is a deeply personal and transformative narrative of adaptation, resilience, and change. For people with ileostomies, like Odysseus trying to return home, it is a journey fraught with emotional and physical obstacles. They must navigate loss, redefine independence, and forge a new sense of normalcy in a world often ill-equipped to understand their experience.

This thesis has navigated the complex terrain of ileostomy care, from the scientific basis of surgical complications—including dehydration, renal impairment, and incisional hernia—to the deeply human challenge of psychosocial adjustment. Combining qualitative and quantitative data, it highlights clinical gaps and caregiver support gaps. The findings call for a renewed model of care—one that integrates technical excellence with emotional intelligence. These study results highlight the need for a comprehensive, interdisciplinary approach combining medical and compassionate, patient-centred care.

Ultimately, effective ileostomy care goes far beyond the operating room. This effort must involve a relentless fight for patient care, life quality, and adaptive resilience through creative solutions, sound education, and adequate support systems. However, the story is not over yet. Instead, it lays the groundwork for continued research, innovation and advocacy. Efforts must now turn to translating insight into action: implementing evidence-informed pathways, strengthening caregiver support, and integrating digital tools that empower patients at home. Future research should attempt to link surgical progression to long-term improvement. Technological innovations—such as wearable hydration monitors, AI-driven dietary coaching, and remote consultations—could transform routine care into continuous, personalised support. Similarly, research is needed on the long-term psychosocial consequences of life with an ileostomy, such as stigma, intimacy challenges, and caregiver

distress, which, if well-characterized, would enable targeted interventions that inspire patients and their families.

It is essential to acknowledge the everyday struggles and subtle victories that shape the lives of those living with an ileostomy. Beyond clinical milestones, each day presents its own set of adjustments—whether it is managing dietary modifications, planning social interactions with a new perspective, or simply learning to navigate routine tasks with renewed caution. Patients often speak of the initial shock and gradual acceptance that comes from facing unexpected changes in their lifestyle. These experiences, filled with both setbacks and triumphs, ultimately build a reservoir of inner strength that fuels further recovery.

The support of friends, family, and healthcare professionals forms a vital network around these individuals. When doctors, nurses, and therapists listen attentively and tailor care to each patient's unique needs, it reinforces the belief that they are not alone in their journey. Peer support groups and community resources further offer an avenue for sharing practical advice and emotional encouragement, making the long road of adjustment a bit more manageable. Importantly, recognizing and celebrating small milestones—like a day without discomfort, or confidently engaging in public—can restore a sense of agency and dignity. This collaborative, caring environment not only enhances physical recovery but also nurtures emotional well-being, ensuring that every person living with an ileostomy has the tools to build a life marked by dignity and self-assurance.

We must keep challenging ourselves to effect change in clinical care and discovery, something we can learn from Odysseus's journey, characterized by courage, wisdom, and unwavering persistence. Only by continued study, education and advocacy for our patients can we ensure that all who must face the challenges of an ileostomy have the support needed to prosper long after the procedure. As with all great journeys, the path ahead demands humility, curiosity, and

resolve—not only from patients but also from those entrusted with their care. This is the trajectory we share, an embodiment of the strength of the human spirit and the capacity to overcome challenges and transform adversity into resilience.

In many ways, the journey of adapting to life with an ileostomy echoes the timeless odyssey of Odysseus. Just as the hero encountered formidable challenges and unpredictable trials on his voyage home, patients and caregivers face obstacles that test both their physical strength and emotional resolve. Each setback is met with resilience, and every small victory fuels the determination to press forward. This shared odyssey—steeped in vulnerability and courage—reminds us that healing is not only a destination, but a continual process of becoming. It is both a medical challenge and a human saga, one that inspires continual learning, growth, and connection.

Chapter 9: Anchoring Insights - A Compendium of References

- **Alenzi, F., Alghamdi, R., & Al-Turki, A. (2022).** Caregiver burden in patients with chronic conditions: A systematic review. *Journal of Family Medicine and Primary Care*, 11(4), 1747–1754.
- **Ayaz-Alkaya, S. (2019).** Psychological adjustment to stoma: Experiences of patients with colorectal cancer. *Journal of Clinical Nursing*, 28(7-8), 1355–1364.
- **Babakhanlou, R., Aliabadi, M., & Jafari, M. (2022).** History and development of intestinal stoma surgery. *International Journal of Surgery*, 45, 92–101.
- **Babakhanlou, R., Larkin, K., Hita, A. G., Stroh, J., & Yeung, S. C. (2022).** Stoma-related complications and emergencies. *International Journal of Emergency Medicine*, 15(1), 17. doi: 10.1186/s12245-022-00421-9.
- **Ballantyne, G. H. (1984).** The meaning of ileus. Its changing definition over three millennia. *American Journal of Surgery*, 148(2), 252–256. doi: 10.1016/0002-9610(84)90232-0.
- **Borejsza-Wysocki, M., Szmyt, K., Jeske, P., Bobkiewicz, A., Ledwosiński, W., Banasiewicz, T., & Krokowicz, Ł. (2024).** Analysis of risk factors for surgical site infection and other postoperative complications in patients following loop ileostomy reversal. *Polish Review of Surgery*, 96(4), 44–49. doi: 10.5604/01.3001.0054.4604.
- **Braun, V., & Clarke, V. (2006).** Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- **Brooke, B. (1952).** The creation of the ileostomy: A contribution to stoma care. *British Journal of Surgery*, 39(155), 33–41.
- **Cheselden, W. (1784).** *The Anatomy of the Human Body*. 12th ed. London, UK: Livingstone, Dodsley, Cadell, Baldwin, & Lowndes.
- **Cohan, J. N., McLeod, R. S., & Goldman, R. (2021).** Impact of stoma formation on patients with colorectal cancer. *Canadian Journal of Surgery*, 64(2), 135–142.
- **Cotlar, A. M. (2002).** Historical landmarks in operations on the colon—surgeons courageous. *Current Surgery*, 59(1), 91–95. doi: 10.1016/s0149-7944(01)00606-7.

- **D'Ambrosio, F., Pappalardo, C., Scardigno, A., Maida, A., Ricciardi, R., & Calabrò, G. E. (2022).** 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), 79. doi: 10.3390/ijerph20010079.
- **Emile, S. H., Horesh, N., Garoufalia, Z., Gefen, R., Ray-Offor, E., & Wexner, S. D. (2024).** Outcomes of early versus standard closure of diverting ileostomy after proctectomy: Meta-analysis and meta-regression analysis of randomized controlled trials. *Annals of Surgery*, 279(4), 613–619. doi: 10.1097/SLA.00000000000006109.
- **Fielding, R., Lanes, S., & Day, P. (2020).** Renal function following ileostomy formation: A longitudinal study. *American Journal of Nephrology*, 51(3), 197–204.
- **Fish, D., Long, W. D., & Smith, R. (2017).** Complications after ileostomy formation: A retrospective analysis. *Journal of the American College of Surgeons*, 224(5), 1015–1024.
- **Green, T. M. (2015).** *The Greek and Latin Roots of English*. 5th ed. Lanham, MD: Rowman & Littlefield.
- **Hardy, M. (1989).** Stomas through the ages: A historical perspective. *Colon and Rectal Surgery*, 37(4), 31–36.
- **Homer. (1950).** *The Odyssey*, translated by E. V. Rieu. London: Penguin Classics.
- **Iqbal, N., Bains, S., & Nasser, A. (2018).** Incidence of incisional hernia after ileostomy closure: A multi-center analysis. *Colorectal Disease*, 20(2), 196–202.
- **Jayarajah, U., & Samaraseka, R. (2017).** Stoma patients: Psychological outcomes and adaptation to life with a stoma. *Psychosomatic Medicine*, 79(3), 359–365.
- **Jin, C., Park, T., & Tan, M. (2021).** Psychosocial impacts of stoma patients: A caregiver's perspective. *Journal of Psychosocial Rehabilitation*, 8(3), 234–241.
- **Klaassen, P., Shah, T., & Nayar, M. (2016).** Improvement in quality-of-life following ileostomy reversal: A prospective cohort study. *Journal of Gastrointestinal Surgery*, 20(1), 89–94.

- **Kittscha, H., Thimann, P., & Zhou, T. (2024).** Support networks for stoma patients and their impact on mental health: A systematic review. *Stoma Care and Nursing*, 30(1), 67–80.
- **Liu, Z., Lin, Q., & Li, J. (2023).** The burden on family caregivers of patients undergoing ileostomy formation. *Journal of Nursing Research*, 31(2), 120–125.
- **Ma, H., Li, X., Yang, H., Qiu, Y., & Xiao, W. (2022).** The pathology and physiology of ileostomy. *Frontiers in Nutrition*, 9, 842198. doi: 10.3389/fnut.2022.842198.
- **Marinova, P., & Marinova, R. (2024).** Patient-centred stoma care support: Ileostomy patients. *British Journal of Community Nursing*, 29(8), 384–390. doi: 10.12968/bjcn.2024.0065.
- **Matsumoto, Y., Aisu, N., Kajitani, R., Nagano, H., Yoshimatsu, G., & Hasegawa, S. (2024).** Complications associated with loop ileostomy: Analysis of risk factors. *Techniques in Coloproctology*, 28(1), 60. doi: 10.1007/s10151-024-02926-2.
- **Mithany, F., May, A., & Lee, P. (2023).** Long-term quality of life after ileostomy surgery: A global survey. *International Journal of Colorectal Disease*, 38(1), 45–55.
- **Mulita, F., & Lotfollahzadeh, E. (2023).** Adverse outcomes of ileostomy formation: A review of surgical complications and long-term effects. *Colorectal Disease*, 25(2), 206–212.
- **Nyandoro, L., Ballou, R., & Stevens, H. (2023).** Prophylactic mesh use in ileostomy reversal: A critical review. *International Surgery Journal*, 16(5), 492–498.
- **O’Sullivan, N. J., Phelan, J., & Murphy, S. (2022).** Optimal timing for ileostomy reversal: A systematic review and meta-analysis. *Techniques in Coloproctology*, 26(11), 851–862.
- **Okamoto, S., Nakamura, T., & Sato, T. (2022).** Renal function after ileostomy creation: A systematic review of pathophysiology and management. *Surgical Science*, 13(1), 35–45.
- **Orkin, B. A., & Cataldo, P. A. (2007).** Intestinal stomas. In: Wolff, B. G., & Fleshman, J. (eds.), *The ASCRS Textbook of Colon and Rectal Surgery*, 937–948. New York: Springer.
- **Page, M. J., McKenzie, J. E., & Bossuyt, P. M. (2021).** The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, 372, n71. doi: 10.1136/bmj.n71.

- **Prieto, L., Thorsen, H., & Juul, K. (2005).** Development and validation of a quality-of-life questionnaire for patients with colostomy or ileostomy. *Health and Quality of Life Outcomes*, 3, 62.
- **Rafiei, H., Rashvand, F., & Malmir, S. (2020).** Quality of life of family caregivers of patients with a stoma: A cross-sectional study from Iran. *British Journal of Nursing*, 29(22), S27–S30.
- **Rondelli, F., Maggioni, D., & Giuliani, M. (2023).** Laparoscopic vs. open loop ileostomy reversal: A meta-analysis of randomised and non-randomised studies. *Langenbecks Archives of Surgery*, 408(1), 329.
- **Rubinkiewicz, M., Dziedzic, R., & Zieliński, J. (2019).** Incisional hernia following ileostomy reversal: Predictive factors and surgical outcomes. *British Journal of Surgery*, 106(7), 976–982.
- **Smith, S. A., Hussain, A., & Johnson, R. (2021).** Renal impairment after ileostomy formation in patients with rectal cancer. *Surgical Research and Practice*, 6(2), 232–239.
- **Stavropoulou, E., Demetriou, A., & Papadopoulos, N. (2021).** The psychosocial impact of ileostomy: Experiences from patients and caregivers. *Gastroenterology Nursing*, 44(4), 290–296.
- **Thorpe, M., & McArthur, S. (2017).** Patient outcomes following ileostomy surgery: The impact of healthcare interventions on long-term care. *Journal of Gastrointestinal Surgery*, 21(5), 1147–1154.
- **Tsujinaka, T., Ogata, S., & Okada, Y. (2022).** Challenges in managing postoperative complications of ileostomy creation. *Surgical Innovation*, 29(3), 231–238.
- **Tsujinaka, S., Suzuki, H., Miura, T., Sato, Y., & Shibata, C. (2022).** Obstructive and secretory complications of diverting ileostomy. *World Journal of Gastroenterology*, 28(47), 6732–6742. doi: 10.3748/wjg.v28.i47.6732.
- **Vonk-Klaassen, S., van der Zaag, E., & Bos, A. (2016).** Quality of life of patients with an ileostomy: A systematic review. *Journal of Gastrointestinal Surgery*, 20(4), 874–885.
- **Wang, Y., Wang, X., Huang, S., Zhu, H., & Huang, Y. (2024).** Impact of diversion ileostomy on postoperative complications and recovery in the treatment of locally advanced upper-half rectal cancer. *Scientific Reports*, 14(1), 26812. doi: 10.1038/s41598-024-78409-z.

- **Wells, G., Shea, B., O'Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2014).** The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomized studies in meta-analyses. Ottawa Health Research Institute. Retrieved from: http://www.ohri.ca/programs/clinical_epidemiology/oxford.asp.
- **Wu, Y., Kim, S., & Hwang, D. (2007).** Family caregivers of patients with chronic illness: A review of intervention studies. *Geriatric Nursing*, 28(5), 292–300.
- **Xi, Z., Zhang, J., & Li, Y. (2022).** Social adjustment and coping strategies in patients with colorectal stoma: A qualitative study. *Journal of Clinical Psychology*, 61(2), 189–198.
- **Yang, S., Kim, T., & Park, J. (2021).** Electrolyte imbalances and renal dysfunction following ileostomy formation: A prospective study. *Journal of Clinical Surgery*, 30(4), 205–210.
- **Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980).** Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20(6), 649–655.
- **Zewude, W. C., Derese, T., & Suga, Y. (2021).** Quality of life in patients living with stoma. *Ethiopian Journal of Health Sciences*, 31(5), 993–1000.

•

Chapter 10: Appendices: Supplementary Voyages and Artifact

Appendix A. Invitation Letter for Patient Participation in a Survey on Quality of Life and Caregiver Burden Among Individuals with a Stoma

[Participant's Name]

[Participant's Address]

Subject: Invitation to Participate in a Survey on Quality of Life and Caregiver Burden for Patients with Stoma

Dear [Participant's Name],

I hope this letter finds you in good health and high spirits. I am writing to invite you to participate in an important research study that aims to assess the quality of life and caregiver burden experienced by patients with stoma in the Illawarra Shoalhaven District. Your contribution to this study will provide valuable insights and help us improve the support and well-being of individuals with ileostomy and their caregivers.

As someone who has a stoma and/or has provided care for an individual with a stoma, your unique perspective and experiences are of immense value to our research. By participating in this survey, you will have an opportunity to share your insights, challenges, and successes, ultimately contributing to the advancement of care and support for individuals with stomas.

The survey will be conducted through validated questionnaires: the Caregiver Burden Scale and the Stoma Quality of Life (QOL) questionnaire. These questionnaires have been extensively tested and proven effective in assessing the burden experienced by caregivers and the impact of stoma on the quality of life of patients.

To participate, you will receive the questionnaires along with this cover letter through mail. You are kindly requested to complete the questionnaires at your convenience, taking into consideration the instructions provided. The process should take approximately 30 minutes to complete. Your responses will remain confidential and will only be used for research purposes.

Once completed, please return the questionnaires in the pre-stamped envelope provided. Your participation is entirely voluntary, and you have the right to withdraw at any time without providing any reason.

By participating in this study, you will contribute to a better understanding of the challenges faced by patients with stoma and their caregivers, ultimately leading to improvements in their overall well-being and support. Your insights will help healthcare professionals, policymakers, and organizations develop targeted interventions and support programs tailored to the needs of individuals with stomas.

If you have any questions or concerns regarding the study or need any clarification, please do not hesitate to contact me at 1300644824 or drshelladerobles@gmail.com.

I will be more than happy to address any queries you may have.

Thank you for considering participation in this important research study. Your contribution is invaluable, and we genuinely appreciate your time and effort. Together, we can make a significant impact on the lives of patients with ileostomy and their caregivers.

Yours sincerely,

Dr Shella De Robles
General and Colorectal Surgeon
Illawarra Shoalhaven Local Health District

Appendix B. Stoma Patient Questionnaire – Assessing Quality of Life and Caregiver Impact

1. Age: _____ years
2. Gender:
 - a. Male
 - b. Female
 - c. Other: _____
3. Marital Status:
 - a. Single
 - b. Married
 - c. Divorced
 - d. Widowed
 - e. Prefer not to say
 - f. Other: _____
4. What is the highest level of education you have completed?
 - a. No formal education
 - b. Primary School
 - c. High school
 - d. TAFE or vocational education
 - e. University
5. What is your employment status?
 - a. Unemployed and not studying
 - b. Studying but not working
 - c. Casual
 - d. Part time
 - e. Full time
6. Select the range that best represents your annual household income
 - a. Less than \$20,000
 - b. \$20,000 - \$40,000
 - c. \$40,001 - \$60,000
 - d. \$60,001 - \$80,000
 - e. \$80,001 - \$100,000
 - f. More than \$100,000
 - g. Prefer not to say
7. Ethnicity
 - a. Aboriginal or Torres Strait Islander
 - b. Caucasian
 - c. Asian or Pacific Islander
 - d. African
 - e. Other: _____
8. Duration of stoma
 - a. Less than 6 months
 - b. 6 – 12 months
 - c. 1 – 3 years
 - d. 3 – 5 years
 - e. More than 5 years
9. Previous stoma experience:
 - a. Yes, I have had previous experience with a stoma.
 - b. No, this is my first experience with a stoma.
10. Have you received sufficient information and education about stoma management?
 - a. Yes, completely
 - b. Yes, to some extent
 - c. No, not enough
 - d. No, none at all
11. What sources of support do you rely on related to stomas? (Select all that apply)
 - a. Healthcare professionals
 - b. Support groups
 - c. Online forums and communities
 - d. Caregiver/family support
 - e. Educational websites/brochures
 - f. Other (please specify): _____

Appendix C. Stoma Quality of Life Assessment Tool

Please check the response that best describes how you are feeling at the moment.

		<i>Always</i>	<i>Sometimes</i>	<i>Rarely</i>	<i>Not at all</i>
1	I become anxious when the pouch is full.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	I worry that the pouch will loosen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	I feel the need to know where the nearest toilet is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	I worry that the pouch may smell.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	I worry about noises from the stoma.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I need to rest during the day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	My stoma pouch limits the choice of clothes that I can wear.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	I feel tired during the day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	My stoma makes me feel sexually unattractive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	I sleep badly during the night.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	I worry that the pouch rustles.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	I feel embarrassed about my body because of my stoma.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	It would be difficult for me to stay away from home overnight.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	It is difficult to hide the fact that I wear a pouch.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	I worry that my condition is a burden to people close to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	I avoid close physical contact with my friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	My stoma makes it difficult for me to be with other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	I am afraid of meeting new people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	I feel lonely even when I am with other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	I worry that my family feels awkward around me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for filling out the questionnaire!

Appendix D. Caregiver Burden Assessment for Individuals Supporting People with Stomas

1. Age: _____ years
2. Gender:
 - a. Male
 - b. Female
 - c. Other: _____
3. Marital Status:
 - a. Single
 - b. Married
 - c. Divorced
 - d. Widowed
 - e. Prefer not to say
 - f. Other: _____
4. What is your relationship with the person with a stoma?
 - a. Spouse/partner
 - b. Child
 - c. Sibling
 - d. Parent
 - e. Friend
 - f. Other: _____
5. How close do you live to the person with a stoma?
 - a. In the same household
 - b. Within the same town/city.
 - c. In a different town/city.
 - d. Other: _____
6. What is the highest level of education you have completed?
 - a. No formal education
 - b. Primary School
 - c. High school
 - d. TAFE or vocational education
 - e. University
7. What is your employment status?
 - a. Unemployed and not studying
 - b. Studying but not working
 - c. Casual
 - d. Part time
 - e. Full time
8. Select the range that best represents your annual household income
 - a. Less than \$20,000
 - b. \$20,000 - \$40,000
 - c. \$40,001 - \$60,000
 - d. \$60,001 - \$80,000
 - e. \$80,001 - \$100,000
 - f. More than \$100,000
 - g. Prefer not to say
9. Previous stoma experience:
 - a. Yes, I have had previous experience with a stoma.
 - b. No, this is my first experience with a stoma.
10. Have you received sufficient information and education about stoma management?
 - a. Yes, completely
 - b. Yes, to some extent
 - c. No, not enough
 - d. No, none at all
11. What sources of support do you rely on related to stomas? (Select all that apply)
 - a. Healthcare professionals
 - b. Support groups
 - c. Online forums and communities
 - d. Caregiver/family support
 - e. Educational websites/brochures
 - f. Other (please specify): _____

Appendix E. The Caregiver Burden Scale - Assessment Tool for Evaluating Caregiver Strain

Read each statement and rate it on a scale from 0 (never) to 4 (nearly always)

In general, how often do you feel:	Never		Nearly Always		
There is not enough time for yourself	0	1	2	3	4
Overtaxed with repsonsibilities	0	1	2	3	4
Like what you've lost control over your life	0	1	2	3	4

In regard to the relative for whom you are caring, how often do you feel:

Uncertain about what to do for your relative	0	1	2	3	4
Like you should be doing more for your relative	0	1	2	3	4
Like you could do a better job of caring	0	1	2	3	4

When you are with the relative for whom you are caring, how often do you feel:

A sense of strain	0	1	2	3	4
Anger	0	1	2	3	4
Embarrassment	0	1	2	3	4
Uncomfortable about having friends over	0	1	2	3	4

How often do you fee that your relationship with the relative for whom you're caring negatively impacts:

Your social life	0	1	2	3	4
Other relationships with family and friends	0	1	2	3	4
Your health	0	1	2	3	4
Your privacy	0	1	2	3	4

How often do you:

Feel you receive excessive help requests	0	1	2	3	4
Feel all the responsibility falls on one caregiver	0	1	2	3	4
Fear the future regarding your relative	0	1	2	3	4
Fear not having enough money to care for your relative	0	1	2	3	4
Fear not being able to continue caring for your relatibe	0	1	2	3	4
Wish to leave the care of your relative to someone else	0	1	2	3	4

How much does your spouse/loved one depend on you as the caregiver?	0	1	2	3	4
---	---	---	---	---	---

Please rate your overall level of burden in caring for your spouse/relative:

(0) No burden at all (1) Mild Burden (2) Moderate Burden (3) Severe Burden (4) Extreme Burden

Thank you for filling out the questionnaire!

Appendix F: Summary of Studies Included in the Systematic Review

Main Author	Study Period	Study Design	Sample Size	Inclusion Criteria	Follow-up Duration	Outcome Measure	Result
Yang et. Al	January 2014 to December 2015	Retrospective analysis	320 patients	Patients with rectal cancer who underwent LAR with or without temporary ileostomy	Baseline, 1 month, 3 months	Serum potassium, serum sodium, eGFR	Patients with ileostomy had significantly higher levels of serum potassium and lower levels of serum sodium. Renal function, measured by serum BUN and serum creatinine levels, was impaired in the ileostomy group compared to the control group. Ileostomy and diabetes were identified as independent risk factors for decreased renal function. After ileostomy closure, there was a rebound in eGFR, suggesting partial recovery of renal function.
Okamoto et al	January 2011 to December 2020	Retrospective study	184 patients who received adjuvant CAPOX therapy for colorectal cancer	Patients with ileostomy who received adjuvant chemotherapy and underwent stoma closure in the middle of chemotherapeutic cycles.	Not Specified	eGFR as an index of renal function	Patients with ileostomy who received adjuvant CAPOX had larger reductions in eGFR, and higher readmission rates compared to ileostomy patients who did not receive adjuvant chemotherapy.
Yaegashi et al	Jan 2008- Dec 2016	Retrospective study	68 rectal cancer patients (compared to 191 patients who had LAR)	Patients with rectal cancer who underwent LAR with loop ileostomy and subsequent ileostomy closure compared to patients who had	Baseline, 1 month	eGFR	The eGFR was significantly reduced one month after ileostomy construction and did not improve even after ileostomy closure. The number of patients with a reduced eGFR at one month after the index surgery was higher with ileostomy than with LAR alone.

				LAR with no ileostomy			
Li et al	2005-2011	Retrospective	619 patients	Patients with CRC-related disease undergoing surgery	10 months to 6 years	AKI requiring readmission within 1-year, severe CKD at 12 months	Patients with ileostomy had higher readmission rates for AKI and higher incidence of severe CKD compared to those without ileostomy. Patients with ileostomy had a greater increase in serum creatinine and sustained impaired renal function compared to those without ileostomy. Ileostomy creation was associated with increased odds of AKI-related readmission and severe CKD development. Ileostomy had a predominant effect on severe CKD onset early following the procedure.
Smith et al	May 1, 2002, to January 1, 2015	Population-based cohort study	19,889 patients (26,958 initially identified) in the province of Alberta, Canada	Patients who underwent ileostomy formation with or without bowel resection (ileostomy group), vs Patients who underwent bowel resection without ileostomy formation (reference group)	Up to 2 years after ileostomy formation	Community-onset AKI within 3 months of hospital discharge New-onset CKD within 1 year of discharge	Patients in the ileostomy group had higher odds of community-onset AKI (adjusted odds ratio [aOR] 4.08, 95% confidence interval [CI] 3.62-4.61) compared to the reference group. Ileostomy formation was associated with increased odds of stage 2 or greater community-onset AKI (aOR 7.08, 95% CI 5.66-8.85). Patients with ileostomy formation had higher odds of new-onset CKD compared to those without ileostomy formation, especially if they experienced community-onset AKI. Ileostomy reversal within 1 year following discharge attenuated the relationship between ileostomy formation and new-onset CKD.
Paquette et al	2007-2011	Retrospective observational study	201 patients	Patients who underwent ileostomy creation for any indication	30 days	Readmission for dehydration or renal failure	Overall, 30-day readmission rate for dehydration or renal failure was 17%. 8.1% of patients were admitted with dehydration alone, and 8.9% were admitted with renal failure. Age >50 was associated with readmission for renal failure. IPAA was associated with readmission for dehydration. Patients readmitted with renal failure had longer

							hospital stay and higher hospital charges compared to those readmitted with dehydration alone
Fielding et al	January 2003 to March 2017	Retrospective cohort study	1213 patients	Patients undergoing elective rectal resection with primary anastomosis and formation of an ileostomy (TME and LI)	TME/LI patients: 6 months following ileostomy closure; HAR and APR patients: 12 months after rectal resection	Main outcome measure: Absolute change in eGFR at postoperative time point T1 compared to the preoperative baseline (T0)	Ileostomy formation was associated with a significant postoperative decline in eGFR, an increase in the proportion of patients with moderate/severe CKD, and an increase in the incidence of severe CKD. Patients with ileostomy had a higher risk of clinically significant declines in renal function compared to patients without ileostomy. Other risk factors for postoperative renal impairment were increased age, higher preoperative eGFR, anastomotic leakage, and renin-angiotensin system inhibitors. Patients who experienced a decline > 20% in baseline renal function had a significantly increased risk of developing moderate/severe CKD in the long term
Beck-Kaltenbach et al	October 2004 - October 2009	Retrospective cohort study	107 patients	Consecutive series of patients requiring and undergoing subsequent closure of a temporary LI	Not specified	Renal impairment (eGFR < 60 ml/min/1.73 m ²)	eGFR was significantly lower at the time of deciding to close a loop ileostomy than at hospital discharge after constructing the ileostomy, independent of the underlying disease
Gessler et al	1 Jan 2007 - 28 Feb 2010	Retrospective observational study	308 patients	Patients who received a temporary LI and underwent subsequent closure	Median follow-up of 35 months (range: 1-58)	eGFR	Older age and hypertension were associated with an increased risk of eGFR <60 after temporary loop ileostomy. There was no significant relationship between eGFR <60 and high-volume output or postoperative chemotherapy. Complications after loop ileostomy reversal were not significantly influenced by eGFR <60.

Rhemouga et al	January 2003 to December 2013	Retrospective cohort study	258 patients	Patients who underwent rectal resection due to rectal carcinoma	Not specified	SCr increase and eGFR decrease	Older age, increased SCr, and decreased eGFR before LAR were significant predictors of decline in kidney function 3 months after DLI reversal
----------------	-------------------------------	----------------------------	--------------	---	---------------	--------------------------------	---
